

UNIVERSITY OF SOUTHAMPTON

FACULTY OF SOCIAL SCIENCES

Gerontology

Pathways into Informal Care Provision

by

Mrs Maja Emilie Fuglsang Palmer

Thesis for the degree of Gerontology

May 2019

Copyright © and Moral Rights for this thesis and, where applicable, any accompanying data are retained by the author and/or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This thesis and the accompanying data cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder/s. The content of the thesis and accompanying research data (where applicable) must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holder/s.

When referring to this thesis and any accompanying data, full bibliographic details must be given, e.g.

Thesis: Maja Emilie Fuglsang Palmer (2019) "Pathways into informal care provision", University of Southampton, Faculty of Social Sciences, Department of Gerontology, Doctoral Thesis, 358pp.

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL SCIENCES

Gerontology

Doctor of Philosophy

PATHWAYS INTO INFORMAL CARE PROVISION

by Maja Emilie Fuglsang Palmer

In England informal care is pivotal to the care provision system. Population ageing contributes to growing demands for social care, in addition to the rising cost of health care, and government policy are therefore increasingly relying on informal carers. The patterns of informal care provision, carers' characteristics and the impact of care provision have been studied to a large extent, nevertheless little is known about the dynamic pathways into informal care provision, which is a central part of ensuring future care provision.

Using data from the English Longitudinal Study of Ageing (ELSA) Waves 4 (2009) to 7 (2015), this thesis aims to explore the pathways into informal care by individuals aged 50 and over, in order to better understand possible predictors of short and longer-term transitions into the caring role. The research used bi- and multivariate cross-sectional analysis of Wave 7 and multivariate longitudinal statistical analysis of Waves 4 to 7.

The results showed that 18% (N=1,604) of the sample in Wave 7 had provided informal care within the last week. The longitudinal analysis showed a high short-term (between 2013 and 2015) turnover of carers entering and leaving the caring role. Longer-term (between 2011 and 2015) transitions revealed that almost 40% of the 'repeating carers' had transitioned between caring for different care-recipients, suggesting a '*serial carer*' effect. Informal carers were found to be in better self-reported health prior to initiating the role compared to non-carers, which points to evidence of a '*healthy carer effect*'. Among working carers, remaining in part-time employment was associated with repeated care provision, implying that part-time employment may be a pathway into informal care, however when age was controlled for, this effect was no longer significant.

This thesis adds new evidence to our understanding of dynamic care provision patterns and the effects of care provision. It is recommended that policymakers take a holistic approach to policies supporting carers and consider the highly complex and individual journey both into and out of care provision.

Table of Contents

Table of Contents	i
Table of Tables	vii
Table of Figures	xi
Research Thesis: Declaration of Authorship	xiii
Acknowledgement	xv
Abbreviations	xvii
Chapter 1 Introduction	1
1.1 Background.....	2
1.1.1 The demographic changes influencing the supply of and demand for informal care.....	6
1.1.2 Public spending, benefits and government policies related to informal care provision.....	12
1.2 Research questions and rationale.....	18
1.2.1 The significance of the study.....	21
1.3 Structure of the thesis.....	22
Chapter 2 Literature review	25
2.1 Introduction.....	25
2.2 Theoretical concepts of informal care provision.....	26
2.2.1 Life-course perspective and the pathways into informal care provision.....	26
2.2.2 Perspectives of feminism theories on the pathways into informal care provision.....	29
2.2.3 Inter- and intra-generational relationships and informal care provision.....	31
2.3 Empirical literature review on informal care provision.....	37
2.3.1 Evidence from the cross-sectional studies: a snapshot of informal carers and the determinants of care.....	37
2.3.1.1 Prevalence, intensity and type of care provided.....	37
2.3.1.2 Socio-demographic characteristics of the informal care providers.....	40
2.3.1.3 Health of informal care providers.....	43
2.3.1.4 Employment and socio-economic characteristics of informal care providers.....	45
2.3.1.5 Other associated factors related to the informal care providers.....	47
2.3.2 Evidence from longitudinal studies: the longer-term effects and changes related to informal care provision.....	50
2.3.2.1 Positive and negative health impact on the informal care providers.....	52

Table of Contents

2.3.2.2	The effects of employment and occupying multiple roles on the provision of informal care	54
2.3.2.3	The effects of social contacts and family size on the pathways into informal care provision	59
2.3.2.4	Informal care provided to grandchildren	60
2.4	Gaps in the literature	62
2.5	Conceptualising the pathways into informal care provision	63
2.6	Summary.....	65
Chapter 3	Methodology	67
3.1	Introduction	67
3.2	The English Longitudinal Study of Ageing	68
3.2.1	The study population of The English Longitudinal Study of Ageing	70
3.3	Key measurement concepts and variables	72
3.3.1	Dependent variables	72
3.3.2	Independent variables	73
3.3.2.1	Sociodemographic variables	73
3.3.2.2	Socioeconomic variables	79
3.3.2.3	Health variables	84
3.3.2.4	Informal care variables	90
3.3.3	Change variables, <i>Phase II</i> and <i>III</i>	93
3.3.3.1	Change to caring status	93
3.3.3.2	Changes to the caring intensity.....	93
3.3.3.3	Changes to the direction of care	95
3.3.3.4	Change to Self-reported health status	95
3.3.3.5	Changes to Economic Activity	96
3.3.4	Summary	97
3.4	Binary logistic regression analysis design.....	98
3.5	Weighting.....	99
3.6	Data Quality	100
3.6.1	Sensitivity analyses.....	101
3.6.2	Non-response and Attrition of the ELSA	102
3.7	Summary.....	104
Chapter 4	Phase I: Methodology and Results of the cross-sectional analysis.....	105
4.1	Introduction	105
4.2	The sample population of ELSA Wave 7	105
4.3	Descriptive statistical data analysis design	107
4.3.1	The demographic and socio-economic characteristics of the all respondents, by non-carers and carers, the ELSA Wave 7	108
4.3.2	The demographic and socio-economic characteristics by gender, in the ELSA Wave 7	112
4.3.3	Caregiving patterns by gender, the ELSA Wave 7	117

4.3.3.1	Caring characteristics by age, direction of care and the intensity of care, the ELSA Wave 7	119
4.3.4	Summary of the descriptive statistical <i>Phase I</i> analysis of the ELSA population Wave 7	124
4.4	The predictors of care provision, <i>Phase I</i>	125
4.4.1.1	<i>Phase I</i> MODEL 1: Predictors of care provision	128
4.4.1.2	<i>Phase I</i> MODELS 2 and 3: Predictors of care provision by sex	135
4.4.1.3	<i>Phase I</i> MODEL 4: Predictors of higher intensity of care provision	142
4.4.2	Summary of the logistic regression <i>Phase I</i>	148
4.5	Summary of <i>Phase I</i>	149
Chapter 5	<i>Phase II & III: Methodology and Results of the longitudinal analysis</i>	151
5.1	<i>Phase II: Results of the longer-term trajectories of informal care provision between 2009 (Wave 4) and 2015 (Wave 7)</i>	151
5.1.1	The sample population of ELSA Wave 4 to Wave 7	153
5.1.2	The longitudinal statistical data analysis design of longer-term transition in <i>Phase II</i>	155
5.1.3	A demographic and socio-economic comparison of carers and non-carers between 2009 and 2015	156
5.1.4	Introduction to the longer-term predictors of becoming a future carer	162
5.1.4.1	<i>Phase II</i> MODEL 5: Predictors of becoming a future carer	162
5.1.4.2	<i>Phase II</i> MODEL 6 and 7: Longer-term predictors of becoming a future carer – by sex	168
5.1.5	Summary of the logistic regression of becoming a future carer	171
5.1.6	<i>Phase II</i> MODEL 8 and 9: the effects of a caring break on the carer’s health	172
5.1.7	<i>Phase II: Longer-term transitions in caring characteristics</i>	180
5.1.8	Case studies	184
5.1.8.1	Frank (ID: 107006)	187
5.1.8.2	Edward (ID: 120438)	187
5.1.8.3	Margret (ID: 119009)	189
5.1.8.4	Daphne (ID: 118184)	190
5.1.9	<i>Phase II: Summary of longer-term transitions</i>	191
5.2	<i>Phase III: Short-term transitions of informal care provision between 2013 (Wave 6) and 2015 (Wave 7)</i>	193
5.2.1	The sample population of ELSA Wave 6 and Wave 7	194

Table of Contents

5.2.2	<i>Phase III: Descriptive analysis of the demographic and socio-economic characteristics short-term transitions by caring status</i>	195
5.2.3	<i>Phase III: Short-term transitions between intensity and directions of care</i>	201
5.2.4	Introduction to the <i>Phase III</i> binary and multinomial logistic regression analysis design	205
5.2.4.1	<i>Phase III</i> MODEL 10 and 11: Short-term predictors of change in self-reported health by caring status and by change to caring intensity	206
5.2.4.2	<i>Phase III</i> MODEL 12: Short-term predictors of change in economic activity by caring status	211
5.2.4.3	Summary of short-term changes to health and economic activity by caring status	214
5.2.5	<i>Phase III</i> MODEL 13: Predictors of discontinuing care	214
5.2.6	<i>Phase III: Summary of short-term transitions</i>	220
5.3	Summary of chapter 5, the longitudinal data analysis	221
Chapter 6 Discussion and conclusion		223
6.1	Introduction	223
6.2	Discussion: The Cross-sectional evidence	223
6.2.1	Who are the informal carers in England?	223
6.2.1.1	What are the gender differences between the carers?	224
6.2.1.2	How old are the informal carers?	224
6.2.1.3	Is one's marital status important?	225
6.2.1.4	Do people living in the North of England provide more care and does one's ethnic background make one more likely to provide care?	226
6.2.2	How many hours of care do carers provide and who are the care-recipients?	226
6.2.3	What are the predictors of providing care in 2015 and do such predictors vary according to gender?	229
6.2.4	Among informal carers, what are the predictors of providing over 20 hours of care per week?	230
6.3	Discussion: The longitudinal evidence	231
6.3.1	Short and long-term transitions and trajectories of informal care	231
6.3.2	The socio-demographic differences between caring statuses	232
6.3.3	Which socio-demographic characteristics in 2009 predict caring in 2015? And do the predictors vary by gender?	232
6.3.4	Does the timing of the care provision have an impact on the carer's health?	235

6.3.5	The association between economic activity and pathways into informal care provision	238
6.3.6	How do carers transition between different levels of intensity of care?	240
6.3.7	How do carers transition between different directions of care?	242
6.3.8	Among those who cared in 2013, what are the predictors of discontinuing care in 2015, compared to repeating care provision in 2015?	245
6.4	Limitations of this thesis and future directions of research.....	246
6.5	Policy implications and recommendations	249
6.5.1	<i>‘Starting Well’</i> - supporting the initial start of the journey....	250
6.5.2	<i>‘Maintaining Well’</i> - ensure good health and support working carers to remain in employment.....	251
6.5.2.1	Working-age carers.....	252
6.5.2.2	Older carers	253
6.5.3	<i>‘Discontinuing Well’</i> - the needs of the former carers	253
6.6	Contributions to research and conclusion.....	254
Appendix A	Quality of studies – methodological and limitations....	257
Appendix B	ERGO Ethics approval email	260
Appendix C	Direction of care.....	261
Appendix D	Comparison of the bivariate and multivariate including and excluding grandchildren	262
Appendix E	Sensitivity analysis – alternative cut-off points for intensity of care provision	275
Appendix F	Percentage of carers by direction of care, gender and self-reported health	278
Appendix G	Codebook: regression variables	279
Appendix H	Codebook: Matrix variables	280
Appendix I	Correlation matrix: Female respondents.....	281
Appendix J	Correlation matrix: Male respondents.....	282
Appendix K	Correlation matrix: Informal carers	283
Appendix L	Flowchart of sample including Wave 3 to 7.....	284
Appendix M	Caring characteristics before and after filter question applied, the ELSA Waves 6 and 7.....	286
Appendix N	Correlation matrix: Female future carer	287
Appendix O	Correlation matrix: Male future carers.....	288
Appendix P	Description of the socio-demographic characteristics of the overall sample of the ELSA Wave 7.....	289
Appendix Q	Detailed description of direction of care by sex.....	292
Appendix R	Detailed frequencies of the direction of care by age ...	293
Appendix S	Cross-tabulation of care and intensity (hours).....	294
Appendix T	Model 1: Binary regression wave 7, all blocks	296
Appendix U	Model 2: Binary regression wave 7 females, all blocks	297
Appendix V	Model 3: Binary regression wave 7 males, all blocks ...	298
Appendix W	Model 4: Binary regression wave 7 carers, all blocks...	299

Table of Contents

Appendix X	Binary Regression Wave 4 to 7, Female and male future carers	300
Appendix Y	Cross-tabulation of the age by timing of the caring episode	304
Appendix Z	Phase II: Transitions in the care directions Waves 4 to 7	305
Appendix AA	Model 5: Binary regression ‘repeating carers’ compared to ‘discontinued carers’, all blocks	306
Appendix BB	Alternative ‘Sandwiched’ scenarios.....	307
Appendix CC	Cross-tabulation of care provision and age of care-recipient	308
List of References	309

Table of Tables

Table 1	Carer and disability eligibility for benefits	16
Table 2	Research questions and statistical analysis plan.....	67
Table 3	Study population by ethnicity, the ELSA wave 7	75
Table 4	Derived variable: Marital status	76
Table 5	Derived variable: Household structure.....	77
Table 6	Derived variable: Region	78
Table 7	Best description of current situation (Wpdes), the ELSA Wave 7	80
Table 8	Derived variable: Economic activity	81
Table 9	Derived variable: Housing tenure	84
Table 10	Derived variable: Self-reported health	85
Table 11	Derived variable: Limiting Long-Term Illness	88
Table 12	Limiting Long-Term Illness by difficulties with ADLs, the ELSA Wave 7.....	89
Table 13	Number of people cared for by direction of care, the ELSA Wave 7	91
Table 14	Derived variable: Direction of care provided.....	92
Table 15	Derived variable: Caring intensity, ELSA Waves 5 to 7	94
Table 16	Derived variable for the change to self-reported health status in 2013 (Wave 6) and 2015 (Wave 7)	96
Table 17	Economic Activity in Wave 6 (2013) by Economic Activity in Wave 7 (2015), the ELSA	96
Table 18	Derived variable: Transition of Economic Activity in Wave 6 (2013) & Wave 7 (2015)	97
Table 19	Comparison of outcomes for different caring intensity level cut-off points.....	102
Table 20	Descriptive statistics: Total sample by non-carers and carers	110
Table 21	Descriptive statistics: Non-carers and carers, by sex, the ELSA Wave 7.....	114
Table 22	Descriptive statistics: Informal carers, by sex, the ELSA wave 7	118
Table 23	Correlation matrix: All respondents , the ELSA Wave 7	127
Table 24	Method comparison Model 1 : All respondents, the ELSA Wave 7	128
Table 25	Modelling strategy Model 1 : Informal care provision - all respondents, the ELSA Wave 7	130
Table 26	Logistic regression Model 1 : Predictors of care provision - all respondents, the ELSA Wave 7	133
Table 27	Method comparison Model 2 : Female and male respondents, the ELSA Wave 7	136
Table 28	Modelling strategy Model 2 : Informal care provision - female respondents, the ELSA Wave 7	137

Table of Tables

Table 29	Modelling strategy Model 2 : Informal care provision – male respondents, the ELSA Wave 7	138
Table 30	Modelling strategy Model 4 : Providing care for more than 20 hours per week - carers, the ELSA Wave 7	143
Table 31	Logistic regression Model 4 : predictors of care provided more than 20 hours per week, the ELSA Wave 7	146
Table 32	Distribution of the caring episodes.....	155
Table 33	Comparison of characteristics future caring status at 2009 (Wave 4 baseline) and 2015 (Wave 7).....	159
Table 34	Correlation matrix: All respondents, the ELSA Wave 4.....	163
Table 35	Method comparison Model 5 : All future carers, ELSA Wave 4.	164
Table 36	Model 5 : Predictors of becoming a future carer (longer-term)	166
Table 37	Method comparison Model 6 and Model 7 : male and female future carers, the ELSA wave 4	168
Table 38	Modelling strategy for Model 8 : Multinomial regression of self-reported health change by timing of care provision.....	173
Table 39	Self-reported health and timing of the longer-term caring episode	174
Table 40	Model 8 : The effect of a care-break on change in self-reported health outcome from 2009 to 2015.....	175
Table 41	MODEL 9 : The effect of a care-break on change in self-reported health outcome from 2009 to 2015, Spousal carers	178
Table 42	The intensity of care over the three waves (longer-term).....	181
Table 43	The direction of care over the three Waves (longer-term)	181
Table 44	The short-term transitions between caring Wave 6 (2013) and Wave (2015).....	195
Table 45	Descriptive summary by short-term caring status	197
Table 46	Short-term transition in intensity (hours per week) of care between Wave 6 (2013) and Wave 7 (2015)	201
Table 47	Short-term transition in intensity of care between Wave 6 and 7 - Female	202
Table 48	Short-term transition in intensity of care between Wave 6 and 7 - Male	202
Table 49	Short-term transition in direction of care between Wave 6 and 7	203
Table 50	Short-term transition in direction of care between Wave 6 and 7 - Female	204
Table 51	Short-term transition in direction of care between Wave 6 and 7 - Male	205
Table 52	Self-reported health status in (Wave 6) 2013 by self-reported health in Wave 7 (2015), the ELSA.....	206
Table 53	Model 10 : Multinomial regression by short-term change to self-reported health status	208

Table 54	Model 11: Multinomial regression by short-term change caring intensity and self-reported health status 210
Table 55	Model 12: Multinomial regression by short-term change to economic activity 213
Table 56	Caring intensity of ‘Discontinued carers’ (provided care in 2013, but not in 2015) 215
Table 57	Direction of care of ‘Discontinued carers’ (provided care in 2013, but not in 2015) 215
Table 58	Method comparison Model 13: ‘Discontinued carers’ and ‘repeating carers’, the ELSA 216
Table 59	Model 13: Determinants of discontinuing providing care compared to repeated caring 218
Table 60	Appendix C: Count of possible combination of direction of care 261
Table 61	Appendix D: Descriptive summary of analytical sample, by caring status comparing the inclusion of grandchildren..... 262
Table 62	Appendix D Descriptive summary of analytical sample, by caring status and sex, excluding grandchildren..... 264
Table 63	Appendix D: Descriptive analytical summary of caring characteristic comparing inclusion of grandchild carers, by sex..... 266
Table 64	Appendix D: Binary logistic regression of the total population of the ELSA Wave 7, excluding grandchildren. 267
Table 65	Appendix D: Binary logistic regression of the MALE population of the ELSA Wave 7, excluding grandchildren. 269
Table 66	Appendix D: Binary logistic regression of the FEMALE population of the ELSA Wave 7, excluding grandchildren. 271
Table 67	Appendix D: Binary logistic regression of over 20 hours of care per week, the INFORMAL CARERS of the ELSA Wave 7, excluding grandchildren. 273
Table 68	Appendix E: Descriptive characteristics of carers at alternative cut-off points of intensity of care provision..... 275
Table 69	Appendix E: Predictors of care provision at alternative cut-off points of intensity..... 276
Table 70	Appendix G: Variable labels for binary logistic regression models 279
Table 71	Appendix H: Variable labels for correlation matrices 280
Table 72	Appendix I: Correlation matrix females, the ELSA Wave 7..... 281
Table 73	Appendix J: Correlation matrix males, the ELSA wave 7..... 282
Table 74	Appendix K: Correlation matrix Informal carers only, the ELSA Wave 7..... 283
Table 75	Appendix M: Caring characteristics by filter question Waves 6 and 7..... 286
Table 76	Appendix N: Correlation matrix: the FEMALE sample of the ELSA Wave 4..... 287

Table of Tables

Table 77	Appendix O: Correlation matrix: the MALE sample of the ELSA Wave 4.....	288
Table 78	Appendix Q: Detailed cross-tabulation of Direction of care by gender	292
Table 79	Appendix R: Detailed cross-tabulation of Direction of care by age	293
Table 80	Appendix S: Cross-tabulation of direction of care and caring intensity – The overall caring subsample of the ELSA Wave 7	294
Table 81	Appendix S: Cross-tabulation of direction of care and caring intensity – The male caring subsample of the ELSA Wave 7: ..	294
Table 82	Appendix S: Cross-tabulation of direction of care and caring intensity – The female caring subsample of the ELSA Wave 7:	295
Table 83	Appendix T: Model 1 binary regression model of the ELSA wave 7, containing all blocks	296
Table 84	Appendix U: Model 2 binary regression model of the ELSA wave 7, containing all blocks	297
Table 85	Appendix V: Model 3 binary regression model of the ELSA wave 7, containing all blocks	298
Table 86	Appendix W: Model 3 binary regression model of the ELSA wave 7, containing all blocks	299
Table 87	Appendix X: Binary logistic model of the odds of becoming a future FEMALE carer	300
Table 88	Appendix X: Binary logistic model of the odds of becoming a future MALE carer (filtered).....	302
Table 89	Appendix Y: Age and timing of the caring episode	304
Table 90	Appendix Z: Transitions in the care directions Waves 4 to 7 ..	305
Table 91	Appendix AA: Model 3 binary regression model of the ELSA wave 7, containing all blocks	306
Table 92	Appendix CC: Informal care provided the past week: age(s) of person/people cared for: 65 years plus	308

Table of Figures

Figure 1	Family and societal generation timeline	9
Figure 2	Dimensions of solidarity in intergenerational family relations .	35
Figure 3	The Notion of Serial Carers	51
Figure 4	The complex pathways of opportunity costs of care provision.	56
Figure 5	The Informal Care Model.....	59
Figure 6	Conceptualising the pathways into informal care provision	64
Figure 7	Self-reported health - five categorical underived variable, the ELSA Wave 7.....	86
Figure 8	Self-reported health - three categorical derived variable, the ELSA wave 7	87
Figure 9	Self-reported health - three-category variable by age, the ELSA wave 7.....	87
Figure 10	Hours spent looking providing care last week, the ELSA Wave 7.....	790
Figure 11	Flow chart of excluded respondents, the ELSA Wave 7.....	106
Figure 12	Age by sex, the ELSA Wave 7.....	107
Figure 13	Percentage of carers by hours of care provided per week and direction of care, the ELSA Wave 7	119
Figure 14	Percentage of carers by age and direction of care, the ELSA Wave 7	120
Figure 15	Percentage of carers by marital status and direction of care, the ELSA Wave 7	121
Figure 16	Percentage of carers providing either extra-residential care or co-residential care by the intensity of care, the ELSA Wave 7.....	122
Figure 17	Percentage of carers providing either extra-residential care or co-residential care by direction of care, the ELSA Wave 7	123
Figure 18	Forest plot of the predictors of care provision – female respondents, the ELSA Wave 7.	140
Figure 19	Forest plot of the predictors of care provision – male respondents, the ELSA Wave 7	141
Figure 20	Flowchart of the composition of the study sample, the ELSA Waves 4 to 7.	154
Figure 21	Forest plot of the longer-term predictors becoming a future carer by gender, the ELSA Waves 4, 5, 6 and 7	170
Figure 22	Longer-term transitions between directions of care, the ELSA Waves 5 to 7	183
Figure 23	Flowchart of excluded respondents – the ELSA Waves 6 and 7.....	194
Figure 24	Caring status in 2015 by sex	196
Figure 25	Short-term caring status in 2015 by marital status.....	199
Figure 26	Short-term caring status in 2015 by self-reported health.....	200

Table of Figures

Figure 27	Appendix F: Percentage of carers by direction of care, gender and self-reported health.....	278
Figure 28	Appendix L: Flowchart of sample including Wave 3 to 7	285
Figure 29	Appendix P: Percentage of all respondents by age and sex, the ELSA Wave 7	289
Figure 30	Appendix P: Percentage of all respondents by age, sex and self-reported health, the ELSA Wave 7	290
Figure 31	Appendix BB: Comparison of two generations at risk of being sandwiched.....	307

Research Thesis: Declaration of Authorship

Print name:	Maja Emilie Fuglsang Palmer
-------------	------------------------------------

Title of thesis:	Pathways into Informal Care Provision
------------------	--

I declare that this thesis and the work presented in it is my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references below]:

Signature:		Date:	
------------	--	-------	--

Acknowledgement

“No one said it would be easy, but no one said it’d be this hard. No one said it would be easy, no one thought we’d come this far”.

(Bottrell, B. *et al.* 1993, Track 7).

It was indeed not easy, but with much appreciated help, kindness and support from many people over the last three years, I have come this far. I am so very grateful for the small gestures of a much needed coffee and walks/talks, and also for all the substantial and constructive feedback and help, I have received. It has meant the world to me, and I would not have been able to do this PhD without it.

Firstly, my sincere gratitude goes to my two amazing supervisors Professor Athina Vlachantoni and Professor Maria Evandrou for their never-ending support, advice and guidance. The PhD journey is fascinating and inspiring, but also at time very challenging and testing. The passion, motivation and encouragement I got from Athina and Maria shaped my PhD journey, and kept me on track, but most importantly, made my journey a very unique and a pleasant experience. It is rare to find that magnitude of enthusiasm, which I got from my supervisors. Thank you both for being so incredibly patient with me and for believing in me when I doubted myself. I could not have asked for better supervisors. You are an inspiration.

I owe a huge debt of thanks the ESRC South Coast Doctoral Training Partnership (SC-DTP) and the Centre for Population Change (CPC) for providing me with the funding which gave me the opportunity to pursue my dream of doing a PhD. I would also like to thank the Department of Gerontology at the University of Southampton for all the great debates, talks and support. There will always be special place in my heart for all members of the teams mentioned, all of who would, without fail, be there when needed the most, be it for a chat or sorting out issues.

Lastly, I would not have made it this far without the support of my husband, Barry Palmer; my mother, Aase Nielsen; my brothers, Tonny Fuglsang Nielsen and Michael Fuglsang Hansen; and my aunt, Grethe Hansen. I dedicate this thesis to all of you. Thank you for sitting through hours of listening to me talk about my research. My mum and my aunt in Denmark have been my inspiration for this PhD, and have provided never-ending support. Above all, special thanks and recognition are due my dear husband. I remember the look on his face when I came home one day and said, “I decided to keep on studying, so I am going to do a PhD!” Thank you for keeping your patience with my crazy running challenges,

injuries and, at times, manic stress levels (there seems to be a positive correlation between running and PhD stress, which is yet to be tested for level of significance - maybe my next PhD?). I promise I will get one of those “real” jobs now.

Abbreviations

ADL: Activities of Daily Living

IADL: Instrumental Activity of Daily Living

CI: Confidence Interval

COPNI: Commissioner for Older People for Northern Ireland

DLA: Disability Living Allowance

DH: Department of Health

DHSC: Department of Health and Social Care

DWP: Department for Work and Pensions

GOR: Government Office Region

ELSA: The English Longitudinal Study of Ageing

ERGO: The Ethics and Research Governance

ESRC: The Economic and Social Research Council

HLE: Healthy Life Expectancy

HR: Hazard Ratio

HSE: The Health Survey of England

LA: The Local Authority

LE: Life Expectancy

LLTI: Limiting Long-Term Illness

LTI: Long-Term Illness

NAO: National Audit Office

NCRM: National Centre for Research Methods

NHS: The National Health Service

NLW: The National Living Wage

NSSEC: The National Statistics Socioeconomic Classification

OECD: The organisation for Economic Co-operation and Development

ONS: The Office for National Statistics

OPCS: Office of Population, Censuses and Surveys

OR: Odds ratio

SES: Socio-economic Status

SHARE: The Survey of Health, Ageing and Retirement in Europe

SPA: State Pension Age

SRH: Self-reported health

UK: United Kingdom

UKDS: UK Data Service

WHO: World Health Organization

Chapter 1 Introduction

Providing informal care for a loved one is becoming an increasingly common experience for individuals, and informal carers have been identified as a key prerequisite in ensuring that individuals in need of care continue to experience a good quality of life (Hirst, 2002; Balducci *et al.*, 2008; AgeUK, 2017). Providing care can be rewarding for the individual carer, as it can strengthen the bond between the carer and the person cared for. Furthermore, carers have reported health benefits, as a result of having new meaning and purpose to life by providing care (Hiel *et al.*, 2015; Caputo *et al.*, 2016). Nevertheless, providing informal care often occurs alongside one's employment, family and social life, and this may place the carer in a position where they have to make difficult choices; should they solely focus on care provision, can they juggle both caring and working if they are of working age, or could they afford to pay for formal care to be provided? The pathways into care provision can therefore also be a stressful experience with potential adverse effects on the health, emotions and finances of the care provider (Carmichael and Ercolani, 2016). The pathways into care provision are guided not only by the carer's choices and opportunities, but are also influenced by demographical changes.

The population in the United Kingdom (UK), as indeed globally, is ageing as people are living longer (DeSa, 2017). In England there are over 20.1 million people aged over 50, accounting for over a third of the total English population (ONS, 2017e). The proportion of the population aged over 65 in the UK has increased from 14% in 1974 to 18% in 2016 and this proportion projected to rise to 26% by 2066 (ONS, 2018b). This, along with the fact that spending on social care in England has decreased in real terms since 2010, has resulted in social and healthcare resources being stretched, and raises challenges for the delivery of care to vulnerable individuals in the community (Hiel *et al.*, 2015; ONS, 2017g). As a consequence, the government is increasingly relying on the provision of informal care (*Ibid*). There are currently an estimated 7 million informal carers of all ages in the UK (Buckner and Yeandle, 2015). However, demographic changes, such as lower fertility rates, the increase in the labour market participation for women and older people, and an increase in divorce rates have resulted in concerns for the future supply of informal care (ONS, 2013d; Evandrou *et al.*, 2015b; Hoff, 2015; Pickard, 2015). Each of these changes will be discussed in more detail in the next section.

Chapter 1

Using the English Longitudinal Study of Ageing (ELSA), this study aims to gain a better understanding of individuals' pathways into informal care provision, as this is a central part of ensuring future care provision and to support carers in their different caring roles. The terms 'informal carers' and 'carers' will be used interchangeably throughout the study, and unless otherwise specified, the care provided will be assumed to be unpaid and all carers are aged over 50 (see section 1.1 for the definition of informal care).

This thesis is made up of 6 chapters. Chapter 1 introduces the background of informal care, and discusses why it is important to gain further understanding of the pathways into informal care. Chapter 1 also outlines the research questions and the rationale for conducting this research. Chapter 2 draws together the theories of informal care, and the past and current literature on informal care provision. The material in this chapter also guides the methodology and analysis plan by conceptualising the pathways into care provision. Chapter 3 details the sample population used for the data analysis, as well the broader methodological approach. Chapter 4 presents the description of the cross-sectional (*Phase I*) methodology, including both descriptive and logistic regression analysis and results. Chapter 5 details the longitudinal data analysis methodology (*Phase II* and *III*) and the results. Chapter 6 critically examines the key findings of this research in the light of existing evidence and specifies its contribution to research and its policy implications, as well making recommendations for further research directions (see also section 1.3).

1.1 Background

A common definition of an informal carer is someone who: '*... spends a significant proportion of their life providing unpaid support to family or potential friends. This would be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problem*' (HM Government, 2008 p.19). Scholars have for decades debated how to define informal care, however it is generally agreed that the provision of informal care is unpaid and outside the framework of organisational or professional work (Hiel *et al.*, 2015). The tasks carried out by a carer may involve help with personal care or supervision, household chores or other practical errands, transport to doctors, social companionship, emotional guidance or help with arranging professional care (Beesley, 2006; Broese van Groenou and De Boer, 2016).

A caveat of the term 'informal carer' is that the 'informal' nature of the care could be perceived as misleading, as it does not fully incorporate the magnitude of the

tasks involved in providing care, nor does it describe the dedication and scale of the commitment of the individual providing care (Beesley, 2006; Broese van Groenou and De Boer, 2016). Moreover, many informal carers feel that they had little or no choice in taking on their role (Beesley, 2006; Heath *et al.*, 2018), and this may be due to a lack of support from other family members or due to public services not meeting the needs of the person needing care (Larkin and Milne, 2014; Heath *et al.*, 2018). A pragmatic approach would suggest that the degree of choice available to carers will differ depending on their individual circumstances and those of the people needing care; for some, the degree of choice may be more constrained than for others (Al-Janabi *et al.*, 2017). Understanding of the carers' motivations, choices and constraints is critical when considering the individual's pathway into informal care and will be further discussed in sections 2.2 and 2.3.2.2.

Formal care, on the other hand, has been defined as including services which are paid for by the local authority or by the user (National Audit Office [NAO], 2014). Around 2.1 million people in the UK received some level of informal care in 2014 (ONS, 2016e) and there were 873,000 people in England receiving formal long-term care during 2015/2016 (NHSDigital, 2017). The more common formal care services are (1) *Home Care*, consisting of help with personal tasks in and around the home, (2) *Day Care*, which is care provided outside the home, and which also provides a respite for informal carers, or (3) *Care provided in Care homes or nursing homes*, which offer 24-hour support in a residential setting, and this type of service also offers the highest levels of support (Pannell and Blood, 2012). Nursing homes additionally provide assistance from qualified nurses, including care for complex care needs and palliative care (Thomas, 2006; Pannell and Blood, 2012). Respite care for the carer includes replacement care, day-trips, holidays or other leisure activities (Brimblecombe *et al.*, 2017; NHS, 2018). As the care provided in institutional settings is primarily formal and complex in nature, it is anticipated that individuals living in such settings will not themselves be providing care to others. Therefore, this study will only focus on individuals living in private households in the community, thereby excluding respondents living in an institution (see also section 4.2 for further justification of the exclusion of these respondents from the data analysis).

Historically, care provided to older people across Europe has relied on informal care - primarily from family members (World Health Organization [WHO], 2008). During the 19th century, the state involvement in the health and social welfare of older people grew, however it did not displace family-care provision. During the

Chapter 1

20th century, large-scale institutions and hospitals became the dominant forms of care provision (Ibid). Nevertheless, from the 1950s onwards, criticism of such places grew from professionals and care-recipients, due to the often poor conditions and impersonal nature of care provided (Österle and Rothgang, 2010). Since the 1960s, policies have started to promote community-based, integrated and home-based care, as an alternative to institutional care, thereby allowing for more independent home-based living (WHO, 2008). In England, there was not a direct policy shift from institution-based care to family-care, but rather a shift to community-based formal services prompted by the 1988 Griffiths Report, and only subsequently a greater emphasis on family-based care (Langan, 1990; WHO, 2008). This shift in how care was provided followed a continuum of policy changes from ‘doing “to” people, to doing “for” people and then doing “with” people’ (Langan, 1990; Jones, 2007). The intention of these policies was that people should have more choice and control, and be ‘in charge’ of performing activities ‘by’ themselves, although with the assistance to do so, and as the 2006 Whitepaper ‘*Our Health, Our Care, Our Say*’ stated with “*more choice and a louder voice*” (Department of Health [DH], 2006). This move was also seen as a way to stem the public spending on residential and nursing homes (Jones, 2007). The attention on the choice of the care-recipient in public social care policies has been an improvement, but it still points to debate on whether providing informal care is perceived to be a free choice by the individuals concerned (Al-Janabi *et al.*, 2017). Moreover, public policies are often more focussed on the economic challenges of an ageing population, rather than direct support of older people (Lloyd, 2010). This will be further discussed in section 1.1.2.

Differences in how people in need are cared for can be seen between developed and developing countries, and even within the economically developed regions, there are vast contrasts. European countries differ widely in the extent to which they rely on informal care. For example, 20% of people over 50 in the Czech Republic and Belgium provided care in 2015, whereas this was less than 10% in Poland and Portugal, and this does not include care provided to children or grandchildren (Organisation for Economic Co-operation and Development [OECD], 2017). The variations in the number of people providing care across Europe are due to cultural differences in the delivery of intergenerational support, but also to a difference in the delivery of the social welfare systems of the countries (Haber Kern and Szydlik, 2010) (see also section 2.2.3, for further details of cultural norms). In the UK, informal care also plays a significant part in the healthcare and social system, and 32% of men and 41% of women aged over 50

with at least one limitation with daily activities¹, rely exclusively on informal sources of support in later life (Breeze and Stafford, 2010). An estimated 10-12% of all adults aged over 16 years provide some kind of informal care to family members, friends, neighbours or others (Dahlberg *et al.*, 2007; Vlachantoni *et al.*, 2013; Evandrou *et al.*, 2015b; Robards *et al.*, 2015). This proportion has remained relatively stable over the last 30 years (Pickard, 2002), although the proportion of carers who provide intense care (more than 20 hours per week) has increased over the last decade or so (Robards *et al.*, 2015), (see also section 2.3.1.1). Caring frequently forms part of a long-term dyadic relationship between adult children and their parents, or between spouses (or partners) (Carers UK, 2015; Pickard, 2015). The relationship of these dyads does not only determine the likelihood of someone entering the pathway of caring provision, but also the intensity and nature of the care provided.

Understanding the pathways into informal care provision firstly requires an understanding of how pathways are distinguished between transitions and trajectories. A transition is a discrete life change, or the onset of a change, often accompanied by a socially shared event, for example from being single to becoming married (Elder, 1994). A trajectory is the individual's sequence or the progression of long-term patterns of stability and change, and can include multiple transitions (*ibid*). Early and later life trajectories are interrelated and can therefore affect the status of older people in the family and their sources of support (Hareven, 1996b). A trajectory could, for example, be an individual's occupational career, which follows a long-term pathway, including education and making the most of employment opportunities, as well as individual choices (*ibid*). The pathways into informal care are complex and dynamic. Some individuals may become informal carers following a family member experiencing a traumatic health-related event, and this may be a one-off event with a relatively fast recovery period, which requires only a short-term caring episode (Barrett *et al.*, 2014). Others may move into the caring role following the birth of a child with disabilities, which circumstantially places that individual (and their partner) on a long-term trajectory of care provision (*ibid*). Still, some individuals may transit between caring for various people, such as their children and parents (Barrett *et al.*, 2014). Sections 2.3.1.1 and 2.3.2.2 will further explore these transitions.

¹ This included three measures of self-reports of physical functioning: activities of daily living (ADL), instrumental activities of daily living (IADLs) and motor skills or strength (Breeze and Stafford, 2010). A detailed discussion of ADLs and IADLs can be found in chapter 3.

Chapter 1

Given the complexity of an individual's pathway into informal care provision, upholding a dynamic perspective in mapping these pathways is necessary to understand the changes which carers typically experience. Furthermore, it highlights the heterogeneity in the type, intensity, and the duration of the care provision, and the cumulative impact such provision can produce (Hirst, 2002) (further discussion on cumulative effects can be found in sections 2.2.1, 2.3.1 and 2.3.2.1). Establishing the temporal order of life events related to care provision is also needed for fully understanding the relationship between the caring role and the carers' health, employment and financial circumstances (Ibid). The concepts of transitions and trajectories are key elements of the conceptual framework of this study, which is discussed in section 2.5. However, it is not only the individual's life-course and experiences which shape their response to the caring role, but also key structural dimensions, such as demographic changes to the supply of and demand for informal care provision, which are discussed in the following section.

1.1.1 The demographic changes influencing the supply of and demand for informal care

The increase in the demand for informal care is driven by the increase in life expectancy (LE) and the increasing gap between LE and health life expectancy (HLE). In 2016 the LE at birth for English men was 79.5 years and 83.1 years for women. Aged 65, English men can expect to live for a further 19 years and women for a further 21 years (ONS, 2016c). Over the last decade, the UK has also seen overall improvements in individuals' HLE, and the number of years an individual could expect to spend in "good" health in 2015-17 was 63.1 for males and 63.6 for females (ONS, 2018a). Since 2012 the improvements seen in HLE have plateaued (ONS, 2016d). These changes to LE and HLE have had and will continue to have, an impact on the demand for and supply of care in the future. From a demand perspective, if the rise in LE has outpaced the increase in HLE, more older people may need support and care for longer (Appleby, 2013; AgeUK, 2017). On the other hand, changes in both LE and HLE would imply an increase to the pool of available informal carers, as older people are also more likely to provide informal care (OECD, 2011). Nonetheless, this will only apply if the health of the carers is preserved by providing the necessary support needed by carers (AgeUK, 2017) (how carers are best supported will be further discussed in sections 1.1.2 and 2.3.2.2). At the same time, it is not only LE and health which affect the supply of and demand for informal care, but other demographic factors

such as fertility and changes to the typical family structure also play an important part in how informal care is provided.

The availability of informal carers is affected by the demographic changes taking place over the life-course, including decreased and delayed fertility in the younger generations (Grundy and Henretta, 2006) and the pathways into care provision is for example influenced by number of adult children a care-recipient have (see also section 2.3.1.5). One of the most profound demographic changes is the fertility transition, reflected in the long-term decline in the number of children born per woman, which has already happened in developed countries and is currently happening in developing countries (Mason, 1997; McDonald, 2000; Bongaarts, 2009). Although fertility rates in the UK recovered during the 2000s to reach near-reproduction levels at almost two births per woman (Hoff, 2015), there has been a postponement the first childbirth and the average age at birth of the first child was 30 years in 2014 compared to 27 years in 1990 (ONS, 2016a). Demographic shifts represent an ever-present structural change in modern society, however the postponement of the first birth is affecting the future supply of adult children available to provide care to their parents. Pickard (2015) projected that the number of people under the age of 65 who provide intense care to older parents would need to increase by over 40% between 2007 and 2032 if supply were to keep pace with demand (see also section 1.2).

Moreover, this substantial decline in fertility, taken together with changes in the timing of transitions associated with marriage, parenthood and grandparenthood, and changes to family roles and norms, have led to contrasting and complex family structures (Haberkern and Szydlik, 2010; Lowenstein and Katz, 2013). Family generations are covering more years until the emergence of the subsequent generations, which has led to a smaller and more 'vertical' family structure and a cohort with both dependent children, and with ageing and potentially fragile parents, the so-called 'sandwich generation' (Grundy and Henretta, 2006; Government Office for Science, 2016). The consequences of the changes to the family structure will be covered in detail in section 2.2.3.

The supply of informal care is not only affected by the decline of adult children available to provide care for parents, but also by the motivation of the available children. There have been conceptual hypotheses of a decline in the filial obligations and changes to intergenerational relationships, which may also have affected the willingness of younger cohorts to provide informal care (Demey *et al.*, 2013; Pickard, 2015), however such hypotheses have been debated (Evandrou

Chapter 1

et al., 2016). As it can be difficult to capture changes to filial obligations and intergenerational relations, scholars have explored how a person may expect their own care to be provided (i.e. expectations of formal state provided care or informal care provided by family) (Demey *et al.*, 2013). However, these may only offer partial answers to whether future cohorts will repeat the patterns of care provision (*ibid*). The concepts of altruism and reciprocity are critically addressed in section 2.2.3, as well as a further discussion of intergenerational support.

Scholars have argued that changes to the family structure have contributed to the breakdown of the traditional family structures in both developed and developing countries (Aboderin, 2004; Silverstein *et al.*, 2006). However, Harper (2006) points out that the traditional nuclear family is actually ill-fitted for a post-modern society, and that alternative family forms are emerging, including an increase in multigenerational relationships (Bengtson, 2001). The increase in divorce rates, especially in later life, may have contributed to this breakdown and although the overall divorce rate has fallen, the number of men aged over 65 divorcing increased by 23% between 2005 and 2015, and for women aged over 65 this increased by 38% (ONS, 2017c). This is partly caused by the increase in the overall population aged over 60, but it also reflects a growing social acceptance of divorce/separation in later life (Grundy and Henretta, 2006; ONS, 2017c). The increase in divorce and remarriage also contribute to more complex family networks, where older parents may have relationships with biological children, as well as with stepchildren (Hoff, 2015). However, some scholars have debated whether such complex family structures decrease the reliability of family support, as more older family members may potentially need support (Brown and Lin, 2012; Broese van Groenou and De Boer, 2016). Conversely, it could also be argued that more complex structures increase the number of family members available to provide care, but this may lead to multifaceted negotiation between siblings and other relatives in how care is provided (Ganong *et al.*, 2009; Hoff, 2015) (see also section 2.3.2.3).

Greater internal mobility not only within England, but also across Europe has also affected the traditional family structures and more family members are living at considerable distances from each other (WHO, 2008). In addition to distance among family members, a sharp increase in the number of people living alone is expected, and is particularly marked in older age (Community and Local Government, 2010). By 2033, it is estimated that 41% of all households in England will consist of individuals living alone, compared to only 12% in 1961 (*ibid*). As spouses and partners are an important source of informal care (Demey

et al., 2013; Pickard, 2015), such changes in the patterns of relationships and cohabitation may lead to a shortage of care within the household. Indeed, projections for 2032 show that the demand for care from spouses is likely to increase much faster than the demand for care from children (Pickard, 2015). Nevertheless, with the rise of *de facto* single persons (persons who may be married but living in single households) in need of care, the demand for care from adult children will continue to increase (*ibid*) (this will be further discussed in session 2.2.3).

The demographic changes described so far have not affected the population equally, rather different generations have had different experiences. This study concentrates on the population aged over 50 living in England, however this population is not homogenous and spans over various generations, as seen from Figure 1. Figure 1 shows how the mid-life baby-boomer generation is “sandwiched” between parents, children and grandchildren, as well as the birth year of the included generations of this study (i.e. the baby-boomers and the oldest old).

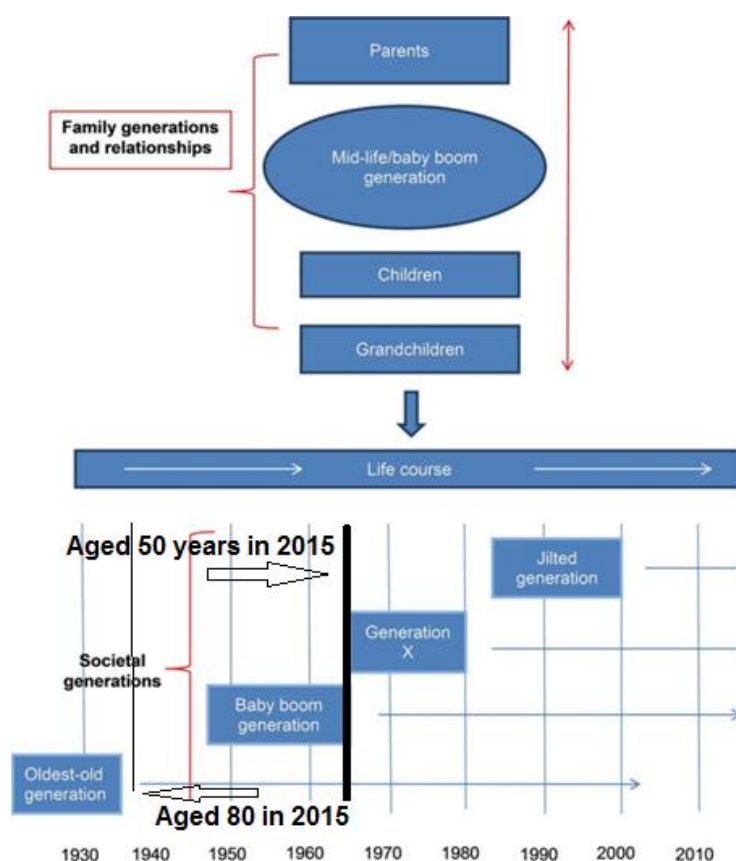


Figure 1 Family and societal generation timeline
The solid lines represent the threshold birth year of respondents aged 50 and 80, respectively, when the ELSA Wave 7 data were collected.

Source: Adapted from Keating *et al.* (2015).

Chapter 1

In the UK, there were two post-war 'baby-boomer' cohorts, each having markedly different life experiences and expectations (Bristow, 2016). The 1946-50 'first baby-boomers' were born into a time of post-war austerity, with rationing and selective education. The 1960-65 'second baby-boomers', on the other hand, grew up in the consumer-spending booms of the 1960s and had the benefits of comprehensive secondary education (Evandrou and Falkingham, 2006). This advantage, however, reversed for the two cohorts when they entered the job market; the first cohort entered the job market during the economic upturn of the 1960s, whereas for the second cohort this happened during the 1970s when the economy was entering recession, resulting in a rise in unemployment (Ibid). The baby-boomers became the focus of academic interest at the beginning of the 21st century, as they were the first cohort of such a large size to survive into later life (Tomassini, 2005; Bristow, 2016).

The baby-boomers are also of particular interest, as many are included in the midlife 'sandwich generation', having both ageing parents and children in need of support (see Figure 1). The demographic changes and how they have impacted the family structure, and consequently how intergenerational support is distributed, has led to an expansion of the term 'sandwich generation'. For example, the term "The Club Sandwich Generation", defines as individuals in their 50s and 60s, sandwiched between their ageing parents, adult children and grandchildren (Abramson, 2015) and the "Panini Sandwich Generation" includes older adult carers who themselves face the challenges of ageing simultaneously with having caring responsibilities (Ibid). Juggling multiple roles may inevitably have an effect on individuals' ability to provide care, and questions arise as to how mid-life adults could divide their effort between helping their older parents, and their own children. Moreover, whether such 'juggling' might cause a reduction of help provided towards either of the generations, will be further discussed in sections 2.2.3, 2.3.1.5 and 2.3.2.2. As well as the sandwich generation, the 'oldest-old' generation (see also Figure 1), is included in this study. Conventionally this generation is defined as those aged over 85, and this is the generation more likely to experience frailty, illness and dependence in comparison with those aged aged 65-84 (Tomassini, 2005). This generation are themselves also more likely to be needing care, but at same time for the individual in the 'oldest-old' generation, providing care may also be more challenging than for someone of a younger generation.

The demographic changes covered until this point have related to family structures and age, however gender norms and roles have also had a profound

effect on the pathways into care provision. Since the 1970s there has been a considerable increase in women's labour market participation in the UK, and since women are the most likely providers of informal care, this has also led to women often having to combine multiple roles within the family and labour settings, such as being a 'sandwich generation' (Vlachantoni *et al.*, 2013; Stone *et al.*, 2015). In 1971, 53% of women were in employment, compared to 71% in 2017 (ONS, 2017f). However, there is still a marked gender inequality in working hours and 42% of all employed women work part-time, compared to only 12% of employed men (Ibid). Female labour market participation is only set to rise in the future, mainly as an effect of highly qualified women entering the labour market (Hoff, 2015). Women are more likely to experience social pressure to provide care (Bauer and Sousa-Poza, 2015), which often means that women either take time out of the labour market or reduce their working hours in order to combine care provision with paid work, especially if the hours of care provision intensify (Gomez-Leon *et al.*, 2017). This may leave women at a disadvantage over the life-course, both socially and economically (Glaser *et al.*, 2005; Robards *et al.*, 2015; Stone *et al.*, 2015). This is further discussed in section 2.2.1

In addition to the effect of intergenerational relationships and gender, the availability of informal carers is also affected by the economic resources of the carer (Demey *et al.*, 2013; Pickard, 2015). Being in paid employment for some offers the opportunity to provide support by paying for formal care, which may be considered as a form of intangible informal care (i.e. financial support, rather than physical or practical). Moreover, having enough savings may also mean that an adult child (or a spouse or partner) is in a position to reduce their working hours in order to provide informal care, but vice versa, financial restraints may also mean that they cannot afford to stop working, thereby limiting their availability to provide care (Adler and Newman, 2002; Vlachantoni *et al.*, 2015). The potential causal direction between care provision and employment will be further discussed in section 2.3.2.2.

At the same time, the rate of employment of workers over the age of 50 has grown significantly from 55% to 70% over the past 30 years, and the employment of individuals aged over 65 has doubled in the same time period from 5% to 10% (Department for Work & Pensions [DWP], 2015). The recent trends in employment, especially for women, are partly due to the increase in the state pension age (SPA). The Pension Act 2011 set to accelerate the recommendation of the previous Pension Act (1995) to increase the SPA for both men and women. Starting in April 2016, women's SPA was set at 63 years and will in November

Chapter 1

2018 reach 65 years in line with men's. The equalised SPA will then rise for both genders to 66 by October 2020 (Thurley and Keen, 2017), however, the increase in the SPA may result in a drop in the future supply of informal carers (see further discussion in section 1.1.2).

As mentioned, the government is relying on informal carers to provide care, but at the same time the government is also trying to reconcile this with an increase in employment. How public spending and policies have helped to shape the nature of informal care provision is discussed in the following section.

1.1.2 Public spending, benefits and government policies related to informal care provision

The previous section has focused on demographic changes, which have had a significant impact on the demand and supply of informal care. However, policy changes have also had an important influence on individuals' pathways into informal care provision.

Public expenditure on social services for older people is projected to rise under the current funding system based on the drives of long-term care demands from around £7.2 billion in 2015 to £18.7 billion in 2040, under the assumption of current care demands and unit costs of care services (Wittenberg *et al.*, 2018). The numbers of disabled older people in households receiving informal care is projected to increase by 116% by 2070, and care provided by a spouse or partner is projected to increase faster than of that provided by an adult child. Nevertheless, to avoid unmet caring needs of parents, care provided by adult children is required to increase by 60% over the next 25 years (Ibid).

Informal care has long been important to the Government, and although it is difficult to put a value on informal care (Bauer and Sousa-Poza, 2015) attempts have been made to valorise informal care; a report from Carers UK estimated that the economic value of the contribution made by informal carers in the UK in 2015 was £132 billion per year (Buckner and Yeandle, 2015). This is close to the total annual cost of health spending in the UK (Ibid). This section provides an overview of planning and future of formal care and relevant policies aimed at informal carers, the benefits and support available for carers.

Informal care has been seen as a significant substitute for formal care, and as a way to reduce the cost to Local Authorities (LAs) (Kalmijn and Saraceno, 2008; Dykstra, 2010). Informal care is, however, associated with indirect costs to the government, including the loss of workforce, social exclusion of carers, as well as an adverse effects on the carers' health, which then present a direct cost to the

NHS (Wanless *et al.*, 2006). On the other hand, formal care results in a direct expense to the health and social care budget for local authorities. A QualityWatch programme report by The Health Foundation and The Nuffield Trust tracked the quality of health and social care services in England between 2010 and 2015 (The Health Foundation and the Nuffield Trust, 2014). A long-term mismatch between the demand for adult social care and public resources was noted, which was due to the increase in demand and the constrained budgets across the public sector (Ismail *et al.*, 2014). With a projected shortfall of 16,000 informal care providers by 2032 (Pickard, 2015) an important policy question is whether the supply of informal care will continue to meet demand if nothing further is done to support the carers (Carmichael *et al.*, 2010). Furthermore, from a policy perspective the challenge will be to balance the government's reliance on the future supply of informal care as a main resource of care when this supply is shrinking.

Policy makers depend on research to guide their policies, however surveys into informal care provision are relatively recent. The 1985 Office of Population, Censuses and Surveys (OPCS) '*Informal Carers Survey*' was a large-scale survey that focused on informal carers in the UK. It represented a historic landmark, as it was the first survey to attempt to collect data on the hitherto unrecognised "domestic labour force" (Arber and Ginn, 1990). It was seen as the first official recognition of any kind of domestic labour as an essential contribution to the community (Ibid). In 2001, the UK census included for the first time a question asking whether the respondents provided any form of informal care (Hanratty *et al.*, 2007), and this further led to an increase in research on various aspects of informal care provision, such as for example Robards *et al.* (2015) who explored transition is caring and caring intensity between 2001 and 2011.

Over the last few decades, government policies have had an increased emphasis on supporting the individual carer (Beesley, 2006). In 2006, The King's Fund commissioned a review led by Sir Derek Wanless (Wanless *et al.*, 2006), which set out to determine how much should be spent on social care for older people over the next 20 years, and highlighted the care needs and the shortcomings of the social care system. The review set out comprehensive recommendations on how to optimise the social care system, including recommendations for greater support for carers. The review came in the light of a reduction in the supply of informal care and increased demands for formal care, which would otherwise make the cost of social care prohibitively high (Ibid).

Chapter 1

The outcome of the Wanless review, and building on the first-ever Carers' strategy '*Caring for carers*', published in 1999 (DH, 1999), was the English Carers' Strategy 2008-2018 '*Carers at the heart of the 21st-century families and communities*' published in 2008 (HM Government, 2008). The vision of the strategy was as follows:

'Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen'. (HM Government, 2008, p.5).

The strategy originally set 4 outcomes to be achieved by 2018, however, in 2010 the Coalition Government refreshed the strategy, issuing a policy document entitled '*Recognised, valued and supported: next steps for carers strategy*' (DH, 2010). This new strategy retained the original outcomes, but inserted four priority areas.

1. Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in the planning individual care packages
2. Enabling those with caring responsibilities to fulfil their educational and employment potential
3. Personalised support both for carers and those they support, enabling them to have a family and community life
4. Supporting carers to remain mentally and physically well

(DH, 2010).

Since the publication of the revised document some progress has been made to support carers in key areas. This includes the legal reforms offering the right to request flexible working arrangements to all employees; better integration between health and social care; and improved entitlements to assessment for carers of all ages, such as, for example, carer's eligibility for support being independent of the person they care for (DH, 2014). In 2018 the Government released the document '*Carers Action Plan 2018 -2020 – Supporting carers today*' (DHSC, 2018). The plan retains the strategic vision from the 2008 document, but sets out Government's commitment to supporting carers through actions across five priorities emerging from the carers' Call for Evidence, with focus on delivery and tangible progress (Ibid).

In England, publicly-funded care makes up only a minority of the total value of adult care, and this proportion is decreasing (NAO, 2014) (see also section 1.1.2). The introduction of the Care Act 2014, which came into force in April 2015 ensured the legal entitlement for carers to be assessed by their local authority, regardless of how much care they provide (Legislation.gov.uk., 2014). Services provided include institutional care and community-based services, and the latter can be in/around the house support, such as home-care or in the form of direct payments for users to purchase their own support in order to enable people to live independently (Doyle, 2012; Ismail *et al.*, 2014). Direct payments are a form of benefits paid directly by the LAs to the care-recipient, which offer the individual the freedom to organise the services they need themselves and to pay directly (Jarrett, 2015). However, in the Carers UK (2018) report 'State of Caring 2018' it was highlighted that only 67% of carers had received a Carer's Assessment in the last 12 months (Ibid). For an informal carer, a means-tested Carer's Allowance is available, see Table 1. Other benefits available to the carer may include Pension Credits, supplementary benefits for children, increased social benefits and Specified Adult Childcare Credits (Carers Trust, 2017; GOV.UK, 2019).

As seen from Table 1, the benefits for the informal carer are dependent on the benefits attached to the care-recipient.

Table 1 Carer and disability eligibility for benefits

	Benefit	Eligibility	Amount	Notes
Direct payment to the carer	Carer's Allowance	<ul style="list-style-type: none"> Over 35 hours a week caring The person cared for must receive either (i) Attendance allowance, (ii) PIP or (iii) DLA Earn no more than £120 a week (after taxes, care cost while you are at work and 50% of what you pay into your pension) Not in full-time education i.e. more than 21 hours a week 	£64.60 a week	<ul style="list-style-type: none"> No extra pay is given to the care if caring for more than one person. Automatic NI credit Carer's Allowance can affect other benefits for both the carer and care-receiver
	Carer's Credit	<ul style="list-style-type: none"> Caring for someone over 20 hours per week 	National Insurance credit	<ul style="list-style-type: none"> Carer's Credit helps to bridge the gap in the NI records towards the State Pension earning
	Specified Adult Childcare Credits	<ul style="list-style-type: none"> If you are a family member over 16, but under the SPA and caring for a child under 12 (usually while the parent or main carer is working) 	National Insurance credits	<ul style="list-style-type: none"> This would be edible for grandparents
Direct payment to the care-recipient	Personal Independence Payment (PIP)	<ul style="list-style-type: none"> Aged 16-64 Have long-term health condition or disability and difficulties with 'daily living or getting around' 	£22.65-£145.35 per week	<ul style="list-style-type: none"> The needs and rate are regularly reassessed PIP has replaced DLA for adults
	Attendance Allowance	<ul style="list-style-type: none"> Aged over 65 Have a physical disability (incl. sensory disability, e.g. blindness), a mental disability (incl. learning difficulties) or both Your disability is severe enough to need help caring for yourself or someone to supervise you, for your own or someone else's safety Not living permanently in hospital or in accommodation provided by or funded by a local council 	£57.30 - £85.60 per week	<ul style="list-style-type: none"> Attendance allowance is not included when assessing for the eligibility for other benefits May increase the amount paid for other benefits Not means-tested for income and savings

DLA: Disability Living Allowance, NI: National Insurance, PIP: Personal Independence Payment.

Source: GOV.UK (2019).

LAs use a common framework of four bands of need in order to determine eligibility for individual packages of services (critical, substantial, moderate or low needs) in line with their risk and potential loss of independence. The eligibility varies across English LAs in terms of which groups are entitled to public support (Fernandez *et al.*, 2013). In addition to inequality between LA in the eligibility for services, LAs' spending on adult social care in England fell by 8% in real terms between 2009-10 and 2016-17 (Simpson, 2017). The population has been growing during this period, however over the same period the spending on adult social services per adult fell by 13.5% in England (Ibid). The spending on older people has seen the greatest reduction in the area of adult social care, with a cut of 12%; and it is projected to continue to fall. Prior to 2015, an overall tightening of local eligibility criteria was observed, leading to only those with critical or substantial needs being entitled to publicly-funded care across much of England (Fernandez *et al.*, 2013). In fact, in 2012, up to 87% of individuals aged over 65 lived in areas where LAs only provided services to those with 'substantial' care needs (The National Audit, 2014). The 2014 Care Act set a national standard of minimum eligibility criteria in order to ensure greater consistency across England (Fernandez *et al.*, 2013; DH, 2016). This could lead to a reduction in the disparity of informal care provided across England (more details is provided in section 2.3.1.5). Nevertheless, the reduction in social care spending, leads to fewer people supported by social care benefits although more people are in need of care, which is known as the 'care gap' (Pickard, 2015). This care gap, further lead to increased reliance on informal care.

Due to the increased pressure on the service system and the informal carers, the policymakers are facing a trade-off. On the one hand, the need for adult care in the community can only be met if individuals, mainly family members, continue to provide informal care. Conversely, it is a priority for the government to keep people in work for longer. The increase in the SPA came as a consequence of the growing population aged over 50, but as this age group also includes the individuals most likely to provide care, a decline in labour market participation may still happen, particularly among women, if no alternative services or support for carers are in place (Pickard, 2015). Although there will be increased demand for health and social care services, due to the increase of older people, it is important that LAs realise when planning for future care provision that a large proportion of older people are also contributing to the economy and to society in a range of ways, including the provision of informal care (Evandrou *et al.*, 2015a).

Chapter 1

A report from NHS England (2017) argued three primary reasons how effective support to informal carers would save the NHS money, namely 1) carers' health status would improve, therefore requiring less health and social care, 2) the carer would have more time and therefore be able to work and 3) the person with care needs will be better supported and therefore require less health and social care. A common support services provided to carers are respite care (Brimblecombe *et al.*, 2017). However, studies found contradictory evidence on the impact of respite care, with most not being able to detect any physical or psychological effect on carer's health (Pickard, 2004; Brimblecombe *et al.*, 2017). Cost-effectiveness of the support services is an important factor for policymakers when considering what services to commission. Nevertheless, respite continues to play a vital part in the approach to support carers and rightly so as carers often report high levels of satisfaction with respite care, and respite care has been associated with delayed admission to institutional care for the care-recipient (Pickard, 2004). Respite care does not only relate to the health of the carers, but also on their employment. Pickard (2018) estimated that the cost of 'replacement care' services to people cared for by working carers was £2.5bn per year, which is lower than the £2.9bn public expenditure costs of carers leaving work. There is therefore, an economic incentive to ensure carers are able to stay in employment should they wish to. It should be acknowledged, that working carers often continue to provide care, so therefore it may be more relevant to refer to 'complementary care' rather than 'replacement care' (Pickard, 2018).

Therefore, policy planning needs to take into consideration how best to support informal carers, especially older carers. This thesis aims to add to the evidence base of how to best develop policies to support informal care providers.

1.2 Research questions and rationale

The pathways into informal care provision will vary enormously between individuals and their given circumstances. Moreover, the pathways might be affected more by who is receiving the care rather than the distinct sociodemographic characteristics of the care provider. Using data from the English Longitudinal Study of Ageing (ELSA), this research aims to explore the pathways into informal care provision and the characteristics associated with different pathways. The research sets out to understand possible predictors of short, medium and longer-term transitions and trajectories into the caring role. The sample population in this study are individuals aged over 50 and living in private households in England. The research questions will be addressed using

cross-sectional descriptive analysis of the ELSA Wave 7 (2015) and longitudinal data analysis of the ELSA Waves 4 (2009), 5 (2011), 6 (2013) and 7 (2015). A justification for the choice of these specific waves can be found in section 3.2. An illustration of how each research question links to the temporal pathways and the methods of analysis can be found in section 2.5, Figure 6.

This research will explore the complexity of the pathways into informal care provision by investigating the following research questions:

1. Who are the informal carers in England?

- a. How do the socio-demographic, socio-economic and health characteristics of respondents in the ELSA differ between carers and non-carers, and between women and men?
- b. How and to whom do the informal carers in the ELSA provide care, and does this differ between female and male care providers?
- c. What are the predictors of providing care in 2015 (the ELSA wave 7) and do the predictors vary according to gender?
- d. Among informal carers, what are the predictors for providing over 20 hours of care per week?

2. What are the longer-term trajectories into informal care provision?

- a. What are the main socio-demographic differences between the caring statuses in 2009 (Wave 4) (i.e. future non-carers, 'repeating carers', 'intermittent carers') and how do these differ between caring statuses in 2015?
- b. What are the predictors of becoming a future carer according to the individual's socio-demographic characteristics in 2009? And do the predictors vary by gender?
- c. Does the timing of the care provision have a health impact on the carer?
- d. How do carers transition over a longer period of time between different intensities and directions of care?

3. Between 2013 (Wave 6) and 2015 (Wave 7) how did respondents transition between caring statuses (i.e. non-carers, 'repeating carers', 'discontinued caring', 'new carers')?

- a. How did carers transition between the intensity of care and directions of care?
- b. Among those who cared in 2013, how are changes in health status associated to the caring status in 2015?

Chapter 1

- c. Among those who cared in 2013, how are changes in economic activity associated with the caring status in 2015?
- d. Among those who cared in 2013, what are the predictors of discontinuing care in 2015 compared to repeating care provision in 2015?

The research questions were set to establish a broad, yet deeper understanding of individuals' pathways into care provision. Research Question 1 uses data from a single point in time in order to establish key information of who the carers are and their characteristics, as well the different caring patterns (i.e. who is the care-recipient, intensity of care, where is the care provided). The remaining research questions explore different aspects of the dynamic nature of care provision over time, using different timeframes for the analysis. Research Question 2 further builds on the evidence from Research Question 1 in order to explore the longer-term transitions into care (over 4 waves) and how these might gradually affect the carer's health (Ferrucci *et al.*, 1996). Such longer-term transitions and their effect are compared with shorter-term transitions between two waves through Research Question 3, which was designed to explore patterns of change more closely, with a bigger sample size (as the attrition between 2 waves is lower). Moreover, Research Question 3 can also detect potential sudden health shocks which carers may experience, rather than a gradual improvement/deterioration in their circumstances over time (Ayis *et al.*, 2006). Lastly, Research Question 3 examines short-term transitions in terms of the respondents' economic activity, offering insights into individuals' decisions about the retirement process (Cahill *et al.*, 2011).

The current research exploring pathways into informal care has mainly focused on older people receiving care (Suanet *et al.*, 2012; Vlachantoni *et al.*, 2015). This study will take the perspective of the informal carer to contribute to the understanding of the pathways into informal carer provision. This is important in order to comprehend the complex composition of care provision for future needs and how to ensure the health and wellbeing of the informal carers (see also section 1.2.1 regarding the significance of this study).

The study draws on the difference in motives and effects of providing care based on the relationship between the carer and the care-recipient, from hereon also refer to as the direction of care, as this relationship is associated with the gender, age and health of the care provider (see also sections 2.2.3 and 2.3.2.3). Both intergenerational care and intra-generational care are examined, the latter

referring to care provided by one's spouse or partner. Intergenerational care includes care provided by adult children to parents and/or parents-in-law; care provided to other relatives and/or friends; and care provided to grandchildren (i.e. grandparenting). Although the definition of informal care introduced in the beginning of this chapter specified support towards someone who is ill, frail or disabled, this study nevertheless also include support provided towards grandchildren. The inclusion of care provided to grandchildren is important in the context of the baby-boomer cohort, as this cohort are increasingly taking the role of multigenerational carers (O'Loughlin *et al.*, 2017). Moreover, providing care to a grandchild can have adverse health effect for the carer, particularly if provided at high intensity (Glaser *et al.*, 2010). Grandparenting may also reduce employment rates for women and facilitate early retirement (Van Bavel and De Winter, 2013; Lumsdaine and Vermeer, 2015) (further critical discussion of this decision is included in sections 2.2.3, 2.3.2.3 and 3.3.2.4). A distinction is also made between co-residential care (i.e. when the carers and care-recipient are living in the same household); and extra-residential care (i.e. when the carer does not live with the care-recipient), as this further influences the intensity level of the care provided (see sections 2.3.1.1 and 3.3.2.4). It is assumed that intra-generational care is co-residential unless otherwise stated.

1.2.1 The significance of the study

This research uniquely adds to the existing literature on informal caring in the following three ways: firstly the main significance lies in the fact that no other existing studies have explored the dynamic pathways into informal care provision using recent and nationally-representative data, and mapping out how gender and the direction of care can affect such pathways. Existing research in this area has explored characteristics associated with the pathways of older people requiring and receiving informal care, encompassing demographic factors, socioeconomic status and health factors (Pickard *et al.*, 2000; Grundy and Read, 2012; Vlachantoni *et al.*, 2015).

Secondly, this study adds to the understanding of the complexity of the pathways into informal care provision, including exploring shorter-term transitions and longer-term trajectories. Whilst other cross-sectional studies have identified the prevalence of informal caring and the key characteristics of carers, they have not provided insights on the repetition or continuation of informal caring over prolonged time periods (Jacobs *et al.*, 2014; Haberkern *et al.*, 2015). Although there have been a number of longitudinal studies on informal care provision,

Chapter 1

most have covered only two time points (Pickard, 2002; Hiel *et al.*, 2015; Vlachantoni *et al.*, 2016; Doebler *et al.*, 2017). Moreover, unlike this research, most existing work has focused on one single issue i.e. health and mortality or the employment situation of informal carers (see also section 2.4 for gaps in the literature). Historically, research into informal care has predominantly focused on experiences of women providing informal care (see for example Henz, 2004; Leinonen, 2011; Barnett, 2013), whereas this research aims to emphasise the potential difference in caring pathways of women and men separately.

Thirdly, unlike other studies, this study includes informal care provided to grandchildren. These three aspects help to establish the evidence of the caring patterns and will help to recognise how best to support carers relative to their circumstances, which is fundamental in order to protect and enhance the health and wellbeing of informal carers and to ensure the future supply of informal care.

1.3 Structure of the thesis

Following the introduction Chapter 2 presents the literature review related to informal care provision. A vital part of exploring pathways into informal care is understanding the motivational mechanisms behind the individuals' choices. Therefore the theories of ageing and care provision, including the life-course perspective, modernisation and feminism, and intergenerational relationships are evaluated. The second part of the chapter examines the empirical evidence on informal care provision, starting with cross-sectional studies followed by longitudinal data studies. This structure reflects the aims and structure of this thesis' own analysis of the ELSA data. Although the main focus is on England, comparisons are also drawn with Europe, North America and Australia, based on their demographic similarities (i.e. their population is ageing (DeSa, 2017) and their high level of social progression, measured as meeting basic human needs, foundations of wellbeing and opportunities (The Social Progress Imperative, 2017). Moreover, it examines the evidence on the key socio-demographic characteristics of informal carers and the long-term effects of care provision on the carers' health and employment. Lastly, this chapter provides the conceptual framework and highlights the gaps in the existing literature.

Chapter 3 is devoted to the data and ethical approval. This chapter outlines the study population and provides a rationale and critique of the data variables used in this study, as well as a discussion of issues concerning weighting, data quality and ethics.

Chapter 4 present the methodology and results of the cross-sectional data analysis of the ELSA Wave 7 (2015), as required by Research Question 1. The methods include descriptive statistics (frequencies and percentages) and binary logistic regression analysis in order to explore the factors associated with providing informal care at one point in time.

Chapter 5 presents the results of the longitudinal data analysis of the ELSA. Firstly, the methodological approach to address Research Question 2 is presented, followed by the results and a narrative description these. This part of the analysis uses the ELSA Waves 4 (2009) to 7 (2015) to analyse the longer-term predictors of becoming a future carer. The next part of the chapter focuses on the methodology and results used to address Research Question 3. This likewise uses longitudinal data analysis, to explore the shorter-term transition between Waves 6 (2013) and 7 (2015) of the ELSA in order to provide a detailed picture of how the care intensity and the care-recipients change over time, and the effects of such changes on the carer's health and economic activity.

Chapter 6 revisits the research questions and the results from this study by bringing this together in a critical discussion and in the context of existing literature. This chapter aims to highlight the significance and implications of the study. It addresses the research limitations and provides an evaluation of how this study has contributed to the existing body of knowledge which can inform future policy, research and practice, as well as future research directions. The chapter concludes with a concise summary of the research contribution.

Chapter 2 Literature review

2.1 Introduction

This literature review provides an insight into the factors associated with the pathways into informal care provision. The objective of this review is to explore the literature in order to establish the determinants and predictors involved in the transitions and trajectories of informal care provision, using both theoretical and empirical evidence.

The literature review is divided into two main parts: the theoretical perspective and empirical evidence and each parts are further divided into subsections. Theories of gerontology start with the fundamental idea that human development over the life-span is driven by an ongoing interchange between individuals and their social and physical environment (Bengtson *et al.*, 2009). Theories attempt to solve and rationalise the questions we encounter (Ibid), such as why do some countries rely more on family members to care for older people than others; and what leads an individual onto the pathway of informal care provision? The empirical literature provides evidence to support and counter the theoretical perspectives. The chapter will conclude by establishing the gaps in the literature.

The search strategy incorporated searching written literature including books, grey literature, and electronic and individual journal publications. Electronic databases included: Pubmed, AgeINFO, Cumulative Index to Nursing and Allied Literature (CINAHL) and Web of Science (WoS). Furthermore, a citation search and a manual search of the bibliographies of key articles was carried out. The databases covered a broad spectrum of disciplines related to the aim of the thesis from healthcare, politics, and health economics to articles exclusively focussing on gerontology and older age. Grey literature searches included website searches of voluntary organisations and governmental agencies the UK such as: AgeUK (Age Concern), Independent Age, Direct.Gov.org and Institute for Fiscal Studies.

The theories and empirical evidence used for the literature review primarily originate from developed countries unless otherwise mentioned. The first part of the review introduces the theoretical concepts of informal care provision.

2.2 Theoretical concepts of informal care provision

This section focuses the theories of ageing related to informal care provision. It is important to explore such concepts as they can help classify behaviours and causal relationships, as well as guide the research (Bengtson *et al.*, 2005b). Three theories will be drawn upon in this thesis, namely the life-course perspective, feminism, and intergenerational relationships. The life-course perspective is presented as the overarching concept, as over time multiple influences from both society and family have factored in the decision whether or not to provide informal care (Alwin, 2012). Theories of feminism focuses on population changes and the political perspective related to the availability of informal care providers, as well as the gender perception of care provision (Allen and Walker, 2008). Lastly, theories of intergenerational relationships, including altruism, reciprocity and solidarity, provide a direct focus on aspects of informal care provision and the relationship between the carer and care-recipient (Kalmijn and Saraceno, 2008). As it will become clear, no theory sits in a vacuum; they are interlinked and overlapping, and these links are highlighted along the way. The section concludes with a conceptual framework summarising the concepts explored and their direct relevance to the research objectives.

2.2.1 Life-course perspective and the pathways into informal care provision

The life-course perspective proposes that throughout the entire life-span, individuals are influenced by environmental exposures, including biological, physical, social, and behavioural factors, but also life experiences (Elder, 1994; Hareven, 1996a). Rather than a theory, the life-course perspective is often considered a concept or paradigm with four underlying dimensions: the interplay of human lives and historical times, the timing of life transitions, linked and interdependent lives, and human agency in choice (Elder, 1994; Haveren, 1996a; Alwin, 2012). The life-course perspective is useful when exploring pathways into informal care provision, as it draws on multidisciplinary approaches and relies on both macro- and micro-social levels of analysis, which is essential for addressing the research questions set in this thesis. Moreover, it allows for deviations in the life-span trajectories related to life events, crises and social changes (Elder and Rockwell, 1979; Elder, 1994). To understand individuals' pathways into informal care provision, it is necessary to reflect on the life stages and transitions, which led the individual down a particular path. The life-course perspective attempts to explain how time and cohorts shape the ageing process, age-related transitions

and life trajectories; what came before and how individuals and societal factors helped to shape any given phase of the life-course (Elder and Rockwell, 1979; Dannefer and Settersten, 2013). The elements and contrasts of these two levels in relation to informal care provision, as described in the following paragraph.

Individuals' position in history, according to their birth year, helps to shape people's role in the social structure (Elder and Rockwell, 1979). The membership of a specific cohort, common experience of historic moments and social changes, is referred to as social age (Ibid). Social age plays a central part, as it identifies age patterns in social roles and timetables, as well as historical time which may have formed norms and cultures related to informal care provision (Elder and Rockwell, 1979). Haveren (1996a) points to the understanding of the variability of patterns of care support in the later years of life, but also as the differences in the expectations of the care-recipients and the carers, who are influenced by their respective social and cultural milieus. Patterns of generational support are shaped by values and experiences, which are either evolved or modified over the entire life-course (Haveren, 1996a). This concept is explored further in section 2.2.3.

Norms are shaped by individual experiences and personal agency, including skills, abilities and goals in addition to personal family relations (Elder and Rockwell, 1979). In complex societies, the individual's life-course consists of multiple interconnected roles, including those of work, partnerships and parenthood, thereby making the timing of life-events multiple and not necessarily single occurrences in an orderly progression (Ibid). Moreover, individuals' needs and circumstance change as they move through life, and such changes may apply to work and residence, but also in social support roles. As some roles are relinquished and others assumed, individuals may for example shift from being a care-provider to being a care-recipient, or the opposite (Kahn and Antonucci, 1980).

The life-course perspective incorporates the principle of 'linked lives' (Bengtson *et al.*, 2005a), which emphasises the interconnectedness of individuals' lives, and which in turn can create unexpected changes and circumstances (Elder, 1994; Bengtson *et al.*, 2005a; Alwin, 2012). Human lives are typically embedded in social relationships with kin and friends across the life-span (Elder, 1994). Consequently, each generation members' life events, such as marriage, childbirth, divorce, health decline and so on, can affect family members of other generations. In relation to informal care provision linked lives, may also constrain or foreclose opportunities, or drain individuals of important resources (Elder,

Chapter 2

1994). A current example is the so-called 'sandwich-generation' (Grundy and Henretta, 2006; Ben-Galim and Silim, 2013) (see also section 1.1.1). This cohort is experiencing the delayed fertility and increased longevity of their parents, often providing care for their own children and/or grandchildren, in addition to their frail parents (Grundy and Henretta, 2006). The rise of the so-called 'sandwich-generation' denotes the theories of intergenerational relationship and exchanges, and demographic changes in the roles of women; both concepts are explored in section 2.2.2. Empirical evidence related to the 'sandwich-generation' follows in section 2.3.2.2.

A central part of the life-course perspective is the notion of cumulative life-histories, which led to the development of the 'cumulative advantage/disadvantage' theory (Dannefer, 2003; Alwin, 2012). The theory suggests that not only can socio-environmental inequalities affect individual differences at multiple time points over the life-span, but also the residues of such influences in individual differences accumulate over time (Alwin, 2012). A more concise definition of this concept was described by Dannefer (2003, p.327) as: '*the systemic tendency for interindividual divergence in a given characteristic (e.g., money, health, or status) with the passage of time*'. As Dannefer (2003) argues, this definition indicates that the divergence is not a simple extrapolation nor is it the cumulative advantage/disadvantage of individuals, but of the population or cohorts for which an identifiable set of members can be ranked. When examining the caring role, the concept of cumulative advantage/disadvantage relevant, and especially cumulative disadvantage can be a direct consequence of the care provision. For example, more women are informal carers, a role which is unpaid, therefore women carers have often invested less time in payable productivity (employment), translating into lower earnings and thereby less accumulated assets, such as savings and pensions, leading to a financial disadvantage in later life (Dannefer, 2003) (see also sections 2.3.2.1 and 2.3.2.2).

Health can also be seen as a cumulative advantage/disadvantage factor. It has long been recognised that there is an association between health and socioeconomic status (SES) (Singh-Manoux *et al.*, 2003; Demakakos *et al.*, 2008). The direction of the causality in the creation of a cumulative advantage/disadvantage of health is, however, a much debated topic (Dannefer, 2003). Some scholars have noted that SES influences one's health status, known as social causation (Adler and Ostrove, 1999), whilst others argue that health status contributes to one's SES, known as a social drift (Marmot *et al.*, 1995). The

concept of social drift argues that poor health affects the ability to work, thereby lowering earnings and assets, which results in a downward spiral of SES (Ibid). These factors can play an imperative role in the pathways into informal care, as the consequences of accumulation can affect whether the individual has the ability to provide care, raising the question if individuals provide less informal care due to poorer health, or whether the provision of care leads to poorer health for the carer (O'Reilly *et al.*, 2008; Mentzakis *et al.*, 2009; Vlachantoni, 2010). See section 2.3.1.3 and 2.3.2.1, for the empirical evidence on this debate.

The life-course perspective clearly plays a central part in understanding different pathways into informal care provision, as demonstrated from this section. It is however important to remember, that the study of ageing embraces a vast diversity and heterogeneity across the cohorts, with multiple nuances at play. The next section departs from the overarching life-course perspective to explore the theories of feminism and modernisation in relation to demographic changes and their effects on informal care provision, some of which were mentioned in this segment.

2.2.2 Perspectives of feminism theories on the pathways into informal care provision

Research has shown that the majority of informal carers are women (Willson *et al.*, 2003; Robards *et al.*, 2015; Stone *et al.*, 2015), it therefore seems appropriate to deconstruct the otherwise gender-neutral theories of ageing by exploring feminism and its relevance to the topic of the current research. Feminist inquiries begin from a women's standpoint (Calasanti, 1993; Allen and Walker, 2008) and originate from two divergent locations: feminist activism, evident in the women's movement for social change; and post-positivist theorising, which is still dominant in most theory-building today (Freeman, 2002 in Allen and Walker, 2008). As argued by Allen (2000) and Bengtson *et al.* (2005b), complex inquiry about structure, process and agency in real life, such as for example the provision of informal care, cannot be experienced at arm's length. A feminist perspective takes a 'bottom-up' perspective, giving a voice to the informal carers, and by applying this method of inquiry it relates critically, self-consciously and accountable to real-life situations. Feminist theories, however, are not solely concerned with women, but rather the perspectives of the theory are rooted in the context of inequalities between otherwise omitted individuals, such as for example older people, childless or unmarried individuals and people otherwise absent in family theories (Reinharz, 1986; Gibson, 1996; Allen and Walker, 2008).

Chapter 2

The norm of women written into social science theories, conforms to the stereotype of the standard family consisting of a breadwinner father, the stay-at-home wife, and their dependent children (Riley, 1999; Bengtson, 2001). Feminists critique such portrayals of women as objectified and inaccurate (Gibson, 1996; Allen and Walker, 2008). Women of the baby-boomer generation, now aged 50 and over, played a crucial part in women's so-called liberation, and they have further benefitted greatly from increased education and labour participation (McHugh, 2012). Nevertheless, this same cohort also belongs to the previously mentioned 'sandwich-generation', in which women still carry out multiple roles, as workers, carers and housekeepers, thereby upholding the stereotype of the nurturing and expected caregiving persona in the family household (see section 2.3.2.2).

Feminist theories transmit how experiences of economic and power relations, between men and women, both in private and in the social context are imbalanced (Willson *et al.*, 2003). Women are often responsible for providing care, be it for their children or for older frail parents, many women therefore do not enter the labour market or sacrifice employment hours (Willson *et al.*, 2003; Gomez-Leon *et al.*, 2017). This may limit women's opportunities to gain promotions, and accruing financial resources compared to men. Moreover, due to a weaker labour market attachment, the lower household earner may be less able to resist the normative obligations of care provision (Willson *et al.*, 2003). This is further considered in section 2.3.2.2. Financial gender inequalities studies have focussed on women's labour force participation, and how women combine home and work responsibilities (Riley, 1999). Family ties are embedded in feminist theorising, as they structure the social relations that create the power differences which has consequences for individual lives (Willson *et al.*, 2003). Allen and Walker (2008) go on to express how caregiving is expected of women, and how women are expected to enjoy such activity as it provides them with an opportunity to experience closeness with family members, this may lead to feeling of ambivalence, which is explored further in section 2.2.3, in relation to the solidarity model.

As just examined feminism has affected norms and social structures, which has led to new formations of family structures. This new structure will enviably lead to changes in intergenerational relationships and the support provided by the family, which is evaluated in the following section.

2.2.3 Inter- and intra-generational relationships and informal care provision

The previous theoretical approaches explored the wider individual and social concepts related to the provision of informal care. The following theories of intergenerational relationships are directly linked to the individual motivational factors associated with care provision and social networks. These theories help to guide Research Questions 1.b and 3.a, which explore the direction of care, i.e. the relationships between the care-provider and the care-recipient. Inter and intra-generational theories further helps to interpret the results of this thesis, as it provides an understanding of the underlying motivations between family members to enter into the caring role.

The theories presented include: **intergenerational obligations and relationships; the exchange theory and the solidarity model**. As the vast share of informal care is provided by adult children (Pickard, 2015), and to explain the adult children's caring patterns and pathways into the caring role, it is important to understand the theoretical motivations of the adult children to provide care for their parents. It is acknowledged that there are alternative theories related to intergenerational relationships, such as the convoy approach, which explores the antecedents and consequences of life-course changes (Thomese *et al.*, 2005). However, the convoy approach share similarities to the linked-lives theory, discussed in section 2.2.1, and are therefore not be presented in any further depth in this review.

Intergenerational support concentrates on the relationship between parent(s) and adult child(ren), nevertheless a high proportion of care is provided by one's spouse/partner (Pickard *et al.*, 2007). Theories related to intra-generational relationships (i.e. caring for a spouse or a partner), such as reciprocity and altruism are examined at the end of this section.

There is no consensus on the definition of intergenerational support among scholars, partly due to the difficulty in empirically capturing changes in the patterns of intergenerational relations (Connidis and McMullin, 2002; Szinovacz and Davey, 2013). Therefore, research of intergenerational support has generally focussed on three areas: patterns of family formation, family living and family norms concerning intergenerational solidarity (Kalmijn and Saraceno, 2008). It has been debated whether globally the role of the family, as a model of social organisation, has been significantly reduced over the past century (Harper, 2006). A shift in the traditional family structure has raised questions over the roles and responsibilities of kin members, and may have contributed to a change in how

Chapter 2

family members perceive intergenerational support (Ibid). The transition from high-mortality/high-fertility societies to low-mortality/low-fertility societies has resulted in an increase in the number of living generations (Harper, 2006). In addition, a decrease in the number of relatives living within these generations has led to a so-called 'beanpole structure' of generations (Bengtson, 2001; Harper, 2006). The perception of intergenerational support and adult children's involvement in the care provision to their ageing parents is closely related to their earlier life-course experience, their ethnic and cultural traditions, and to the historical context affecting their lives (Hareven, 1996a; Gans and Silverstein, 2006). Family interactions across the life-span, but more specifically in older age, are moulded by individual members' cumulative life histories and by the specific historical circumstances that have affected each individual family member over their lives. Filial obligations to older parents refer to the normative expectation that adult children have the duty to support their ageing parents (Silverstein *et al.*, 2006; Stuifbergen, 2011). It is important to note that norms of filial duty are conceptually distinct from personal intentions to provide support and supportive behaviours, though predictive of both factors (Silverstein *et al.*, 2006). Therefore on a practical level, filial norms may change in response to personal circumstances, which are influenced by one's ability to provide care, for example parental care provision may be affected by the adult child's competing demands such as work, marriage or children (Gans and Silverstein, 2006). This is further discussed in sections 2.3.1.5; 2.3.2.2 and 2.3.2.3.

In European countries the intergenerational support is primarily a downwards flow, where parents support their children, however a balance shift occurs and after the age of 70 the parents themselves are likely to become net beneficiaries of support (Albertini *et al.*, 2007; Dykstra, 2010), suggesting a strong association between the direction of care and both the carer and the care-recipients' age. This influences the pathway the individual takes into informal care, not only based on the need of the care-recipient, but also the age of the carer. The perceived relationship between the parent and adult child was applied as a starting point for the concept of the exchange theory. The support is characterised by a multidimensional resource exchange, where the cost and benefit analyse is translated into emotional and financial exchanges (Grundy, 2005; Lowenstein and Katz, 2013) (see also section 2.3.2.2). An exchange relationship continues only as long as it is perceived as being more rewarding than costly for the individuals participating, and this balance is known as reciprocity (Thomese *et al.*, 2005). The balance is maintained if both parties in

this exchange relationship are equally dependent upon each other (Lowenstein and Katz, 2013). Reciprocity can be further defined as either 'direct' or 'time-delayed' (Thomese *et al.*, 2005; Harper, 2006). Direct reciprocity refers to returning support over a limited time period, whereas time-delayed support, as the word infers, is based on reciprocity which covers a greater time span, maybe even the life-span (Thomese *et al.*, 2005). An example of time-delayed exchange is an adult child providing care to parents, as exchange for the care provided to them in their childhood. Although, directly establishing determinants of care provision based on reciprocity between adult children and their parent is out of the scope of this thesis, it is an important driver which is taken into account in the interpretation of the determinant of taking on the caring role or indeed why some choose to discontinue care provision.

In contrast to the exchange theory, the main principle of the altruism theory is that children are motivated by love for their parents; their care provision is primarily driven by parents' needs, derived firstly and foremost by their parents' health conditions (Szinovacz and Davey, 2013). However, the distance between the exchange and altruism theories may be artificial, for example the provision of support to an older parent could be interpreted not as altruism, but rather as a time-delayed exchange (Grundy, 2005). In addition, the adult child providing care to their parent might eventually benefit themselves from their parent being in good health to provide childcare for grandchildren (Haber Kern and Szydlik, 2010). The value of the exchange will change for the recipient in accordance to the provider's motivation (Kohli and Künemund, 2003). If the support was provided conditionally, the balance of reciprocity and control would be uneven and allow for feelings of ambivalence from either party involved (*Ibid*). In this type of care, the adult child's decision of whether to provide informal care is often a practical cost-benefit analysis; if wishing to provide care to a frail older parent, they may provide the care themselves or they may pay for formal care provision (Bianchi *et al.*, 2006). If the adult child's time is 'costly' in financial terms, for instance if they earn high wages, they would find it more cost effective to purchase formal care, whereas an adult child on a low-income might be better off financially through reducing their hours of paid work and providing informal care themselves (*Ibid*). This relates to the concept of 'opportunity cost' which is explored further in section 2.3.2.2. Both the exchange theory and the altruism theory suggest that individuals who have more resources are more likely to provide various types of support (money, time, emotional support) (Parrott and

Chapter 2

Bengtson, 1999). Evidence of reciprocity and altruism is discussed in section 2.3.2.3.

This research uses non-carers as a comparison group, however it is not possible to distinguish if non-carers simply do not have a loved one in need of care or whether they have chosen not to provide care. However, keeping in mind altruism and reciprocity, may offer some clues and help to explain any possible differences in employment and wealth between carers and non-carers (see also sections 2.3.1.4 and 2.3.2.2). Arguably the concept of the exchange theory could be viewed as rather simple, as the motives for providing support are part of a more complex framework of facilitators and barriers, as discussed below.

The changes to the family structure have prompted a rethink of conceptual frameworks for understanding family relationships. One of the most common and dominant frameworks in the literature is the *Intergenerational Solidarity Model* (Lowenstein and Katz, 2013p. 195), depicted in Figure 2. The model consists of six dimensions of parent-child relations: 1) association (contact), 2) affection (or emotional attachment), 3) consensus (or agreement), 4) function (or patterns of instrumental support or resource sharing), 5) normative (norms or expectations of individual obligations to the family and 6) functional (or opportunity structure) (Bengtson and Roberts, 1991). The model illustrates how each dimension has measurable factors, for example 2.a could be measured by counting encounters of face-to-face contact or telephone call over a week (Hogerbrugge and Komter, 2012).

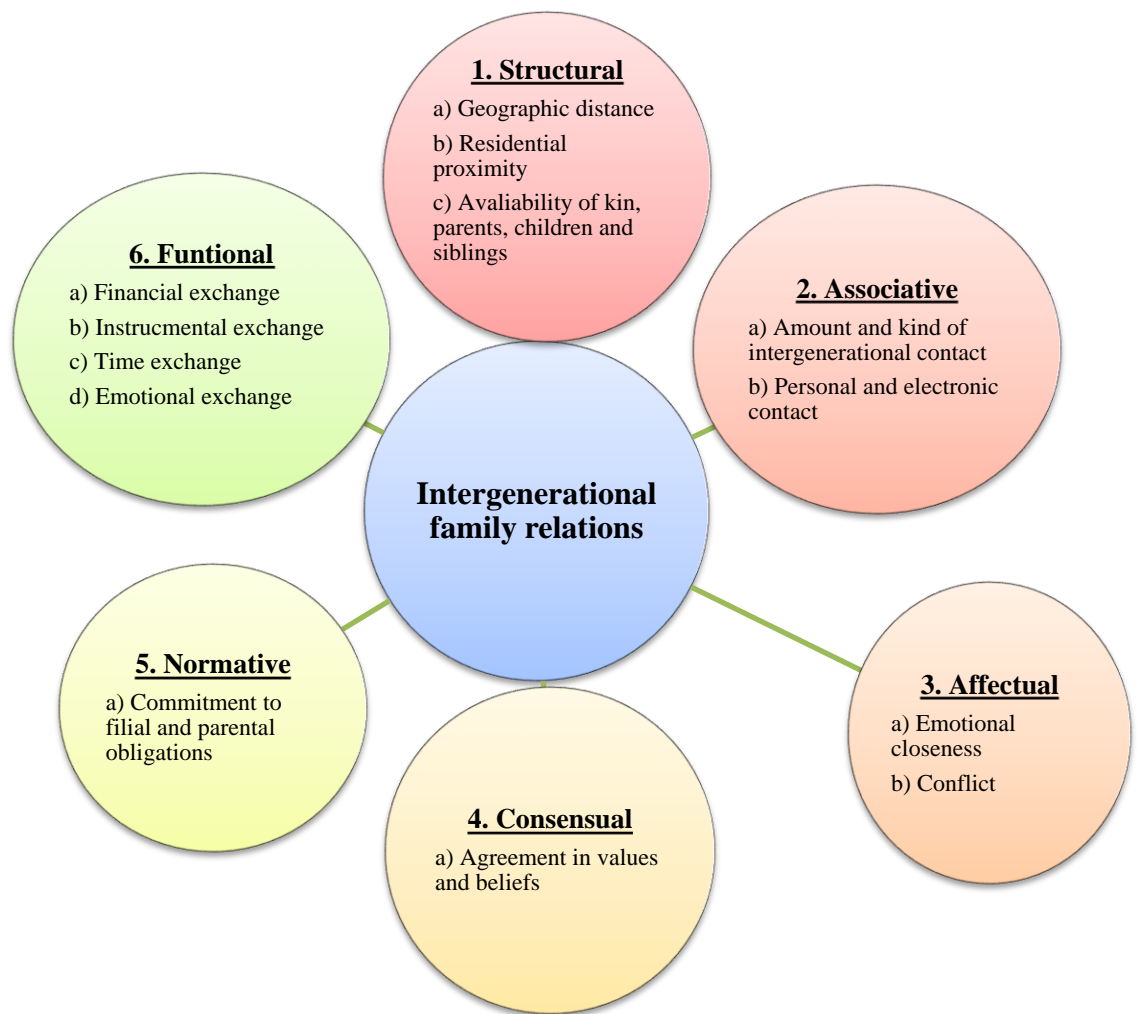


Figure 2 Dimensions of solidarity in intergenerational family relations
Source: adapted from Hogerbrugge and Komter (2012).

The solidarity model focuses on family cohesion, as an important component of family relations and emphasises that intergenerational relations are multidimensional (Lowenstein, 2007). However, some scholars have argued that the word ‘solidarity’ implies consensus in the family relationship, thereby not taking into consideration intergenerational conflict (Connidis and McMullin, 2002; Lowenstein, 2007). Conflict is a normal aspect of family relations and may affect how family members perceive one another, consequently affecting their willingness to provide assistance to each other (Parrott and Bengtson, 1999). The term ambivalence reflects the contradictions and ambiguities in family relationships (Parrott and Bengtson, 1999; Lowenstein, 2007). As discussed, some women may be ambivalent within the caring role, on one hand, they may be gratified by the opportunity to help their kin, but on the other hand, they may also be conflicted by the missed opportunities of paid employment and/or personal time. Intergenerational dependence, as seen in informal care provision, is implicated in the formation of ambivalence (Lendon *et al.*, 2014) and research has shown that the feelings of ambivalence tended to be stronger among adult

Chapter 2

children providing care to their parents, than providing care to a child, friend or spouse (Fingerman *et al.*, 2008).

Until this point, this review has mainly concentrated on the intergenerational support between adult children and parents, however spousal (partner) caregiving is also a significant part of care provision, especially in later life. A partner is the most likely source of informal care provision for married (partnered) older people (Pickard *et al.*, 2007). Although caring for a spouse may be seen as an inherent part of the marriage contract, spouses vary in their willingness to provide care, and their motives for providing care may also be different than caring for a child or parent (Feeney and Hohaus, 2001). The motivation for spousal carers is primarily reciprocity, most likely as a direct exchange, driven by altruism rather than obligation (Ibid). The feelings of ambivalence may also be evident in the caring relationship between spouses (partners). For example, a spouse's diagnosis of dementia may generate experiences of loss of the relationship that once existed (Davis *et al.*, 2011; Keating and Eales, 2017). Although the effect of care provision on the carer's health, emotional and financial state might be somewhat similar regardless of whether the care is provided inter and extra-generational, there is a distinct difference between the two, which is visible throughout section 2.3 and 2.4.

As mentioned, research into intergenerational relationships has also focussed on the patterns of the welfare state, especially the availability of formal care. In Europe, there is a concern that changes in the demographic balance within kinship relations, and increased women's labour market participation, may influence the reduced availability of informal care. There are concerns that this will not be compensated for by the provision of formal care due to a weakening and cuts to the welfare state (Johansson *et al.*, 2003). This may lead to older people and people in need of care having to pay for formal care themselves, leaving more vulnerable individuals at risk and widening the social inequalities gap. The "substitution" hypothesis relates to the view that public transfers crowding out informal support (Kalmijn and Saraceno, 2008; Dykstra, 2010). Studies of Western welfare systems have, however, provided very little empirical support for this. On the contrary, private support has been found to act in a more complementary manner, indicating that families redistribute their resources and provide the kind of care that they are best equipped to provide (Kohli and Künemund, 2003; Kalmijn and Saraceno, 2008; Dykstra, 2010; Lowenstein and Katz, 2013; Verbakel, 2017). This will be further discussed in section 2.3.1.5.

This section covered the theoretical aspect of the motivations of people to provide informal care, considering features of demographical changes and individual motives such as filial norms and values which may influence pathways into informal care provision. The next part explores the empirical evidence on the characteristics of informal care providers and some of the outcomes of providing care, more specifically in terms of the carer's health and employment.

2.3 Empirical literature review on informal care provision

Up to this point, the literature review has concentrated on theories related to providing informal care. The following section compiles the empirical evidence to explore who the informal carers are, and the factors associated with the provision of informal care. The review of the empirical literature starts by examining cross-sectional studies, and establishes the prevalence of informal care provision and the type of care provided. Moreover, socio-demographic factors, such as age, gender, marital status, and the health of the care provider and other associated factors are explored. The second part evaluates longitudinal studies, in order to gain a greater understanding of the causes and consequences of caring. The pathways into informal care are often complex, and by exploring both cross-sectional and longitudinal studies paints a nuanced picture of who the carers are and what influences their pathway into care.

2.3.1 Evidence from the cross-sectional studies: a snapshot of informal carers and the determinants of care

2.3.1.1 Prevalence, intensity and type of care provided

The initiative to provide care is often triggered by one or more events or episodes, which are directly related to the care-recipient. The strongest influence is the deterioration of care-recipient's health (Haber Kern and Szydlik, 2010). Other triggers include financial problems or the loss of the care-recipient's social networks (Pope *et al.*, 2012). For older people, the deterioration of health is often quicker and one adverse health episodes can have a "domino" effect leading to more severe health complications for the older person (Ibid). This can also cause financial problems, especially if the care-recipient has to pay for formal care or home adaptations. Moreover, older adults with cognitive decline and adult children with learning disabilities may have poor judgement and decision-making skills, reflected in financial problems (Pope *et al.*, 2012).

Depending on the study design, the prevalence of informal carers differs, not only across Europe, but also within England, see also section 2.3.1.5. UK Census data

Chapter 2

estimates that 10-12% of adults aged over 16 years are informal carers (Dahlberg *et al.* 2007; Vlachantoni *et al.* 2013; Evandrou *et al.* 2015b; Robards *et al.* 2015) (see also section 1.1). Research focusing on adult carers providing care to people aged over 60 (Arnsberger *et al.*, 2012; Carmichael and Ercolani, 2014), and studies using age-related surveys, such as the ELSA and SHARE (Stone *et al.*, 2015; Vlachantoni, 2010; Hiel *et al.*, 2015) have generally found a higher prevalence of carers. This is to be expected, as older adults are more likely to need care, but older people are also more likely to provide care (Dahlberg *et al.*, 2007; Office for National Statistics, 2013; Lee *et al.*, 2015; Carmichael and Ercolani, 2014).

The intensity of the care provision is often measured using gradients of hours of care per week, but the intensity can also be measured by the number of ADLs and IADLs, which the carer helps the care-recipient with (Burton *et al.*, 2003; Lyons *et al.*, 2015; Carmichael and Ercolani, 2016). Light care has been described as providing fewer than 19 hours per week or providing help with up to 2 ADL/IADL tasks; moderate care as between 20- 49 hours per week and heavy care as over 50 hours per week or helping with more than 3 ADL/IADL tasks (Vlachantoni, 2010, ONS 2013; Burton *et al.*, 2003; Lyons *et al.*, 2015). Other researchers simply divided the intensity to less than 20 hours per week or more than 20 hours per week (Ramsay *et al.*, 2013; Carmichael and Ercolani, 2016). Evidence from the ELSA (Wave 3, 2006) showed that the majority of carers provided light care, whereas approximately 15% provided moderate care; 8% heavy care and just over one-fifth provided round-the-clock (24-hour) care (Vlachantoni, 2010). Yet, it has been suggested that heavy care may account for up to 12% of all informal care provision, if considering the whole UK adult population, and taking into account under-reporting (Shaw and Dorling, 2004).

An important aspect of the intensity of care is the distinction between the types of tasks carried out, however for many surveys and studies it can be hard to separate tasks. This is partly due to the surveys using different measures of the intensity (i.e. time), such as seen in the ELSA and the ONS longitudinal datasets, rather than the actual tasks performed. Likewise, studies which provide information on the tasks, such as help with ADLs, rarely provided detailed information of the specific tasks or time spend carrying out these tasks (Henz, 2004; Lyons *et al.*, 2015; Kim *et al.*, 2016).

The type of task carried out by informal carers can broadly be placed into two categories: 1) '*physical help*', which includes help with walking, feeding or getting

in and out of bed; and 2) help with '*personal tasks*', such as with bathing, using the toilet and taking medication, it should be noted that these tasks are a mixture of difficulties with ADLs and IADLs (Arber and Ginn, 1990; Bonsang, 2009).

Informal care can also be in the form of practical support, for example, gardening, shopping, help with paperwork or financial support; or even simply emotional/social support (Bonsang, 2009). Arber and Ginn (1990) suggested that informal carers could be distinguished between "carers" and "helpers", as the perceived burden attached to the above-mentioned tasks differs by the individual. Moreover, the skill-level needed by the carer varies according to the task (Ibid). For example, a "carer" providing personal caring tasks would require more skills than a helper supporting another individual with for example shopping. Likewise, the relationship between the carer and the cared for may determine the type of care provided.

Studies have suggested that close-kin and friends are more likely to provide personal task, whereas neighbours tend to assist with practical support (Lapierre and Keating, 2012). Adult children may, however, feel reluctant to carry out personal caring for parents, and likewise the parent might be reluctant to let their children perform personal task for them (Bonsang, 2009; Kruijswijk *et al.*, 2015). The 'carer/helper' classifications could be an oversimplification and it is reasonable to note that many informal carers would fall into both categories. Furthermore, it is very likely that over time a '*helper*' will move along the continuum into the '*carer*' category, as the intensity of care increases in line with the recipient's frailty (needs) (Aber and Ginn, 1990).

The intensity of care also varies according to the living arrangements of the carer and care-recipient, and this is also associated with the direction of care (i.e. if the care-recipient is a spouse/partner, parent, child or friend) (Carmichael and Ercolani, 2014). Intergenerational co-residential care has declined by almost 25% between 1985 and 1995 with a concomitant increase in extra-residential care provision (Pickard, 2002). Most co-residential relationships are intra-generational (ONS, 2013), whereas only one-fifth of those caring for a parent/parent-in-law also live with them (Vlachantoni, 2010; Arber and Ginn, 1990). Transitioning into caregiving is over three-times greater the care already co-residing with the parent (OR 3.59) compared to caring for a parent who is living independently (Leopold *et al.*, 2014). Moreover, the odds of providing high-intensity care were also significantly higher, when providing co-residential care (OR 6.05) (Lyons *et al.*, 2015). Although it could be argued that co-residing with the care-recipient saves time on transportation, there is some fallacy attached to the nature of co-

residential care, as often this arrangement takes place when the care-recipient's needs is too great for them to live independently, which in turn would mean increased caring duties (Carmichael and Ercolani, 2014). Since co-residential care usually involves a much heavier investment of time, it is not surprising that the time spent per week providing care is higher for co-residential carers, than those in separate households (Arber and Ginn, 1990; Carmichael and Ercolani, 2014).

Although spousal and parental care is the predominant source of informal care (Pickard *et al.*, 2007; Pickard, 2015), the contribution by other relatives, such as siblings and cousins, friends and neighbours must not be overlooked. A study by Kalwij *et al.* (2014) using the SHARE noted that older couples and single persons received 30% of their informal care from relatives or friends. The authors further argued that the opportunity cost (see section 2.3.2.2 for definitions) for informal carers providing care to another relative or friend was lower, as these carers are more likely to be of similar age to the care-recipient (i.e. aged over 65), therefore it is less likely to have an adverse effect on labour market participation. In addition the carers are also less likely to be of the so-called 'sandwich-generation' (for definition see section 1.1.1), therefore less likely to occupy multiple roles (Kalwij *et al.*, 2014).

2.3.1.2 Socio-demographic characteristics of the informal care providers

This section focuses on the cross-sectional findings of the socio-demographics characteristics of informal carers. It was found that mean age of informal care providers varied according to the sample used in the study or survey. Studies using Census data from 2001 found the provision of care to peak between 45 and 59 years (Shaw and Dorling, 2004; Dahlberg *et al.*, 2007). However, the Census data from 2011 showed this to peak between 50 and 64 years (Lee *et al.*, 2015). It should be noted that Lee *et al.* (2015) used a sub-sample of individuals aged over 50 years, which may have skewed the data to show age to peak at a higher age range. The association between the age of the carer and that of the care-recipient is apparent and related to the relationship between the two. For instance, carers aged between 50 and 59 years are more likely to care for parents/in-laws or/and for grandchildren, the so-called 'sandwich-generation', whilst among the oldest carers, the care-recipient is more likely to be a spouse/partner or another relative (Vlachantoni, 2010).

As well as age, gender is also a major component in the association of providing care, with women providing the majority of the care (Shaw and Dorling, 2004;

Dahlberg *et al.*, 2007; O'Reilly *et al.*, 2008; Del Bono *et al.*, 2009; Pickard, 2015; Robards *et al.*, 2015; Glauber, 2016). Conversely, most studies found that men committed more time to caregiving after the age of 70 (Arber and Ginn, 1990; Dahlberg *et al.*, 2007; Lima *et al.*, 2008; Vlachantoni 2010). Glauber (2016) argued that men simply “caught up” with women, who were already providing care at a higher intensity. Using 2001 Census data, Del Bono *et al.* (2009) in contrast found that after considering marital status, women aged over 65 years were more likely to provide care than men of the same age (OR 1.12). The same study found that after controlling for the number of household members, women (aged over 65) were more likely to provide more than 4 hours of care per week than men (OR 3.77). Gender differences can also be seen in the direction of care. Data from ELSA (Wave 3, 2006) suggested that women were more likely to care for parents/parents-in-law, grandchildren, friends or neighbours or other relatives, whilst men were more likely to provide care for their spouse or partner (Vlachantoni, 2010; Glauber, 2016). However, this could have been confounded by age, as most married men aged over 80 are more likely to still have a living partner, whereas women aged over 80 are more likely to be widowed, due to the gender difference in LE (Del Bono *et al.*, 2009; Carmichael and Ercolani, 2014). Women are also more likely to care for multiple care-recipients simultaneously (Vlachantoni, 2010). Moreover, care provided to parents and others is primarily extra-residential, which may also explain why women, compared to men, have been noted to be more likely to provide extra-residential care (Carmichael and Ercolani, 2013; Glaser and Grundy, 2002). Nevertheless, it cannot be assumed that men do not participate in the multifaceted nature of informal care provision earlier in their life-course, rather men often take up a more passive supportive role to the female caregiver, filling temporary gaps in the home and substituting the care provision when needed (Kruijswijk *et al.*, 2015).

Most carers were married or in a partnership (Glaser and Grundy, 2002; O'Reilly *et al.*, 2008; Evandrou *et al.*, 2015b; Lyons *et al.*, 2015; Robards *et al.*, 2015), although some studies have found that married women compared to single women have a lower probability of providing care to their parents (Lee *et al.*, 2015; Leopold *et al.*, 2014; Pickard, 2015). Feld *et al.* (2010) noted that husbands were less likely to provide care for their wives, should their wife's difficulties with IADL increase, however this was disputed by other studies noting men increased their care provision equal to women in time of need, resulting in men and women providing similar care (Langner and Furstenberg, 2018). It has been suggested that being married may act as a competing factor, limiting the time available to

Chapter 2

provide extra-residential care, as the individual may have other family commitments (Leopold *et al.*, 2014). Nevertheless, other studies have noted that a spouse/partner offers a supportive role, allowing the carer more time to provide care (Kruijswijk *et al.*, 2015), thus acting as a facilitator for informal care provision, rather than a barrier. Del Bono *et al.* (2009) argued that any gender differences observed among married individuals' care provision were entirely explained by the fact that women are more likely to live with a partner, or with another household member in need of care.

Gender differences have also been noted among the care-recipients. For example, most inter-generational dyad was between carers and their mother (Seltzer and Li, 2000; Leopold *et al.*, 2014). The reasons to why are multiple, including differences in norms, culture or emotional closeness between the carer and the care-recipient (Ibid). Henz (2004) noted that caring episodes were often shorter for adult children caring for a father compared to caring for a mother, 2.3 years versus 4.5 years, respectively. This was speculated due to men's higher mortality or a difference in caring arrangements. For example, the wife of the father may have been the sole carer until more help was required, reducing the caring duration for which the adult child (Ibid). Such differences also reflect that most intra-generational carers are women providing care for their male spouse (Glauber, 2016), although not all studies found an association between the gender of the care-receipts and intra-generational caregiving (Carmichael and Ercolani, 2014).

Research into the associations between informal care and ethnicity in the UK has been limited (Beesley, 2006). This has mainly been due to smaller sample sizes in national surveys of ethnic minority groups in the relevant age range, consequently robust statistical analysis of these groups has not been possible (Pickard, 2015). According to the 2011 Census, 9.8% of adults with a Caribbean background provided informal care, 9.7% Indian, 9.1% Pakistani and 8.8% Bangladeshi, compared to 11.1% White British (ONS, 2013b). A few small-scale studies have explored the effect of ethnicity and found that people from Bangladeshi and Pakistani backgrounds were more likely to provide care, than those from other ethnic minority groups. In fact, these two ethnic groups were twice more likely to provide care than those from a White British background, after controlling for other factors including the SES of the care provider (Young *et al.*, 2006; Willis *et al.*, 2013). Young *et al.* (2006) further explored the gender differences in care provision among ethnic minority groups and noted that for most ethnic groups women were 40% more likely to provide care than men. For

Bangladeshi or Pakistani groups, women were twice more likely to provide care than men from the same the background (Ibid). This was thought to be due to an age gap between spouses, and differences in gender roles and norms (Young *et al.*, 2006).

2.3.1.3 Health of informal care providers

A review of cross-sectional studies by Vlachantoni *et al.* (2013) found a mixed relationship between informal care provision and the health outcomes of the carer depending on the research methodology. Some studies reported care provision to have a negative effect on the carer's health, while others found a positive relationship between the two. Analysis of the 2011 ONS LS Census data found that those providing informal care tended to report their health as 'Not Good', compared to non-carers (ONS, 2013a; Ramsay *et al.*, 2013). Arnsberger *et al.* (2012) considered the effects of caregiving on women's self-assessed health status (SAHS), comparing results in three countries (USA, Northern Ireland and China). The authors found that higher education, full-time employment, extra-residential care provision, caring for a female, and caring for an older person predicted better SAHS in female carers. By contrast, low income, higher levels of emotional stress, providing support with ADLs or medical care, caring for a younger person, and being unemployed were predictors of lower SAHS (Ibid). One aspect to note is that the care-recipients were over 60 years of age, which may have added to the stress of care provision, as increased age of the care-recipients, is also associated with higher intensity of care provision (Vlachantoni *et al.*, 2015). Secondly, selection bias should be considered, as higher educated individuals and those with a higher income often report better SAHS regardless of whether they provide care or not (Marmot, 2010) (also see sections 2.3.1.4 and 2.3.2). Equally, studies have noted low-income employment, unemployment and low SES to be correlated with a poorer health status (Singh-Manoux *et al.*, 2003; Demakakos *et al.*, 2008; Marmot, 2010). Consequently, if providing care has a negative effect on health, this could cause social drift in SES (see also section 2.2.3), further widening the SES health inequality gap.

When examining the effects of care provision on the carer's health, a longitudinal study design is more appropriate, as this method is better equipped to evaluate potential causality (see also section 2.3.2). Cross-sectional studies cannot impute causality, and it is therefore not possible to say whether carers are more likely to report poorer health as a consequence of providing care, or if the poor health preceded the care provision. Moreover, the health of the carer changes over time

Chapter 2

(McCann *et al.*, 2004) (see also section 2.3.2.1), the duration of the caring episode in the mentioned cross-sectional studies had not been controlled for, often because of this information was lacking in the national survey.

Many cross-sectional studies are potentially confounded by an element of a '*healthy carer effect*'. The concept of '*healthy carer effect*' originated from the '*healthy worker effect*' and '*healthy hire effect*', which refers to a continuing self-selection process, such that individuals who are employed (in this scenario the individuals who provide care) tend to be healthier than those who are not (Arrighi and Hertz-Picciotto, 1994, p.189). The '*healthy carer effect*' hypothesis that carers who are healthier are self-selected into caregiving role and that they are more likely maintain in the role, thereby displaying better health-related outcomes compared to non-carers (McCann *et al.*, 2004; Fredman *et al.*, 2010). If the health advance is to be sustained over the caring period (i.e. a '*survivor effect*' (Arrighi and Hertz-Picciotto, 1994)), this could be further associated with the theories of cumulative advantage/disadvantage discussed earlier (see also section 2.2.1). From an empirical perspective, this could lead to a widening of the health gap between carers and non-carers, potentially also caused by carers being more physically active (due to the caring tasks) than non-carers, reducing the risks of functional and cognitive decline, however the opposite could also be argued, as argued in section 2.3.2.1.

In addition to the '*healthy carer effect*', there is evidence to suggest carers, who has a long-term illness, have increased resilience and coping strategies allowing them to continue to provide care despite of their own health problems (Martinez-Marcos and De la Cuesta-Benjumea, 2014). In relation to the '*healthy carer effect*', these carers may appear to be in too poor health, but due to a feeling of responsibility, they may downplay their own health problems. In fact, a review on the oldest carers by Greenwood and Smith (2015), highlighted that despite older carers being more likely to have their own health conditions, older carers had a more positive perspectives of the caring role, in addition to better coping strategies and identifying rewards of the role, compared to younger carers. However, as also discussed in the review all caring circumstances are diverse, and an older carer who is fit and healthy and has a good support network, is likely to have a more positive experience the caring experience, compared to a carer (of any given age), who is isolated and have their own health problems (Greenwood and Smith, 2015). This can lead to various interpretations of how caring affects the carers' health by masking the true effect of caring on the carer's health. It is therefore difficult to conclude whether care provision per se causes the carer's

health to deteriorate (or improve) or whether changes to the carer's health are confounded by a selection bias (see also section 2.3.2.1) (Brown and Brown, 2014).

2.3.1.4 Employment and socio-economic characteristics of informal care providers

Economic activity may influence whether or not a person enters into informal care provision, however, not all studies agree on the causal effect of economic activity (employment). As mentioned, a downside of cross-sectional studies is that they cannot establish whether individuals, who are either unemployed or working part-time, have more time to provide informal care, or whether carers decreased their working hours or left work entirely, due to their caring roles. There is evidence from longitudinal studies suggesting that carers tend to reduce their working hours, because of the caring commitments (Leopold *et al.*, 2014; Gomez-Leon *et al.*, 2017). This is further discussed in section 2.3.2.2.

Most studies agreed that providing care has a negative effect on the carer's economic activity (Heitmueller, 2007; Drinkwater, 2015; Walsh and Murphy, 2018). Drinkwater (2015) found that caring for between 20 and 50 hours per week was associated with lower levels of employment for carers compared to non-carers, and employment rates for individuals who provided care for more than 50 hours per week, were up to 27 percentage points lower than for non-carers. Similar effects were noted by Walsh and Murphy (2018) albeit the lower probability was noted for carers providing over 15 hours of care per week. When considering the reverse causality, one study estimated that working 10% more hours per week was associated with a 2 percentage points lower probability women providing informal care, compared to non-carers (He and McHenry, 2016). A similar pattern was seen for spousal care, with those working full-time providing 51% fewer hours of care to their spouse than those not currently employed (i.e. economically inactive), the analysis controlled for the care-recipient's disease, morbidity and sociodemographic characteristics (Lima *et al.*, 2008). Gender permeates the relationship between economic activity and care provision, and women working part-time were more likely to provide care (Plaisier *et al.*, 2015), especially with increased care intensity, compared to individuals (both men and woman) working full-time (Jacobs *et al.*, 2014; Drinkwater, 2015). Some scholars have argued that this may contribute to the gender differences in care provision, as men tend to work more hours and not to combine multiple roles, whereas women are more likely to work part-time and to combine work with care-giving (Carmichael and Ercolani, 2016; ONS, 2018c) .

Chapter 2

As well as employment, social economic status (SES) are associated with the likelihood of care provision, but also with the likelihood of receiving care (Vlachantoni *et al.*, 2015). For example, a negative association has been noted between women receiving informal care and being in the second-richest wealth quintile (Ibid). This is likely a result of having the financial capacity to rely on paid support. However, little research has explored the association between provision of care and the carer's SES. It could be speculated that people from poorer backgrounds are less likely to provide care because they cannot afford to be out of paid employment, or to reduce their working hours. On the other hand, individuals who have fewer resources to pay for formal care on behalf of the care-recipient, may feel obligated to provide the family care themselves as a necessity.

The few cross-sectional studies which have examined the association between the SES of carers and informal care only noted a weak relationship and the evidence varies substantially according to the care-recipient and the intensity of the care provided. Some studies found that having a manual occupational background was negatively associated with caring for a parent (Grundy and Henretta, 2006). This contradicts other studies, which noted that those working in semi-routine and manual-occupations often had looser ties to the labour market, and were therefore more likely to take up informal care responsibilities (Henz, 2004). If the care provision was extra-residential, relatively little difference was seen across the social classes, although a significant association between SES and providing care for a spouse was found (Glaser and Grundy, 2002, Norman and Purdam, 2013). The odds of providing co-residential care gradually increased from higher to lower SES groups (Norman and Purdam, 2013). Moreover, O'Reilly *et al.* (2008) found that individuals providing low-intensity care were more affluent than those providing higher-intensity care. This may be due to a confounding factor of individuals from lower SES were more likely to have a disability, thus being more likely to need care (Glaser and Grundy, 2002; Hanratty *et al.*, 2007) (see also section 2.2.1).

Inconsistencies were also noted in studies using various proxies for SES. Housing tenure, for example, is often used as a proxy for SES, and studies have noted informal carers to be more likely to own their house outright than non-carers (Ramsay *et al.*, 2013; Robards *et al.*, 2015). However, Ramsay *et al.* (2013) noted that this only applied to carers providing light care, compared to providing moderate and heavy care. Other studies showed that social-renters (i.e. renting from the local authority, council or housing association) were more likely to provide care than homeowners (OR 1.82 and OR 2.09 for men and women,

respectively) (Young and Grundy, 2008), however Young and colleagues included a high proportion of unemployed women in the sample, which may have biased the results as this is associated with lower home ownership (Ibid). Ramsay *et al.* (2013) observed a similar pattern among carers when providing over 20 hours of care per week.

An overall positive association between providing informal care and wealth has been noted (Mentzakis *et al.*, 2009; Schmidt *et al.*, 2016). Mentzakis *et al.* (2009) however, found that wealthier males were less likely to provide care, compared to poorer men. It should be noted that Schmidt *et al.* (2016) used the SHARE data and only included participants aged over 60 years, extra-residential care and grandparenting, moreover the study did not account for the intensity of care. As discussed in section 2.3.1.1, age and the intensity of care is positively associated with co-residential care and both are associated with decrease wealth, as higher intensity and co-residential care is considered more costly (Beesley, 2006).

Education was associated with the likelihood of providing informal care, particularly among women. A higher education level reduced the likelihood of providing care (Jenkins *et al.*, 2009; Mulder and van der Meer, 2009), arguably due to the relationship between higher education attainment and a stronger labour force attachment, which in turn acts as a competing factor for providing care. Likewise, higher educated people may be better informed and more equipped to negotiate entitlements of benefits for the care-recipient, and this means that they are less frequently called upon to enter the caregiving role (Haber Kern and Szydlik, 2010). By contrast, other studies have shown that more educated individuals had an increased likelihood of providing care (Bucx *et al.*, 2012; Jacobs *et al.*, 2014; Lyons *et al.*, 2015), however this may only be relevant for the population aged over 60 (Schmidt *et al.*, 2016). Nevertheless, many studies found no association between education care provision (Stuifbergen *et al.*, 2008; Barnett, 2013; Lee *et al.*, 2015).

2.3.1.5 Other associated factors related to the informal care providers

So far this section has focused more on the general socio-demographic and health factors associated with informal care provision. The next part further expands on these factors to explore the role of the family structure, formal care provision, regional effects and geographical proximity of family members.

Multiple roles and family structure

Occupying multiple roles and competing demands on the carers' time, such as from one's employment, marriage or own children, which can act as barriers or facilitators to care provision (Brandt *et al.*, 2009). A study by Lima *et al.* (2008) using the Health and Retirement study (HRS) found that caring for older parents did not interfere with providing care for a spouse or partner, and this applied to both male and female carers. The same was evidenced for adult children providing care for a parent, where proximity had a more profound effect, compared to the competing obligations of employment (Szinovacz and Davey, 2013). On the other hand, Mentzakis *et al.* (2009) noted that co-residential care provision competed with other demanding activities, such as employment and having dependent children. In fact, one study found that siblings who had dependent children had reduced odds of caring for a parent (OR 0.65) compared to childless siblings (Leopold *et al.*, 2014). As mentioned earlier, factors affecting the likelihood of providing co-residential care could be confounded by co-residential care being more labour intensive. It should also be remembered that competing demands such as employment will increase the level of economic resources available to support a parent/spouse or (grand) child in need, thereby acting as a facilitator (Szinovacz and Davey, 2013).

Moreover, as discussed in section 2.2.3, one's motivation for providing care for a spouse is distinctly different from the motivations to provide care to others, such as for example parents and providing care to others and parents are often also combined with occupying multiple roles (Bastawrous *et al.*, 2015). Bastawrous and colleagues (2015) carried out a scoping review of the well-being of adult children carers, and found that such well-being was uniquely impacted by the quality of the parent-child relationship, and the combinations of roles occupied by the carers. This relates to reciprocity and altruism determining the motivations for informal care provision, this is further addressed in section 2.3.2.3.

Formal care provision

Informal care may from a policy perspective be perceived as having less direct cost to the government, than formal caring arrangements, which has led researchers hypothesising on the 'substitution' theory (Kalmijn and Saraceno, 2008) (see also section 2.2.3). Indeed some studies have observed that informal care acted a substitute for paid domestic help, on the other hand the authors noted that formal support with personal care needs, was complementary to informal care provided by adult children (Kalmijn and Saraceno, 2008, Bonsang

2009, Dykstra, 2010). A study conducted by Mentzakis *et al.* (2009) noted the opposite, as formal care complemented less demanding caring tasks and substituted the more skilled and technical tasks. Moreover, the authors noted a gender division; depending on the task, for male care providers formal care acted, as both a substitute and complementary element with their care provision, whereas for female carers formal care only had a complementary effect (Ibid).

Region and geographical proximity

A regional variation in care provision in England was noted and there appears to be a North/South divide of the caregiving propensity, and those living in the north of England were more likely to provide informal care, compared to the rest of the country (Shaw and Dorling, 2004; Young and Grundy, 2008; Drinkwater, 2015). This may be due to the association between deprivation and health, Hanratty *et al.* (2007) argued the burden of caregiving and the carer's own health may combine to produce the most intensive need in the poorer areas. *The inverse care law* was proposed by Julian Tudor Hart (1971) and states that those who are in most need of care are also the least likely to receive it. Shaw and Dorling (2004) associated this with the issues of the provision of formal healthcare services, such as there are fewer professional healthcare workers in the North of the UK compared to the South, emphasising that informal care provision was almost perfectly positively correlated with the need for care in this region ($r=0.97$). This led them to conclude evidence that the 'positive care law' held true for informal care, as the care was provided more where the need was higher (Shaw and Dorling, 2004, p.901). It should be noted that the study conducted by Shaw and Dorling (2004) was a solely ecological study (i.e. aggregated number of medical professional and informal carers in the area), rather than individual data, it cannot therefore be concluded that the sickest people in England exclusively rely on informal care (Shaw and Dorling, 2004).

Research from Europe and North America has shown a strong impact of geographical proximity between family members and the provision of informal care (Stuifbergen *et al.*, 2008; Brandt *et al.*, 2009; Mulder and van der Meer, 2009; Pillemer and Suitor, 2014; Szinovacz and Davey, 2013; Leopold *et al.*, 2014, Haberkern *et al.*, 2015). Pillemer and Suitor (2014) found that living within a 2-hour drive from the care-recipient increased the likelihood providing carer by more than 6 times. If immediate family members were not living in close proximity to the care-recipient, those who were nearest would compensate by providing more support, thereby having a potential 'substitution effect'. This was

observed mostly between siblings, such as sisters providing care for each other, but also between siblings dividing and sharing the care duty towards their parents (Mulder and van der Meer, 2009, Leinonen, 2011). This pattern bears resemblance to the solidarity model shown in Figure 2, section 2.2.3.

As previously mentioned, cross-sectional studies do not provide evidence of possible causality, it is therefore important to also investigate evidence from longitudinal studies, as these provides suggestions for the longer-term effects and changes in informal care provision. The next section therefore examines the evidence from longitudinal studies.

2.3.2 Evidence from longitudinal studies: the longer-term effects and changes related to informal care provision

Using evidence from longitudinal studies, this part of the literature review enables a greater understanding of individuals' pathways into informal care provision. These pathways can be affected by life-course events, such as occupying multiple roles both within the family (caregiving, marital, and parenting) and non-family environments, like employment and SES (Barnett, 2015). Longitudinal studies have the advantage of following a sample population for a longer duration of time and thereby observing any occurring changes, enabling the evaluation of effects of the timings of potential caring episodes, as well as causal pathways. This part of the literature review further supports the interpretation of results relating to the second and third Research Questions set by this study.

The cumulative probability of becoming an informal carer increases with age, and virtually everyone is likely to provide some form of care outside their household at some stage during a full life-span (Hirst, 2002). Almost 6 out of 10 people are likely to have cared for someone in the same household by the time they have reached their 70th year (Ibid). The duration of individuals' provision of care varies, but research estimates that many carers will have provided care for over 5 years by the time they reach the age of 65 years (Seltzer and Li, 2000; Henz, 2004; Plaisier *et al.*, 2015). As previously mentioned, over the last decade, the prevalence of carers has stayed relatively stable, however the intensity of the care provided has increased. Studies have shown a decrease of carers providing 1 to 19 hours of care per week (light care provision), but an increase among those providing care for over 20 hours per week (heavy care provision) (Pickard, 2002; Evandrou *et al.*, 2015; Robards *et al.*, 2015). Increased intensity of care may have a negative effect on the carer's health, as well as on the carers' financial situation,

as they may be less able to work and may face an increased financial expenditure on costs related to the care provision (Carmichael and Ercolani, 2016).

Larkin (2008) introduced the concept of a “serial” carers, to reflect on the phenomenon of caring for one individual, following care provision to a different individual. The concept of “serial” carers challenges the notion that the duration of a caring spell is increasing, due to an increased in LE and need for long-term care (Brown, 2015), but rather the carer’s caring spell is increased, due to the carer remaining within the caring role, albeit caring a different care-recipients. Larkin (2008) conducted a qualitative study of 37 carers and found that 70% had previously provided informal care. The cyclical nature of caring and post-caring in serial carers’ lives in relation to the concept of post-caring trajectories can be seen in Figure 3. Cronin *et al.* (2015) noted a similar post-caring trajectory of carers remaining within the caring role.

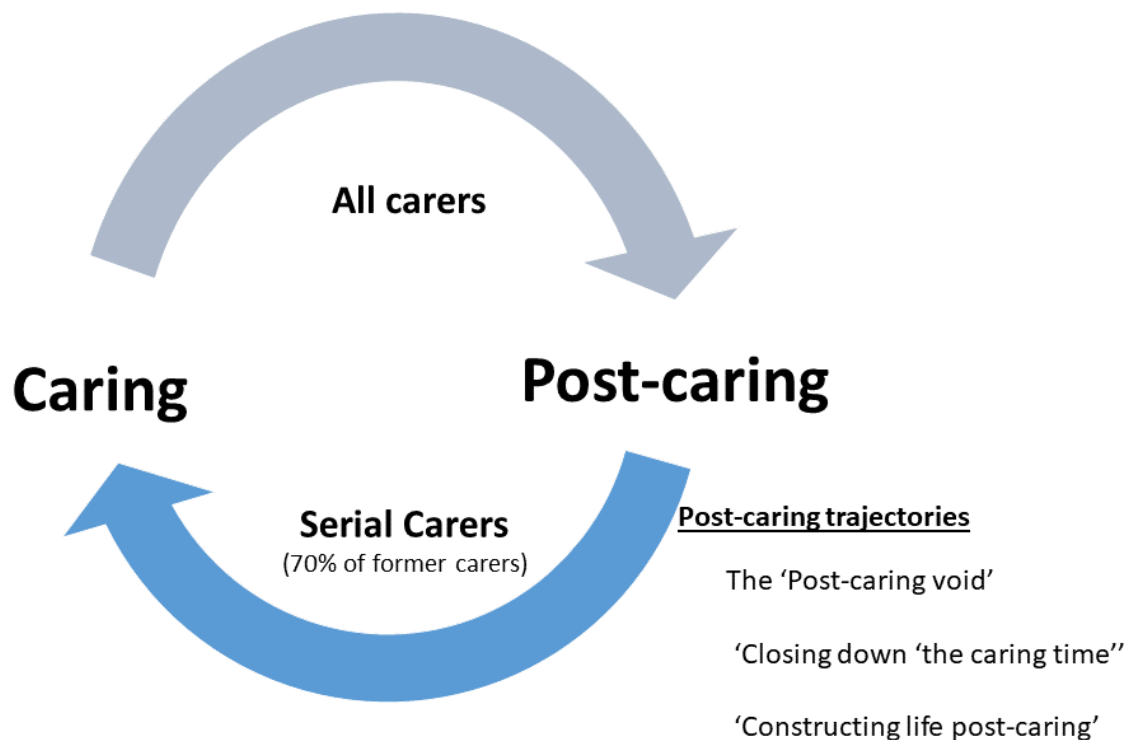


Figure 3 The Notion of Serial Carers

Source: Adapted from Larkin, 2008 p. 1038

The long-term effects of care provision on the carer, both positive and negative, and the consequences of the increased caring intensity have on the carer’s health and economic activity is discussed in further detail in the following text.

2.3.2.1 Positive and negative health impact on the informal care providers

Longitudinal studies on the carers' physical and psychological health have shown complex and conflicting results, as also noted in section 2.3.1. The primary predictive stressors driving the adverse effects on the carers' health are concentrated on the association between health and (a) the duration, (b) the intensity and (c) the type of care provided (i.e. personal or practical) (Kim *et al.*, 2016).

The negative portrayal of informal care provision has generally been the focus that has shaped research and relevant social policy (Brown and Brown, 2014; Roth *et al.*, 2015). Nonetheless, there are also many positive and beneficial dimensions of care provision. Vlachantoni *et al.* (2016) compared caring roles between 2001 and 2011, and noted that providing care in 2011 predicted lower odds of reporting poor health in 2011 (OR 0.64) compared to non-carers. Brown *et al.* (2009) found that providing care to a spouse (both aged over 70) over a 7-year period for at least 14 hours per week, predicted lower mortality in carers compared to spouses not providing care, even after adjusting for care-recipient health, and individual and social differences of the carers (Hazard Ratio 0.64). There was no significant difference between carers who provided less than 14 hours for a spouse and those who did not provide care (Ibid). Caputo *et al.* (2016) saw a 20.7% lower risk of mortality in female carers compared to non-carers, however only when providing extra-residential and low caring intensity. It was argued that this emphasised the beneficial effects of informal care provision, such as the caregiving activity giving meaning in one's life and the carer having a sense of reward (Ibid).

The effect of care provision on the carer's health is likely linked to the care-recipient's support needs (Carmichael and Ercolani, 2014). Caring for someone who is frail due to factors associated with old age may be perceived as less stressful, than for example caring for someone with Alzheimer's or Parkinson's disease, due to the severity and symptoms of these conditions (Davis *et al.*, 2011). On the other hand, it could also be argued that experiencing a loved one suffering from Alzheimer's is by itself a stressful experience, whether or not the person is a caregiver (Brown and Brown, 2014). As previously mentioned in section 2.3.1.1, providing co-residential care is correlated with higher intensity care, which implies that the person being cared for has more disabilities adding increased stress to the caregiver. It could be argued that some of the adverse health effects on the carer are due to research bias and confounding factors. For

example, non-comparable control groups and differences between carers and non-carers already present at baseline, due to for example convenience sampling (Brown and Brown, 2014; Roth *et al.*, 2015).

Hiel *et al.* (2015) used the SHARE data and found a significant moderate association over an 8-year follow-up period between care provision and poor mental and physical health of the carer. A crude model indicated higher odds of poor self-rated health for carers (OR 1.23), although once adjusted for socio-demographic variables and health in previous waves, such effect was no longer significant (Ibid). Studies from North America investigated the relationship between spousal care-giving and a decline in the carer's health, and it was concluded that care provision in itself had no adverse effect on the carer's health; rather, any decline in health was attributed to socio-demographic characteristics, mainly the carer's age (Jenkins *et al.*, 2009; Barnett, 2015).

Data from the North American National Longitudinal Survey of Mature Women, SHARE and ELSA showed that co-residential care (spousal and parental care) predicted an increase in the long-term (>10 years) depressive symptoms and functional limitations of carers, particularly in women (Caputo *et al.*, 2016; Kaschowitz and Brandt, 2017). Using the ELSA, Kaschowitz and Brandt (2017) further noted that providing extra-residential care had a beneficial effect on the carer's mental health, however they concluded that this was an artefact of the 'healthy carer effect'. Hajek and Konig (2016) used longitudinal data drawn from the German Ageing Survey (DEAS) and noted that intra-generational care affected women's cognitive well-being (CWB), however it did not affect their overall mental health. CWB was referred to as the cognitive evaluation of one's life, whereas mental health was an objective measure based on depression scale scores (Ibid). By contrast, Hajek and Konig (2016) noted that male carers providing intra-generational care did not witness an effect on their CWB, but care provision had an effect on the male carers' mental health. The mentioned studies also examined extra-residential care provision, but found no association between care provision and the carer's health (Caputo *et al.*, 2016; Hajek and Konig, 2016). Doebler *et al.* (2017) noted in their study from Northern Ireland that informal care per se was not related to adverse mental health, however there was a strong relationship between the intensity of caregiving and mental ill-health.

There is evidence that the carer's health deteriorated as the intensity of care increased (Carmichael and Ercolani, 2016). Analysis of the 2011 UK Census showed that those providing care for 50 hours per week or over had worse health

than those providing fewer hours of care (ONS, 2013a). The effect of the increase in the intensity of caring might also have an effect on the health outcomes and mortality of the carer. The risk in mortality was positively correlated with the time spent providing care (Burton *et al.*, 2003; O'Reilly *et al.*, 2008; Ramsay *et al.*, 2013). Those providing 50 hours per week had a higher risk of mortality compared to non-carers (OR 1.36 and 1.40 for women and men, respectively) (O'Reilly *et al.*, 2008). The '*healthy carer effect*' was considered, but no evidence of this was found (Ibid). Ramsay *et al.* (2013) argued that increased resilience to negative physiological outcomes in carers, compared to non-carers, might be one possible explanation for these findings. This would advocate for the presence of selection bias and a '*healthy carer effect*'; further discussion on the implication of the selection effect can be found in section 6.4.

Transitioning into and out of the care-providing role may have an effect on both the physical and mental health of the carer (Burton *et al.*, 2003; Lyons *et al.*, 2015). Some researchers have noted that discontinuing the caregiving role enhanced the carer's quality of life and social participation, and decreased their level of stress (Seltzer and Li, 2000; Lyons *et al.*, 2015). Lyons *et al.* (2015) only included carers who had stopped providing care, due to the death of the care-recipient, rather than the care-recipient entering a formal care setting, this might explain the lower stress levels seen in the 'discontinued carers', compared to 'repeating carers'. In contrast, Rafnsson *et al.* (2015) noted that over a two-year period, participants who left the caregiving role experienced a significant increase in their depression levels, compared to non-carers. Overall the studies were limited by not having comprehensive data on reasons for why the carers stopped providing care, making it difficult to adjust for effects of bereavement (Lyons *et al.*, 2015). Moreover, due to the short follow-up period of studies in this area, it is often difficult to extrapolate what the immediate and long-term effects the termination of care provision has on the former carer. Occupying multiple roles also has consequences for the health, as well as financial costs for the informal carer, as the following section will show.

2.3.2.2 The effects of employment and occupying multiple roles on the provision of informal care

As it was also highlighted by the cross-sectional studies and by the theory of feminism (section 2.2.2) informal carers, especially women carers, rarely occupy one sole role, but rather they have multiple roles. Results from the Longitudinal Retirement Survey (LRS) 1988/89-1994, suggested that women carers combining

other roles, such as parenting and paid employment, had nearly three times higher odds of reporting poor health than non-carers (Glaser *et al.*, 2005). A similar pattern was noted by Stone *et al.* (2015), based on the life history interviews from the ELSA Wave 3 (2006). The authors noted that women who had defined periods of full-time work before and after focusing on caring or family life, appeared to have the most favourable later life outcomes in terms of health. In other words, women have better health in later life when multiple roles in their life are performed consecutively and separately (Ibid).

Caregiving responsibilities are known to be facilitators for early retirement and labour market exit decisions (Berecki-Gisolf *et al.*, 2008; King and Pickard, 2013; Carr *et al.*, 2016). Many first-time carers do not change their working arrangement when they first take up the caring role, however with time and/or as the intensity of care increased, more carers made changes to their economic activity, and many carers either decreased their working hours or exited the labour market altogether (Henz, 2004; Leopold *et al.*, 2014; Gomez-Leon *et al.*, 2017). Carers working part-time appeared more likely to reduce their hours of paid employment, than full-time employees (Schneider *et al.*, 2013).

A reduction in working hours endures a financial cost for the carer, such as reduced wages or pay cuts. Lee *et al.* (2015) found that women, who provided care to their parents at an earlier observation, were associated with a lower household income at later observations points. The impact of providing care may be interpreted as a 'direct' or 'indirect' cost (Hill *et al.*, 2011). The direct cost refers to the monetary expenses incurred by the carers, including home-modifications, transport, increased gas and electricity bills, and costs of medication for carers to mitigate any adverse health implication suffered as a result of care provision (Ibid). The indirect costs encompass the *opportunity costs* - time costs and impact on health (Hill *et al.*, 2011). The opportunity cost is an economic concept, and refers to the value sacrificed to undertake a particular activity (Ibid). Opportunity costs in regards to informal care provision relate to foregone earnings, household production and leisure (Sovinsky and Stern, 2016). Research has shown that the opportunity costs are higher for full-time workers with higher earnings, for co-residential carers and those who are caring for longer hours (Carmichael *et al.*, 2010). Figure 4 shows five areas of opportunity costs and how these are interlinked. Some areas are bi-directional and each factor has a knock-on effect on others. For example, a reduction in one's working hours has an impact on the household income and causes a reduction in savings, which can lead to fewer opportunities for leisure time, and which further effect one's health.

Although, Figure 4 paints a predominantly negative picture of care provision, it is however important to remember the opposite side of the story. The benefits of care provision include: skills learned from providing care and a reduction in working hours may increase wellbeing and reduce stress and leisure time (Roth *et al.*, 2015). Care provision can, as before mentioned, also have positive effects on the carer's health and wellbeing. Furthermore, support in form of carer's benefits and respites will help reduce the effect on income and leisure time (see also Table 1, section 1.1.2).

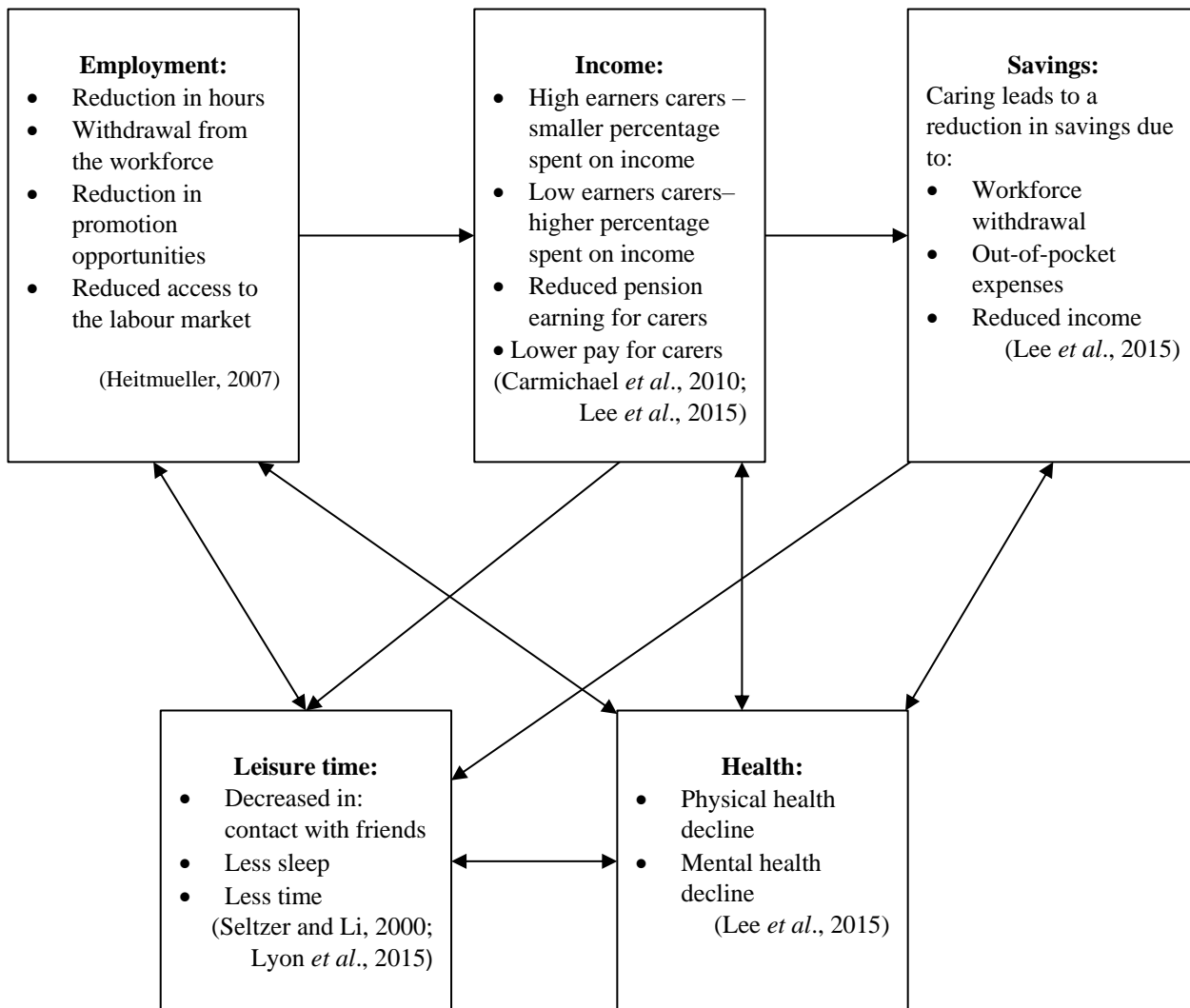


Figure 4 The complex pathways of opportunity costs of care provision
Source: Author's own based on literature

As shown in Figure 4 decision to initiate care revolves around complex factors, including the possibility of combining work and care. Also part of the decision is the person's individual job characteristics, such as working hours, job position and the impact of interruption to employment to that individual. It has been noted that women exposed to high job strain and caregiving had a moderately higher risk of sickness absence, defined as absence from employment for more

than 14 consecutive days (Mortensen *et al.*, 2017). A study from Australia noted that employees who cared for people with more severe needs experienced greater disruptions to their career, when they received limited workplace support, which also led to lower caregiver well-being (Bainbridge and Broady, 2017). The study further advocated for more “caregiver friendly employment” (Ibid, p.65), which the authors defined as for example flexible work arrangements.

Flexible work arrangements have been shown in Austria to decrease the risk of the carer leaving the labour market (Berecki-Gisolf *et al.*, 2008; Schneider *et al.*, 2013). Flexible working arrangements include working from home, reduced hours, job share, flexitime, changing shift patterns and compressed hours. Formal provision of flexible work appear to favour the combination of work and care, flexible work policies at the workplace level are more important than additional flexibility at the individual job level, providing evidence that the working environment and culture is central for carers to remain in employment, however only for carers providing low intensity of care (Bryan, 2012).

As stated in section 2.3.1.1, many studies classified 1 to 19 hours of care per week as light caring and more than 20 hours as moderate to heavy care provision. Therefore, a threshold of 20 hours per week has been set by many studies as the cut-off point for studying the negative effects of care provision. Nevertheless, other studies used other thresholds to examine the effect of the carer. For example, King and Pickard (2013) used a threshold of caring 10 hours per week, and noted that women aged between 50 and 58 years providing less than 10 hours of care per week, were significantly more likely to remain in employment, however this pattern was not observed for male carer providers. It was suggested that this was due to an association between workforce withdrawal and the strength of the labour market attachment. For example, if an individual was working part-time or in a less skill-job, then their labour market attachment was weaker. It has been noted that women with a weaker labour market attachment were 51% more likely to provide care, than those with a stronger attachment (Young and Grundy, 2008).

Being a carer may also restrict people’s access to the labour market, as carers who have previously withdrawn from the labour market have fewer years of work experience (Carmichael and Ercolani, 2016). An increase in the caring intensity and providing co-residential care further increased the detachment from the labour market, as this type of care provision is more time consuming. This in turn makes the carers more likely to reduce their working hours, exit the labour

Chapter 2

market or limiting the availability to enter the labour market (Henz, 2004; Heitmueller, 2007; Schneider *et al.*, 2013; Carmichael and Ercolani, 2016; He and McHenry, 2016). A study from America using the HRS data, explored the likelihood of previously retired carers returning to employment; the authors noted that, compared to non-carers helping a spouse with ADLs or IADLs, reduced the odds of the carers returning to work in the subsequent wave by 78% and 55% respectively (Gonzales *et al.*, 2017). It was also noted that there was no statistically significant difference in the likelihood of returning to work between individuals helping a parent or having multiple caregiving responsibilities compared to non-carers (*ibid*). As a consequence, informal carers are also more likely to experience negative economic outcomes than non-carers, and this especially applies to women (Lee *et al.*, 2015), (see also section 2.2.2).

Some studies have indicated a potentially endogenous relationship between work and care provision, where carers are self-selected from a pool of under-employed or economically inactive individuals, for example in order to bridge spells of unemployment or job seeking, or carers may lack necessary employment skills due to past life events, such as for example an absence of the labour market (Heitmueller, 2007; Naldini *et al.*, 2016). Other studies have suggested that there is a link between an individual's career and providing informal care, for example those with a background in health and social care settings were more likely to provide informal care than individuals who, for example, worked in the financial sector (Young and Grundy, 2008). Likewise, previous history of caring was strongly related to the likelihood of a future transition into a caring role (Carmichael *et al.*, 2010). However, for women especially, local economic, policies and cultural factors, in addition to the availability of formal care, may have an even stronger influence on their choices in relation to care provision and employment (Naldini *et al.*, 2016).

Figure 5 depicts the complexity of the factors involved in negotiating pathways into informal care. Broese van Groenou and Boer (2016) used a model to determine informal care provision at the individual level, in terms of three questions an individual may ask themselves, when deciding whether to provide informal care or not. These questions are: a) do I want to [provide care]? b) do I have to [provide care]? and c) Can I [provide care]? Both questions (a) and (b) can be related to the solidarity model (Figure 2, p. 35), and the availability of alternative sources of support. Question (c) reflects the perceived barriers and the opportunity costs of care provision (Figure 4, p. 56).

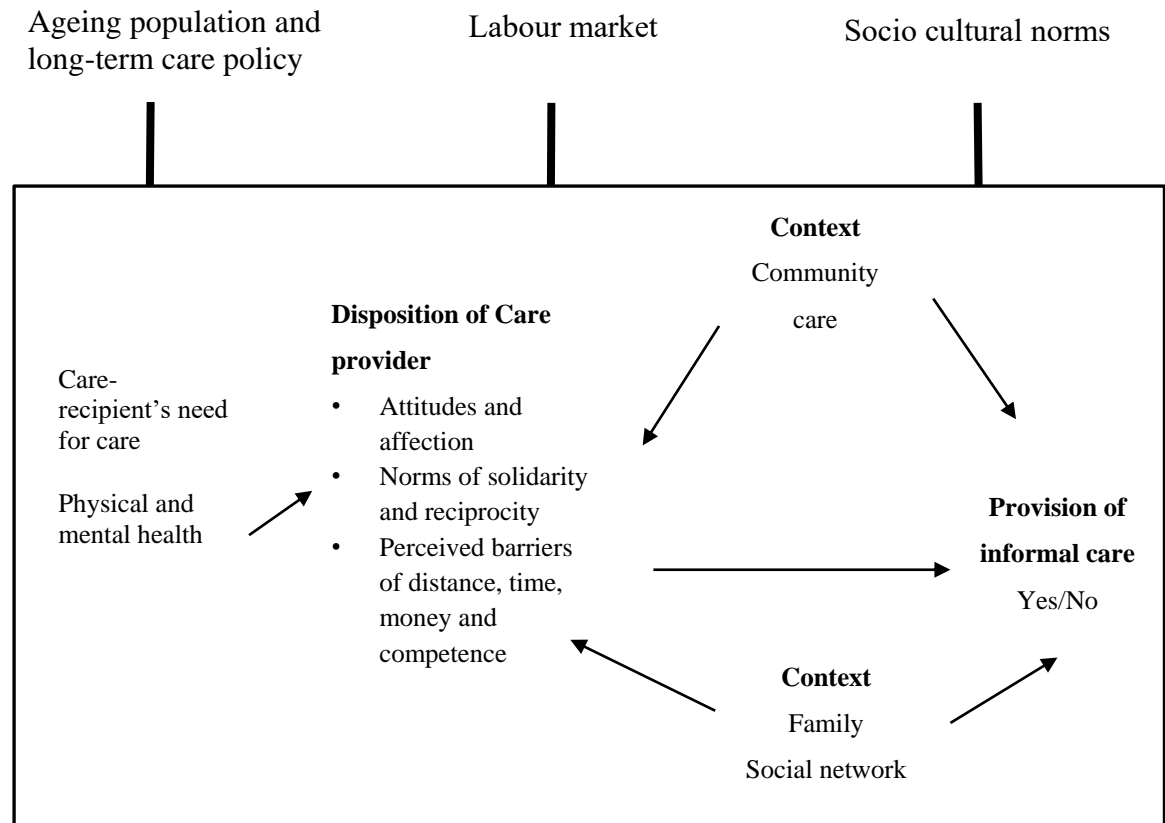


Figure 5 The Informal Care Model

Source: adapted from Broese van Groenou and Boer (2016)

The context of family and social network is described in more detail in the next section.

2.3.2.3 The effects of social contacts and family size on the pathways into informal care provision

As reviewed in the theories of informal care provision, cultural factors may influence the decision to provide care. In accordance with the solidarity model (Figure 2, section 2.2.3), family structure and relationships can have an effect on the likelihood of becoming a carer. Research has shown that a good relationship between parents and the adult child can increase the chances of that child becoming a carer to the parent (OR 2.69). However, having more siblings was associated with a lower likelihood of providing care to a parent (OR 0.93), possibly due to the opportunity of sharing the caring role with one's siblings (Stuifbergen *et al.*, 2008). It has also been suggested that the birth-order, i.e. being the first-born compared to other siblings, increased the probability of becoming a carer (OR 1.76) (Leopold *et al.*, 2014). Another study explored the predicting factors of adult children taking on caregiving responsibilities to older mothers over a 7-year period, and it was noted that children (mainly daughters) identified by their mother at baseline, as the ones she expected to provide care

for her, were significantly more likely (OR 3.01) to provide care within the 7-year time period, than other siblings in the family (Pillemer and Sutor, 2014).

In order to show the motivations for providing care, Szinovacz and Davey (2013) based their research on the theory of altruism, however they found no evidence of altruism in terms of providing care for a parent. Evandrou *et al.* (2016) carried out a study examining whether having received support earlier in the life-course made adult children more likely to support their older parents in later life. In contrast to Szinovacz and Davey (2013), Evandrou *et al.* (2016) found evidence of both altruism and reciprocity, with both sons and daughters who had received support in the past, having a higher likelihood of providing support to their older parents than children who had not received support. It should be noted that this was linked to the type of support provided by the adult child, as instrumental care was associated with previous support received by the adult child, whereas personal/basis care was not (Norton *et al.*, 2013) (see also section 2.2.3 on the theories of linked-lives, reciprocity and altruism).

2.3.2.4 Informal care provided to grandchildren

Although most research into informal care provision has excluded informal care to grandchildren, there is a growing need to include grandparenting. Providing care for a grandchild is one of the ways in which adult children can receive support from a parent. As previously mentioned there is a growing proportion of people being “sandwiched” between providing care for both older parents, as well as either their own dependent children and/or grandchildren (see also section 1.1.1). Indeed, Železná (2016) using data from the SHARE found that the highest proportion of people providing regular care to a grandchild, where those also providing regular care to their parents.

Providing care for grandchildren may be demanding, both physically and emotionally (Di Gessa *et al.*, 2016). Indeed providing high intensity care to a grandchild may be noted to have similar adverse effects on the carer to that noted by the more traditionally defined informal carers (Glaser *et al.*, 2010). These include social isolation of the carer, due to decreased contact with friends and less time for leisure, but also financial burdens to the grandparent (Ibid).

The health impact on older people providing care to grandchildren remains uncertain (Di Gessa *et al.*, 2016). Studies have found a positive association between providing care for a grandchild and the health of the carer. Di Gessa *et al.* (2016) noted that even after controlling for individuals’ earlier health and SES condition, it was grandmothers, but not grandfathers, who had better health

outcomes. A report by Glaser *et al.* (2010) found that providing light care for a grandchild may enhance the well-being of the grandparent providing the care, however more intense care provision did not have this effect. Lastly, O'Loughlin *et al.* (2017), noted that grandparents had poorer self-rated health than carers providing care for other relatives or friends, however this was not statistically significant.

As women's participation in the labour market has increased, so has the demand for childcare, and consequently there is a greater need for grandparents to provide care to grandchildren, in order for the parents (mainly the mother) to enter (or re-enter) the labour market (Glaser *et al.*, 2010). However, a possible conflict may arise between the grandparents' role in the childcare and the policy objective of raising employment rates among the over 50s (Gray, 2005; Glaser *et al.*, 2010). Friedman *et al.* (2015) estimated the transfers of time and money between adult children and parents and noted that more time was being transferred to adult children from their parents than vice versa. The authors could not distinguish how the time transferred was used, and it was presumed that the higher proportion of time devoted to the adult children was in the form of childcare for grandchildren (*ibid.*). Glaser *et al.* (2010) highlighted many of the same issues identified for carers providing care to someone due to illness or fragility, and Lumsdaine and Vermeer (2015) noted an association between women aged over 51 who provided care for grandchildren and a decrease in their labour force attachment. The timing of becoming a grandparent often coincides with approaching retirement, and studies have noted an association between early retirement and grandparenting (Van Bavel and De Winter, 2013).

This thesis includes care provided to grandchildren, even though this can be considered outside the definition of informal care provision. The ELSA, unlike surveys such as HRS and SHARE, does not include a separate question regarding care provided to grandchildren, but rather the question on grandchild care is incorporated as part of the ELSA's general question related to informal care (Hank *et al.*, 2018) (see sections 3.3.1 and 3.3.2.4). Furthermore, as discussed, providing care for a grandchild often coincides with providing care for another family member, and may have a very similar effect on the carers' health and financial situation. It is therefore important when considering pathways into informal care provision.

This concludes the review of the empirical evidence and as seen from both the cross-sectional and longitudinal studies, the associations between providing

informal care, the motivations for doing so and the outcomes for the carers are both complex and multifaceted. Often the literature provided conflicting evidence. The literature included in this review was of generally good quality studies, however as with most literature there are also limitations and these are discussed in Appendix A.

2.4 Gaps in the literature

The literature review has highlighted four main gaps in the literature, which this thesis aims to fill.

Firstly, until the present date no cross-sectional studies have used the ELSA Wave 7 (2015) to establish the characteristics of informal carers in England, which Research Question 1 aims to address. Other studies have used the ELSA Wave 3 (Vlachantoni, 2010) and Wave 6 (McGarrigle *et al.*, 2018).

Secondly, as seen from the literature review there are fewer longitudinal studies on informal care provision than cross-sectional studies. Only a few have conducted longitudinal analysis utilising the ELSA dataset, and if used only covered waves 2 to 6 (Kaschowitz and Brandt, 2017; Rafnsson *et al.*, 2015; Rutherford and Bu, 2017). Moreover, to the best of the author's knowledge no other study as directly compared shorter and longer-term transitions of care provision patterns. Research Question 2 and 3 utilises the ELSA Waves 4 to 7 to establish both the short and longer-term transitions into informal care.

Furthermore, although research has explore transitions in caring intensity (Pickard, 2002; Robards *et al.*, 2015; Evandrou *et al.*, 2015; Vlachantoni *et al.*, 2016), very little is known about how and if carers transition between care-recipients.

Thirdly, Hajek and Konig (2016) emphasised that more research was needed of care characteristics by gender, as well as research separating intra- and inter-generational care provision. To answer Research Questions 1.a, 1.b and 2.a separation by gender is required. Moreover, Research Questions 1.b examines how the caring direction (i.e. providing care to a spouse, other kin or non-kin) which is related to factors such as gender, age, caring activities and health of the care providers.

Fourth and finally, most studies researching informal care and the effect of care provision care have excluded grandchild care (King and Pickard, 2013). This thesis includes all care-recipients, as the evidence suggests that providing grandchild care can have an effect on the availability of time to undertake other

activities, as well as having an effect on the wellbeing of the caregiver (both negative and positive) (Glaser *et al.*, 2010; Lumsdaine and Vermeer, 2015; Schmidt *et al.*, 2016). This is further discussed in section 3.3.2.4.

2.5 Conceptualising the pathways into informal care provision

Figure 5 shows how this study conceptualises the pathways into informal care provision. The phases depict how the different waves of the ELSA are used to address specific research questions and which methodologic approaches are used.

Phase I is related to Research Question 1 and aims to examine who the informal carers are, by conducting a cross-sectional analysis of the ELSA Wave 7 (2015), see section 4.3. Furthermore, *Phase I* also determines the factors predicting informal care provision (i.e. socio-demographic, health and socio-economics), which also serves to guide the next phases.

Phase II is related to Research Question 2. This phase studies the different long-term trajectories of the respondents of the ELSA Waves 4 to 7. This part of the analysis uses a longitudinal approach, see section 5.2. Respondents can have taken one of four different trajectories and cover a time period of 6 years.

Trajectory 1: provided care in all waves ('repeating carers'); trajectory 2: not provided care in any waves (non-carers); trajectory 3: carers who have provided care for two-consecutive waves and trajectory 4: carers who have provided care for none-consecutive waves. It is important to note that the caring status of the respondents between waves is unknown, therefore individuals who did not provide care in either wave may still have provided care at some point in-between the ELSA interviews. Likewise, 'repeating carers' may have had shorter or longer breaks from care provision in-between, this is further this discussed in section 5.2.

Lastly, *Phase III* relates to Research Question 3 and explores the shorter-term transitions between caring statuses between 2013 (Wave 6) and 2015 (Wave 7) and also use a longitudinal approach. The respondents are classified as a) not having provided care in either wave (non-carers), b) provided care in both waves ('repeating carers'), c) provided care in 2013, but not in 2015 ('discontinued carers') and d) did not provide care in 2013, but provided care in 2015 ('new carers'). The same caveats for the caring status as mentioned in *Phase II* apply to this phase as well.

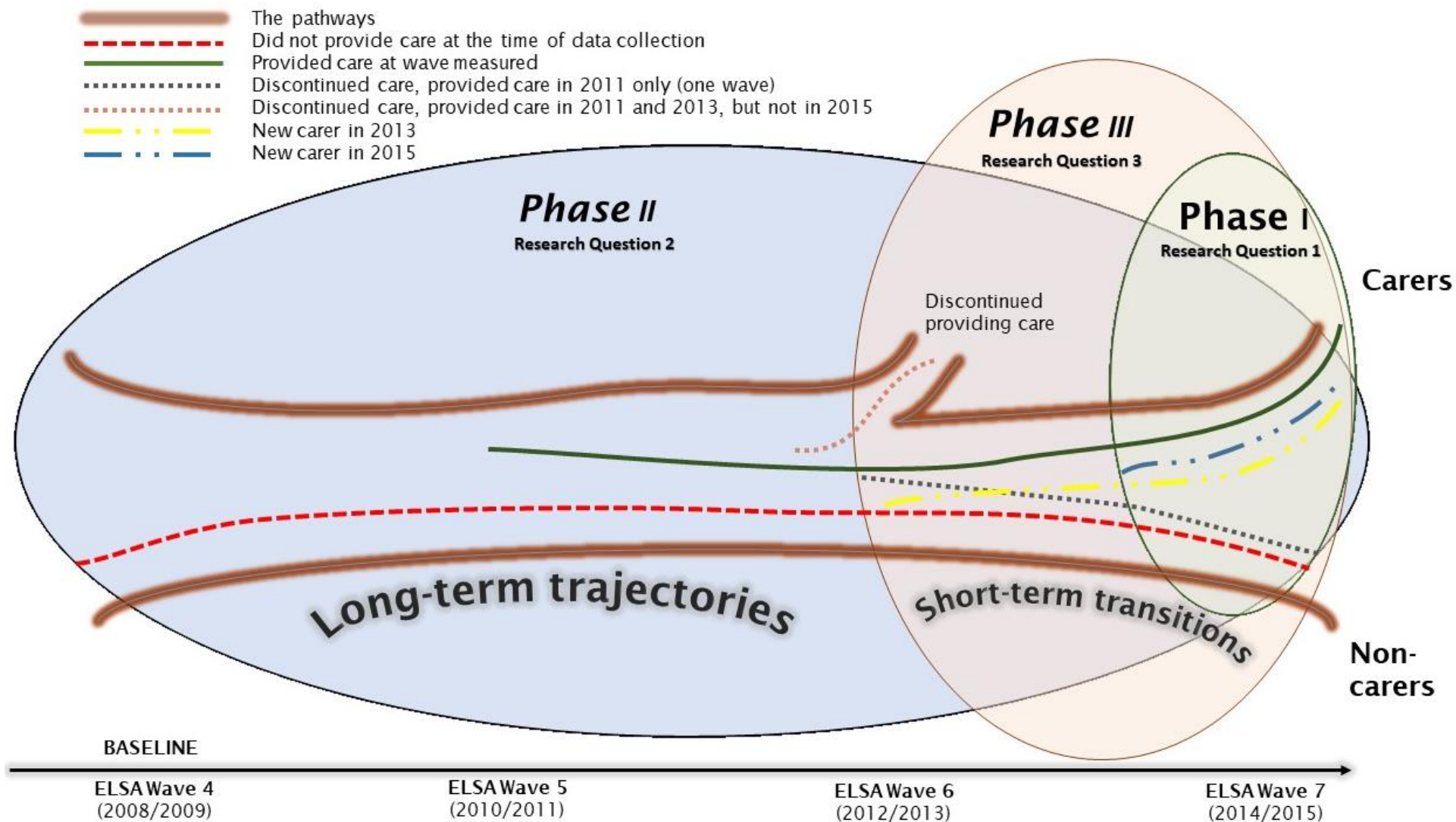


Figure 6 Conceptualising the pathways into informal care provision

It is an assumption that respondents who provided care in the wave measured, provided care repeatedly throughout the period, however these carers may have had break from their caring roles which the survey did not observe. All respondents who provided care at baseline (Wave 4) were excluded from the analysis, see also section 5.1.1.

Source: Author's own

2.6 Summary

The literature review provided theoretical and empirical evidence factors associated with the pathways into care provision, as well as the perceived facilitators and barriers involved in the provision of both intergenerational and intra-generational care. The provision of care was primarily driven by a decline in the health of the care-recipient, but also by the carer's values and norms. The latter was evaluated by the nature of the relationship to the care-recipient and by a cost-benefit analysis. The informal care model in Figure 5, p. 59, depicted the multifaceted and complex interplay between theories on social and personal motivations.

Evidence from cross-sectional studies showed that approximately 12% of the population in the UK provided some form of informal care, with the majority providing care at a low intensity (Vlachantoni *et al.*, 2013). The greatest proportion of informal carers was composed of women aged between 50-64 years. Most carers were married and were either retired or working part-time. Moreover, the majority of carers were in poorer health compared to non-carers. Many socio-demographic factors such as education, housing tenure and wealth showed either a complex relationship with or had no effect on, the likelihood of being an informal carer. Co-residential care was associated with a higher care intensity and spousal care provision (Carmichael and Ercolani, 2014). The facilitators for providing care included: being married, fair health, living in close proximity to or co-residing with the care-recipient, and being a daughter.

Research using longitudinal studies noted that although the numbers of carers have stayed relatively stable over the last decade, the intensity of care has increased (Robards *et al.*, 2015). The duration, intensity and type of care provided, have been identified as stressors which have a potential adverse effect on the carer's health. In addition who the care is provided to (i.e. the direction of care) may also have an important effect on the carer's health outcome (Kim *et al.*, 2016). Transitions between caring statuses can have a negative effect on health outcomes, but can also affect the employment outcomes (Carmichael and Ercolani, 2016; Gomez-Leon *et al.*, 2017). Informal carers were more likely to have worse financial outcomes, due to lower paid working hours or as a consequence of exiting the labour market.

The evidence presented aimed to guide both the methodology and the discussion of this study. The next chapter outlines how the research was carried

Chapter 2

out, detailing the study design, data analysis plan and operational definitions and variables used in this thesis.

Chapter 3 Methodology

3.1 Introduction

This chapter aims to provide a detailed description of the overall methodology used to address the research questions (see section 1.2).

The chapter introduces the English Longitudinal Study of Ageing (ELSA) and Table 2 shows the statistical analysis plan used in each phase (i.e. *Phase I, II and III*, see also section 2.5, Figure 6). A detailed description of the methodology and results each of the phases follows in Chapter 4 (the cross-sectional data analysis) and Chapter 5 (the longitudinal data analysis).

Table 2 Research questions and statistical analysis plan

Phase I	Phase II	Phase III
<ul style="list-style-type: none"> · Research Question 1: Who are the informal carers in England? · Methodology: Bivariate and multivariate descriptive cross-sectional analysis of the ELSA wave 7 (2015) Logistic regression analysis of the ELSA Wave 7 (2015) by gender and intensity of care provision. 	<ul style="list-style-type: none"> · Research Question 2: What are the longer-term trajectories into informal care provision? · Methodology: Bivariate and multivariate descriptive longitudinal analysis of the ELSA waves 4 (2009) to wave 7 (2015). · Logistic regression analysis of the ELSA Wave 74 (2009) by future caring status and by effect of the timing of caring episodes · Case study analysis 	<ul style="list-style-type: none"> · Research Question 3: How did the respondents transition between caring statuses between 2013 and 2015? · Methodology: Bivariate descriptive longitudinal analysis the ELSA Wave 6 (2013) and Wave 7 (2015) · Longitudinal binomial and multinomial logistic regression analysis of transitions by gender and carers status

See also section 1.2 for further detail on the research questions and **Figure 6**: the conceptual framework section 2.5, where the conceptualising of the phases and waves used is depicted.

Source: Author's own.

Ethical permission to conduct the research was received by the University of Southampton's Ethics and Research Governance (ERGO) Committee on 10/06/2016 (ID: 21164), see also Appendix A. The UK Data Service's (UKDS) terms and conditions of appropriate usage of the data were followed (UKDS, 2016). Ethical approval for the data collection of all the ELSA waves was granted from the NHS Research Ethics Committees under the National Research and Ethics Services (NRES) (Natcen Social Research, 2016).

3.2 The English Longitudinal Study of Ageing

The ELSA dataset was chosen as it is particularly focussed on the experience of growing old in England in the 21st century. Furthermore, central to this study, the ELSA collects comprehensive information on informal caring (Steptoe *et al.*, 2013). As the study measures outcomes across a wide range of domains over time, it can be used to examine the causes and impact of outcomes relevant to informal care provision. The ELSA data has been used to produce references at national level reports and thereby informing policymakers for older people and carers alike (Steptoe *et al.*, 2013).

The ELSA's sample population is representative of people aged 50 and over living in private households in England. The initial sample was drawn from households previously responding to the Health Survey of England (HSE), and further refreshment samples were collected at later stages, more details follows in section 3.2.1 (Littleford *et al.*, 2016). The HSE is an annual cross-sectional survey which is designed to monitor the health of the general population (Steptoe *et al.*, 2013). The interviews for the ELSA were carried out at an approximate 2-years interval and completed by a computer-assisted personal interview together with tests of cognitive function and walking speed and a self-completion questionnaire (*ibid*), however this research only used the information obtained from the computer-assisted interviews.

For the purpose of this thesis secondary data analysis was chosen over primary data collection, as it would not have been feasible to collect the breadth of data the ELSA dataset provides. Moreover, the ELSA provides over 15 years' worth of data, making it possible to conduct longitudinal data analysis. One of the primary benefits of secondary data is that it is economical and time-saving, as the data is pre-collected, cleaned, stored in electronic format and statistical survey weights are pre-calculated (Boslaugh, 2007; Cheng and Phillips, 2014). The data collected by the ELSA team is considered to be of high quality due to the rigorous training of the data collectors and specialist coding (UK Data Archive, 2017). The research questions set by this study require a high level of detailed information on the caring patterns to which the ELSA provides. Furthermore, to examine pathways and transitions of caring, longitudinal data with a sufficient sample size is required for a robust analysis, which again the ELSA delivers.

The ELSA provided scope for examining the characteristics of the carers and their relationship to the care-recipient, as well as the nature of the caring role (hours of care provided per week, number of care-recipients, co-residential or extra-

residential care). The ELSA also provides details of the potential impact of caring on the carer's health and employment (King and Wittenberg, 2015). The relative short intervals between the time-points of the data collection are important, as they allow for close examination of nuances in the patterns of care provision, as such patterns may vary considerably over a short time period.

When using surveys data to analyse informal care, it is important to consider the phrasing of the question relating to the care provision. The ELSA asks a very general question, namely: '*Did you look after anyone in the past week?*' Pre-coded options for subsequent replies include for example the respondent's spouse, parent, but also grandchildren, see sections 3.3.1 and 3.3.2.4 for further details. Other surveys in the UK and internationally define informal care in terms of care provided to individuals due to an illness and/or disability or with problems due to older age and therefore exclude care provided towards grandchildren (King and Pickard, 2013; King and Wittenberg, 2015) (see also section 2.4). As this study is also interested in how care provided to a grandchild may shape individuals' pathways into informal care provision, including all directions of care was important. Indeed, as discussed in section 2.3.2.3, providing care for a grandchild is a prevailing feature of intergenerational support, however the analysis was also run separately excluding care to grandchildren to ensure that they were not vastly different from other carers, please refer to Appendix D.

Other data sources than the ELSA were considered for this research, however they were disregarded for various reasons. For example, although the Census includes information on informal care provision, due to its 10-years interval, it would only provide limited information on individuals' pathways and may therefore miss potentially shorter transitions in the caring role, information which is essential addressing to Research Question 2 (Table 2). Furthermore, the Census data provides no information related to the care-recipient (ONS, 2013a). The Census only provides information on the intensity of care provided (hours per week) (Ibid), however knowing the direction of care is essential to addressing the research questions set by this study (Table 2). Another UK-based household longitudinal Survey is the Understanding Society (University of Essex, 2016). The survey dates back to 2009 (Ibid) and therefore includes more recent information than the ELSA dataset. Although, Understanding Society does contain questions relating to informal care provision, including the intensity and the direction of care, the survey is not exclusively devoted to the topics of later life, older people

or ageing. This could make any analysis of care provision by specific subgroups, such as for example males aged over 80, problematic (Victor, 2002). Moreover, as the research questions in this study aims to understand the caring patterns of older adults, the ELSA is better placed to give detailed picture of the pathways into care, particular among the oldest age groups.

It should be acknowledged that whilst there are numerous benefits of using the ELSA dataset, there are also limitations. The inherent nature of secondary data from complex surveys means that the data is not collected with specific research questions in mind, and therefore particular information relevant to the research questions may be lacking (Boslaugh, 2007; Cheng and Phillips, 2014). This concern was overcome by taking a joint 'data-driven' and 'research question-driven' approach (Cheng and Phillips, 2014). In effect, that means that the overarching hypothesis determined which dataset was used, whereas the variables within the dataset, guided the researcher to which research questions it was possible to explore. Another disadvantage of secondary data is as the data is collected by a third party, the researcher has no control over the planning and execution of the data collection process (Boslaugh, 2007; Cheng and Phillips, 2014). In order to obtain a clear sense of how the data was collected the ELSA user-guide was thoroughly examined. Lastly, similarly to other panel studies, the ELSA dataset experienced attrition due to loss at follow-up, which could introduce bias and limit the sample size (Steptoe *et al.*, 2013). However, to some extent such bias is countered by the provision of both cross-sectional and longitudinal weights (addressed in section 3.4). How these limitations of data affected the findings is critically discussed in section 6.4.

3.2.1 The study population of The English Longitudinal Study of Ageing

The ELSA sample included individuals aged 50 or over, living in private households in England at the time of joining the sample. Partners of original sample members and new partners, who have moved into the household since the HSE were also included. One age-eligible family unit was chosen per address and interviews were sought with both members of couples in the unit (Natcen Social Research, 2016). The original cohort at Wave 1 was selected from the HSE (1998, 1999 & 2001), and respondents from Wave 1 were later renamed 'Cohort 1, core member'. Box 1 shows the 5 new cohorts which were subsequently added, as no refreshment sample was added at Waves 2 and 5, and no new cohorts were formed (Natcen Social Research, 2016). Core members were eligible for subsequent waves unless they had since died, asked not to be re-contacted or

moved out of Britain. Respondents remained eligible if they had moved to Wales or Scotland (Ibid).

The sample sizes in the ELSA fluctuate from one wave to the next due to attrition (see also section 3.6.2), additional refreshment samples and of new partners (see also Box 1).

The overall sample size for each wave are as follows (Batty and Steptoe, 2016):

Wave 1 (2002/2003) = 11,391

Wave 2 (2004/2005) = 8,780

Wave 3 (2006/2007) = 8,811 (Refreshment sample: individuals aged 50-53)

Wave 4 (2008/2009) = 11,050 (Refreshment sample: individuals aged 50-74)

Wave 5 (2010/2011) = 10,274

Wave 6 (2012/2013) = 10,601 (Refreshment sample: individuals aged 50-54)

Wave 7 (2014/2015) = 9,666 (Refreshment sample: individuals aged 50-51)

Cohort 1 born on or before 29 February 1952. Selected from Health Survey for England (HSE) 1998, 1999 and 2001. First interviewed at ELSA wave 1 (2002-03) aged 50 and over. Cohort 1 core members and their partners represented 56% of all issued cases at wave 7.

Cohort 3 born between 1 March 1952 and 1 March 1956. Selected from four years of HSE (2001-2004). First interviewed at ELSA wave 3 (2006-07). Cohort 3 core members and their partners represented 10% of all issued cases at wave 7.

Cohort 4 born between 1 March 1933 and 28 February 1958. Selected from HSE 2006. First interviewed at ELSA wave 4 (2008-09) aged 50-74. Cohort 4 members and their partners represented 19% of all issued cases at wave 7.

Cohort 6 born between 1 March 1956 and 28 February 1962. Selected from HSE 2009, 2010 and the first half of 2011. First interviewed at ELSA wave 6 (2012-13) aged 50-55. Cohort 6 core members and their partners represented 9% of all issued cases at wave 7.

Cohort 7 born between 1 March 1962 and 28 February 1964. Selected from HSE 2011, and 2012. The wave 7 'refresher' cohort, i.e. first interviewed at ELSA wave 7 (2014-15) aged 50-51. Cohort 7 core members and their partners represented 6% of all issued cases at wave 7.

Box 1: Five cohorts of people made up the ELSA sample at wave 7

Source: (Littleford et al., 2016)

As established from this section the ELSA dataset is ideally suited to answer the research questions of this study. The following section presents the key variables and measures used for both parts of the analysis.

3.3 Key measurement concepts and variables

As noted from the literature review, key demographic characteristics were associated with the provision of informal care (see also section 2.3.1.2). The age and gender of the carers is undoubtedly important variables when exploring patterns of informal care provision and have been noted by other studies to have an effect on caring patterns (Dahlberg *et al.*, 2007; Lee *et al.*, 2015; Pickard, 2015; Robards *et al.*, 2015; Glauber, 2016). However, many other sociodemographic variables related to the caregiver were also identified in the literature review (see section 2.3), as having important effects on the care provision.

The dependent and independent variables used in the study are presented in turn in greater detail in the following sections. All variables are associated with the carer only, rather than the care-recipient and all variables are relevant in the three phases of the analysis (i.e. the cross-sectional and longitudinal). If used differently in any phase, this is clearly highlighted. The change variables are only used in *Phases II and III*.

3.3.1 Dependent variables

Informal care provision: The primary outcome variable of interest is informal care provision. The dependent variable (ERCAA) was created from the following question: '*Did you look after anyone in the past week? This could be your partner or other people in your household or someone in another household*'. This was further clarified: '*By 'look after' we mean the active provision of care*'. Please note that although the ELSA question uses the term "look after" this study refers to individuals 'providing care' or 'caring for'. The variable ERCAA includes care provided to children, both dependent and independent, and to grandchildren. For further details of the care recipients see section 3.3.2.4

The variable remained a dichotomous variable (i.e. no, yes). If the respondent answered 'yes' to this question, they were subsequently asked a number of follow-up questions relating to their caring activities, such as the number of hours of care provided per week, how many people they cared for and who they looked after.

Caring intensity: As the ELSA dataset does not provide information of the specific caring tasks carried out, time was the only available measure of the intensity, measured as hours per week, as also used by other studies (Carmichael and Ercolani, 2014; Vlachantoni, 2010; Ramsay *et al.*, 2013; ONS, 2013). The intensity

level is associated with the outcomes of providing informal care, both in relation to the carer's health and employment (O'Reilly *et al.*, 2008; Ramsay *et al.*, 2013; Carmichael and Ercolani, 2016) (see also section 2.3.1.1). For the purpose of the binary regression analysis the intensity was dichotomised into 'light care' which was defined as under 19 hours per week and 'heavy care' defined as 20 hours per week or more (Heitmueller, 2007; O'Reilly *et al.*, 2008; Young and Grundy, 2008; Robards *et al.*, 2015; Vlachantoni *et al.*, 2016).

3.3.2 Independent variables

The independent variables, also referred to as explanatory variables, were guided by the evidence found in the literature review (see section 2.3). The independent variables are divided into socio-demographic, socio-economics, health and informal care specific variables.

3.3.2.1 Sociodemographic variables

Age: As highlighted in section 2.3.1.2 age is a key factor in the provision of care, as not only is it associated with the health of the care-provider and thereby their ability to provide care, but also with the direction of care (Vlachantoni, 2010). Age is also related to the time available for care provision, as for example economically inactive (i.e. retired) individuals may have more time to provide care, or if no dependent children are present in the household, factors which are both positively correlated with increased age (Brandt *et al.*, 2009; Mentzakis *et al.*, 2009; Drinkwater, 2015).

Age (Indager) was computed from the date of birth and the date of interview by the ELSA team. Age was initially entered as a continuous variable, and all respondents aged over 90 was classified as 99 years old for confidentiality reasons. Age was used as a continuous variable for the correlation matrix and the calculation of mean age in the descriptive analysis. For the bivariate analysis, the age for the overall sample was used as a four-category variable (i.e. 50 to 59, 60 to 69, 70 to 79, 80 and over). Respondents aged under 50 years were deleted from the dataset (see section 4.2 for justification) and respondents aged over 80 were collapsed into a single category. The reasons for collapsing the highest age category are two-fold: firstly, the cell count for carers aged 90 and over was too low to allow for robust statistical analyses; and secondly evidence of survivor bias (also known as selection bias) was noted, reflected in the health variable and the

Chapter 3

association with health (detail follows in section 3.3.2.3, Figure 9). This bias was minimised by collapsing the highest age range to 80 and over. Setting the age threshold to 80 and over is solely an operational convention and does not infer to treat the over 80s as a homogeneous population. Moreover, the age threshold is a dynamic reflection of ageing itself for example throughout the 1980s people aged over 80 were considered the extreme age group, whilst in the 2010s this has shifted to people aged over 90, even 100 years old (Tomassini, 2005).

For the binary regression the reference category was those aged 50 to 59, as the literature found the younger age range to be more likely to be providing informal care (Shaw and Dorling, 2004; Dahlberg *et al.*, 2007; ONS, 2013; Lee *et al.*, 2015; Robards *et al.*, 2015).

Gender: The literature review noted gender to have a strong effect on whether an individual provided care (see also section 2.3.1.2). Moreover, gender is associated with the caring intensity level, for example women are more likely to provide longer hours of care than men (Bauer and Sousa-Poza, 2015). A separate analysis was carried out for males and females to highlight any such differences between the genders among the carers and non-carers.

‘Gender’ describes those characteristics of women and men that are largely socially created, while ‘sex’ encompasses those that are biologically determined (WHO, 2017). The question in relation to gender in the ELSA is asked: ‘*Can I just check that [^you are] [^male/female]*’. This study uses the term gender as a proxy for sex. Sex is classified by male and female when represented in result tables, as per the responses to the ELSA question, however, in interpretations where gender may interact with social and cultural aspects of care provision the terms of men and women are used.

The variable used for gender was (Indsex). Females acted as the reference for the binary regression, a decision based on evidence from the literature noting females being more likely to provide care (Del Bono *et al.*, 2009; ONS, 2013; Pickard, 2015; Robards *et al.*, 2015; Glauber, 2016).

Ethnicity: Like many national surveys, the ELSA dataset encounters the issue of small sample sizes of ethnic minority groups in the relevant age ranges, thereby not allowing for robust statistical analysis (Pickard, 2015), see Table 3. A decision was made to use the ELSA derived variable white/non-white (nonwhite) for the descriptive analysis and the binary regression.

The variable was derived from ethnic origin (fqethnr), which was originally a variable with a broader range of categories of ethnic minority groups, as seen in Table 3. It should be noted that the overall sample of non-white respondents still remained low at only 5.7% of the total sample (weighted data) (based on ELSA Wave 7). Although this is not representative of the 14% non-white English and Welsh population (ONS, 2012), in England the white ethnic groups does have an older age structure than other ethnic groups, due to the latter's past immigration and fertility patterns (ONS, 2005a).

As the white ethnic group have previously been noted to be more likely to provide care, this was used as the reference category for the binary regression (ONS, 2005a; Young *et al.*, 2006; Willis *et al.*, 2013).

Table 3 Study population by ethnicity, the ELSA wave 7

Ethnic Group	Sample (N)	Unweighted (%)	Weighted (%)
White	8,138	96.5	94.8
Mixed Ethnic Group	22	0.3	0.3
Black	46	0.5	1.0
Black British	33	0.4	0.5
Asian	80	0.9	1.3
Asian British	78	0.9	1.5
Any Other Group	41	0.5	0.6
Total sample size	8,438	100	100

Source: Author's analysis of ELSA Wave 7

Marital Status: Marital status was noted in the literature review to acts as a predictor of informal care provision (Brandt *et al.*, 2009; Lee *et al.*, 2015; Leopold *et al.*, 2014; Pickard, 2015). Being married or partnered may act as a time competing factor, especially for extra-residential care, as it implies that the carer has additional family/household demands occupying their time (Leopold *et al.*, 2014). On the other hand, being married may provide social support, which facilitates the availability to provide care (Kruijswijk *et al.*, 2015) (see also section 2.3.1.2). Conversely, being single, divorced or widowed may again indicate that the respondent has more available time to provide care (Leopold *et al.*, 2014). However, as previously mentioned, being widowed is also associated with age, and age is associated with providing care for a spouse, therefore widowhood may decrease the likelihood of providing care (Del Bono *et al.*, 2009; Carmichael and Ercolani, 2014). On a practical note, marital status is associated with the direction of care, and in order to provide spousal care, it is an assumption that the respondent is married or partnered. It may also be assumed that if an individual is single (not partnered) they will be less likely to provide childcare, as children

Chapter 3

born outside marriage are less likely for the cohorts represented in the sample (ONS, 2017a).

Marital status (Dimar) was based on the question of current legal marital status and was originally entered as an eleven-level categorical variable, and the categories were then collapsed into a four-level variable (i.e. single never married, married, divorced, widowed), see Table 4. Being married acted as the reference for the binary regression, as the literature found most carers belonging to this category (O'Reilly *et al.*, 2008; Evandrou *et al.*, 2015; Lyon *et al.*, 2015; Robards *et al.*, 2015).

Table 4 Derived variable: Marital status

Dimar	Marital
Single	Single
Married (1 st and only marriage)	Married
Civil partnership in a registered same-sex civil partnership	Divorced
Remarried	Widowed
Divorced	
Separated (but still legally married)	
Formerly in same-sex civil partnership	
Widowed	
Surviving civil partner of same-sex civil partnership	

Source: Author's own

Household structure: this variable (Famtype) provides details on the number of people in the household, whilst also controlling for marital status and family size (Connolly *et al.*, 2010). The household structure offers information on possible competing factors, such as other family obligations, but also the possibility of additional family support from within the household to provide care (Mentzakis *et al.*, 2009, Leopold *et al.*, 2014).

The variable was initially entered as an ELSA-derived fourteen category variable, but collapsed to a five category variable (i.e. single, single plus children, couple, couple plus children, and extended families), see Table 5. The reason for reducing the number of categories was to achieve an adequate cell count for the purpose of the regression analysis. The ELSA defines an extended family, as one where relatives other than the spouse or children are living together in the

household². A household consisting of a couple acted as the reference for the binary regression, as the literature review had shown married and cohabitating couple to be more likely to provide care (Hiel *et al.*, 2015; Robards *et al.*, 2015). Moreover, one study found informal caring to be highest when there were two people in the households (Hosseinpoor *et al.*, 2013).

Table 5 Derived variable: Household structure

Famtype	Household type
Single	Single
Lone plus dependent children	Single plus children
Lone plus non-dependent children < 30	Couples
Lone plus dependent children > 30	Couple plus children
Lone plus both	Extended families
Couples	
Couple plus dependent children	
Couple plus non-dependent children < 30	
Couple plus dependent children > 30	
Couple plus both	
Extended family	
Extended family plus children	
Other multiple tax units	
Other multiple tax units plus children	

Source: Author's own

² Note that the ELSA defined famtype in relation to the Head of the household (i.e. homeowner). This means that there may be cases of families who are very similar in structure but might be defined as a different family type. For example, a couple aged 84 and 85 living with a 53-year-old son/daughter, should the 53-year-old is be the homeowner, this household was defined as an extended family. Conversely, a couple aged 86 and 87 living with a 55-year-old son/daughter, with the couple as the homeowners, would be defined as a couple with non-dependent children age over 30.

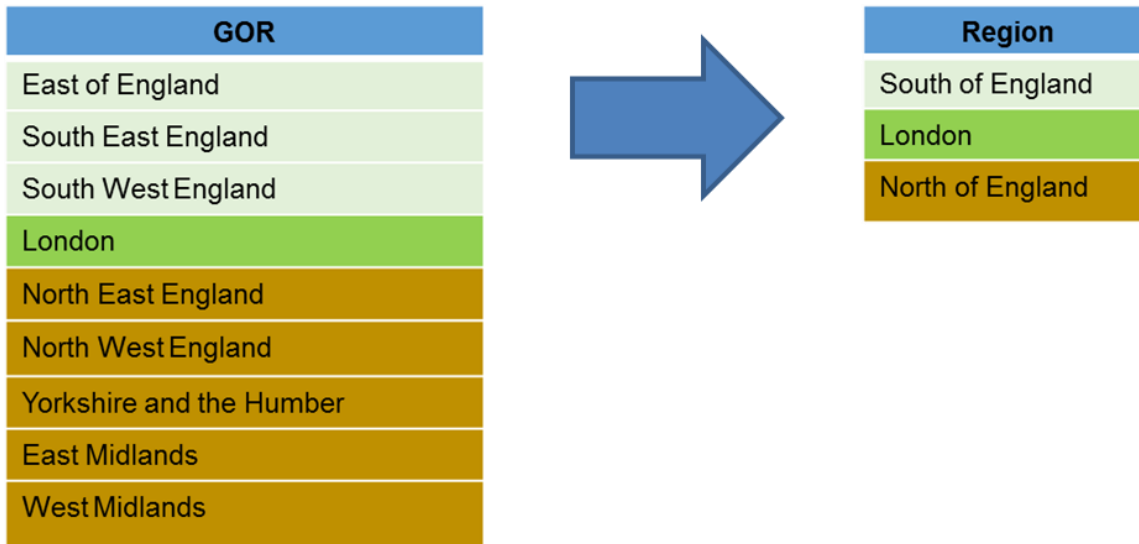
Source:

http://doc.ukdataservice.ac.uk/doc/5050/mrdoc/excel/5050_ifs_derived_variables_description.xlsx

Region: The geographical variable (GOR) determined where the respondent resided, using the Government Office Region (GOR) identifier. Respondents reporting to be residing in Wales and Scotland were excluded from the dataset (see also section 4.2, Figure 11). Excluding these respondents from a statistical perspective created more consistency, as the cross-sectional weights used for the analysis disregarded respondents not from England. Moreover, entitlements to benefits and policies related to informal care differ between the countries making interpretation and recommendation difficult. For information on the weighting used see section 3.4.

The variable was kept as a nine category variable for the descriptive analysis. However, the variable was reduced to a three category variable, see Table 6 to achieve an adequate cell count for descriptive comparison of carers and non-carers by gender, and for the logistic regression analysis. For the purpose of the binary regression, the category of South of England was used as the reference, as this category had the highest proportion of respondent, and as other studies had used this as a reference (Young and Grundy, 2008).

Table 6 Derived variable: Region



Source: Author's own

3.3.2.2 Socioeconomic variables

Measures of socio-economic circumstances of the informal carer are important, as they may influence the carer's ability and decision on whether to enter into the caring role (Wanless *et al.*, 2006). For example, being in employment may limited the time available to provide care. On the other hand, an individual in the highest wealth quintile may have the means to take early retirement in order to provide care (see also section 2.3.1.4).

Socio-economic factors are also strongly associated with health and access to health and social services, thus if not included any carer's health outcome could otherwise be masked by the evident and often dominant effect of one's socio-economic circumstances (Adler and Ostrove, 1999; Grundy and Holt, 2001; Singh-Manoux *et al.*, 2003). The Economic and Social Research Council (ESRC) recommends the use of the National Statistics Socioeconomic Classification (NS-SEC) as a direct measure of SES, which is also the primary government measure of individuals' SES (ONS, 2005b). Nevertheless, in Wave 7 this variable was unfortunately not available in a derived form and therefore in order to ensure consistency it was excluded as a measure for the analysis in all waves.

This research consequently used a variety of proxies and indicators of SES variables including employment, education, housing tenure and access to a car/van.

Economic Activity: As seen from section 2.3.1.4 economic activity may influence whether or not a person enters into informal care. Retired individuals may have more time available to provide care, whereas this may be limited for full-time employee. Moreover, economic activity is also associated with having the potential financial resources to purchase alternative forms of care (Henz, 2004; Mentzakis *et al.*, 2009; Scheider *et al.*, 2013; Leopold *et al.*, 2014; Carr *et al.*, 2016). Research has noted that work time (i.e. full-time or part-time employed) may also be associated with the likelihood of providing care (Schneider *et al.*, 2013; Leopold *et al.*, 2014).

Two variables were used for the analysis of employment status: 1) 'Best description of current situation' (Wpdes), see Table 7 for the categories and 2) the ELSA derived variable 'Economic Activity' (Ecpos). Although these two variables were similar in many aspects, they tell a different story. 'Wpdes' breaks being

'economic inactive' into three categories (i.e. unemployed, permanently sick and looking after home and family).

The 'best description of current situation' does provides a more detailed picture of the nuances of care provision and different circumstances, it may however pose a potential gender bias. As seen from Table 7 there was a marked gender division between respondents classifying themselves as either 'unemployed' or 'looking after home and family'. This could be due to the social desirability of gender roles, where men do not see themselves as 'homemakers' and women do not classify themselves as 'unemployed' (Scott and Clery, 2013). Nevertheless, it may also be that more men were unemployed. Exploratory analysis showed that females looking after the home and family had significantly higher odds of providing care, as also noted by other studies (Beesley, 2006; ONS, 2013c; Evandrou *et al.*, 2015b). However, as also seen from Table 7 is that the cell-count for males looking after the home and family was not adequate to make any robust inference. The possible gender differences will be noted in the interpretation of the results and further discussion of any limitation this may cause can be found in section 6.4. The variable 'Wpdes' was therefore only used for the descriptive summary analysis.

Table 7 Best description of current situation (Wpdes), the ELSA Wave 7

Best description of current situation	Total sample % (n)	Male % (n)	Female % (n)
<i>Retired</i>	50 (5,300)	48 (2,377)	52 (2,923)
<i>Employed</i>	32 (2,117)	34 (927)	30 (1,190)
<i>Self-employed</i>	7 (552)	10 (352)	5 (200)
<i>Unemployed</i>	2 (79)	3 (51)	1 (28)
<i>Permanently sick or disabled</i>	4 (319)	4 (138)	5 (181)
<i>Looking after home and family</i>	5 (438)	1 (47)	7 (391)
Total sample size	100% 8,805	100% (3,892)	100% (4,913)

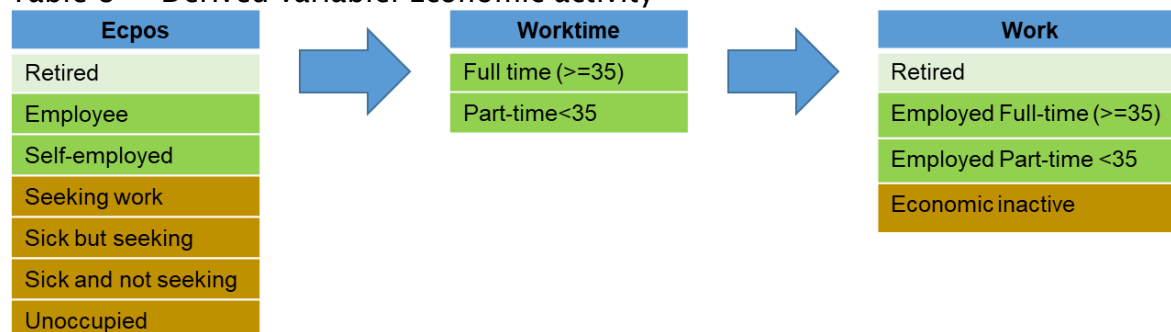
Weighted percentages, unweighted frequencies. (N)=sample number in brackets are unweighted. Between male and female: $\chi^2=299.07$ (df 5, $p<0.001$).

Source: Author's analysis of ELSA of Wave 7.

For the purpose of the binary regression the variable 'Ecpos' was used, in combination with 'worktime' and derived into four categories (i.e. employed full-time, employed part-time, retired, unoccupied (economically inactive)), see Table 8. Although it could be argued that the motivation and the availability between individuals who are sick and not seeking work and those seeking work are different, these individuals are economically non-active (Ramsay *et al.*, 2013; ONS, 2017b), and to ensure an optimal cell count these categories were nevertheless combined. Being retired acted as the reference category for the

binary regression, as the literature suggests that informal carers are more likely to be retired (Young and Grundy, 2008; Hiel *et al.*, 2015; Jacobs *et al.*, 2014).

Table 8 Derived variable: Economic activity



Source: Author's own.

Education: The association between education and care provision have been disputed by studies (see section 2.3.1.4). Some noted carers with higher education had a reduced likelihood of providing care (Jenkins *et al.*, 2009; Mulder and van der Meer, 2009). Contrastingly, others found that higher educated individuals were more likely to provide care (Bucx *et al.*, 2012; Jacobs *et al.*, 2014; Lyons *et al.*, 2015). Still, some studies found no difference the education level between carers and non-carers (Stuifbergen *et al.*, 2008; Barnett, 2013; Lee *et al.*, 2015).

Education is frequently used as a proxy for SES, as education shapes future occupational opportunities and earning potential (Adler and Newman, 2002). Education also provides knowledge and life skills, and it has been noted that better educated people have greater access to information and resources which promotes health, such as access to health services and nutrition (Ibid). These skills may also act in favour of the carer, as a better educated carer may be better able to access appropriate services and benefits associated with care provision. Education level also works well as a proxy for SES in older age, as it remains relatively stable over time (Shavers, 2007). Moreover, respondents in surveys are often more willing to disclose their education level, unlike information about their wealth and income, which makes this a more reliable SES measure (Grundy and Holt, 2001).

It should be noted that the ELSA population consist of cohorts who have had marked differences in access to education pre and post-war (Evandrou and Falkingham, 2006) (see also section 1.1.1). A cross-tabulation of age by education reflected this difference in the cohorts, and it was noted that the education level was negatively associated with age (i.e. the younger age groups were higher

Chapter 3

educated than the older age groups). Education (edqual) was recorded in the dataset as a multi-level variable: (1) NVQ4/NVQ5/Degree or equivalent (equiv); (2) Higher education below degree; (3) NVQ3/GCE/A-level or equivalent; (4) NVQ2/GCE/O-level or equivalent; (5) NVQ1/GSE or grade equivalent; (6) foreign and (7) no qualification. For the purpose of the binary regression analysis, the ELSA derived variable 3-way qualification split (qual3) (i.e. higher than A-level, O-level or equivalent, less than O-level) was used to ensure adequate cell count. The category of less than O-level qualifications acted as the reference category, based on conceptual evidence of an increased likelihood of care provision with lower education (Young and Grundy, 2008; Norman and Purdam, 2013; Robards *et al.*, 2015).

Wealth: Wealth reflects a stock of resources, which is often accumulated over a lifetime. It is therefore an appropriate measure to use in research related to older people (Searle and Köppe, 2014). It has been suggested that the association between wealth and informal care provision is related to the ability to purchase formal private care, thereby lowering the demand for an individual to carry out informal caring responsibilities (Adler and Newman, 2002; Vlachantoni *et al.*, 2015), see also section 2.3.1.4. Moreover, higher wealth can also provide better housing (Adler and Newman, 2002), which may play a part in accommodating co-residential caring, for example, to pay for potential modification needed. Although income is strongly associated with employment and arguably the most direct measure of the material resource component (Grundy and Holt, 2001; Galobardes *et al.*, 2006). Given the age of the ELSA sample, income would act poorly as an indicator of SES and among retired individuals, income and occupation status lose their significance, making wealth a more sensitive indicator for SES for older adults (Allin *et al.*, 2006).

For the purpose of this research, the variable Total Non-pension Wealth (netto_bu_s) was used, which include the sum of savings, investments, physical wealth and housing wealth after financial debt and mortgage have been subtracted (UK Data Archive, Unknown). Total Non-pension Wealth was chosen to ensure consistency across multiple waves, as when the data collection of earlier waves was undertaken, it was not mandatory in England to purchase an annuity with any defined contribution pension wealth before the age of 75 (Blundell *et al.*, 2016). Therefore, pension assets would for this part of the sample be negligible. Total Non-pension Wealth is also commonly used by other ELSA dataset researchers (Grundy and Read, 2012; Rafnsson *et al.*, 2015).

Wealth measures were only available at the benefit unit level, and no equalised measure of wealth was available, as there is no commonly recognised way of adjusting wealth holdings to account for family size (UK Data Archive, Unknown). Quintiles of net total wealth (totwq5_bu_s) were derived from the net total wealth (benefit unit level). For the purpose of the binary regression, being in the highest quintile was used as the reference. The wealthiest category had the largest proportion of respondents, as well as this category has been also been used by other studies (Grundy and Read, 2012).

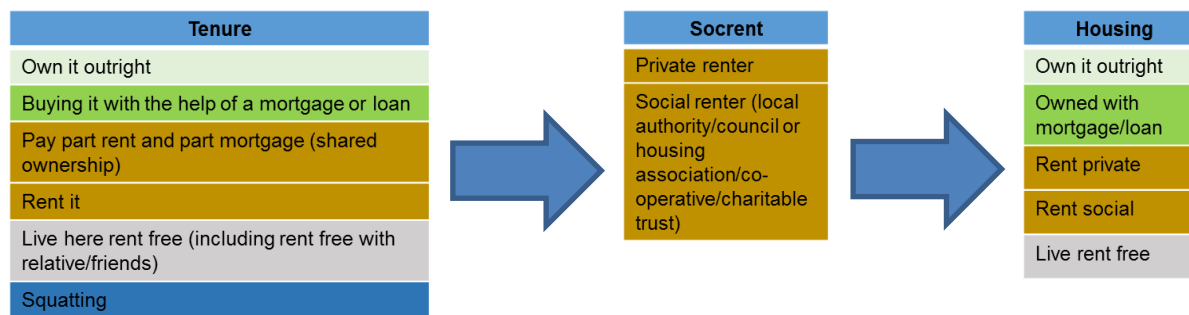
Housing Tenure: Housing tenure measures the material aspect of SES and is generally a central component of most people's wealth (Galobardes *et al.*, 2006). Being an owner-occupier (both owning the house outright and with a mortgage) may be a gateway to better housing, as it provides more control over one's living environment, although it also accounts for a large proportion of the outgoings from income, such as mortgage payments, repairs and maintenance (Hancock, 1998). Older owner-occupiers are likely to have paid off their mortgage or to have a small mortgage in relation to the market value of their home (Ibid). This would imply that people who own their house may have better financial resources to pay for formal care, should it be needed. Moreover, as mentioned in relation to wealth, financial resources are associated with better health, and being an owner-occupier has been found to be an independent predictor of better general health, whereas living in rented accommodation was associated with reporting a poorer SRH (Windle *et al.*, 2006). Housing tenure may also be related to whether individuals move to residential care, and this may be due to owner-occupiers having the option to modify the home in order to provide care at home, which might not be possible in rented accommodation (Connolly, 2012), see also section 2.3.1.4.

The housing tenure was derived from the variable 'tenure' (Hotenu) and 'landlord renting' (Holand) in order to establish whether the accommodation was owned by the respondent or rented. If the tenure was rented, a distinction was made between private (individual) landlord and social landlord (i.e. local authority, council or housing association). 'Hotenu' acted as a filter question for 'holand', therefore only respondents that had said 'yes' to either 'rent it' or 'pay rent and part mortgage (shared ownership)' were asked who their landlord was. The final variable used for the purpose of this research can be seen in Table 9. For the binary regression 'owned outright' was used as a reference, as this category had

Chapter 3

the highest proportion of respondents, and as also used by other studies (Evandrou *et al.*, 2015; Norman and Purdam, 2013).

Table 9 Derived variable: Housing tenure



Source: Author's own

Access to a car or van: Although access to a car or van does not mean ownership, this variable provides a useful indicator of SES, as car ownership can be taken as a proxy for income (Smith *et al.*, 1990; Macintyre *et al.*, 1998). Access to car or van may be a necessity of providing care, especially in providing extra-residential care. The ELSA asked whether the respondent has the use of a car or van when needed, as a driver or a passenger (spcar), which remains as a dichotomous variable (yes/no) in the analysis. The binary regression used having access to a car as the reference, as other studies has found this to be associated with higher likelihood of care provision (Norman and Purdam, 2013; Evandrou *et al.*, 2015).

3.3.2.3 Health variables

Assessing carer's health status is important as health factors, much like SES, can influence the carer's ability and availability to provide care, see also section 2.3.1.3. Health is traditionally seen as a different dimension along the WHO's established definition: "*health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity*" (WHO, 2003). To better understand the broader aspects encompassing these dimensions of health, this research used a variety of health variables, namely self-reported health (SRH), limiting long-term illness (LLTI), activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Each are described in the following text.

Self-reported health: SRH is a subjective measure of health, which is easy and inexpensive to collect (Wu *et al.*, 2013). Studies from developed countries have demonstrated that SRH reflects people's overall perception of their own health and is a good predictor of mortality and functional ability, as it incorporates multiple dimensions of health (Idler and Benyamini, 1997; OECD, 2003). The dimensions include both physical and mental health (physical disability,

psychological health functional and activity limitations, chronic and acute morbidity); self-assessment of severity; awareness of comorbidity; and past health trajectories (Idler and Benyamini, 1997).

SRH (Hehelf) was obtained by the following question: ‘Would you say your health is...’ ‘excellent’ (1), ‘Very good’ (2), ‘good’ (3), ‘fair’ (4) or ‘poor’ (5). For the purpose of this analysis ‘Hehelf’ was reduced to three categories, see Table 10.

Table 10 Derived variable: Self-reported health

Hehelf	Health
Excellent	Good
Very good	Fair
Good	Poor
Fair	
Poor	

Source: Author’s own

Binary regression pre-testing showed a marked difference in results between respondents reporting fair and poor health. Whereas respondents reporting good and fair health had similar patterns in the likelihood of care provision, these two levels were therefore combined. It should be noted that the categories of SRH used by the ELSA, is the scale also used in the United States and Canada, which is *asymmetric* (positively skewed) (OECD, 2003). As seen from Figure 7 the asymmetric scales have caused an upwards bias of the SRH results. A more balanced measure, for example, includes the categories ‘very good, good, fair, bad, and very bad’ (Ibid).

Chapter 3

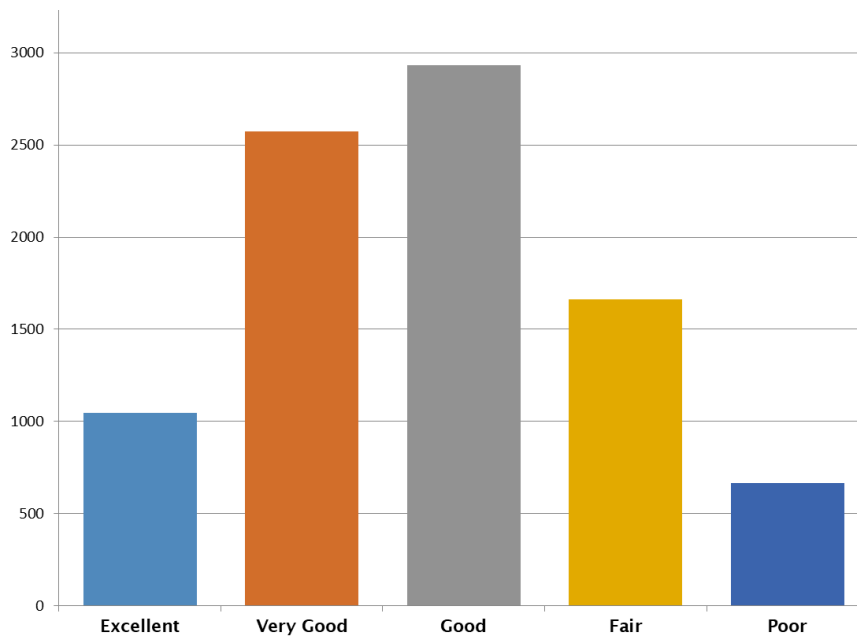


Figure 7 Self-reported health - five categorical underived variable, the ELSA Wave 7

Source: Author's analysis of ELSA

SRH generally deteriorates with age, however older people may have lower health expectations and may therefore be more likely to positively rate their health, compared with younger people with similar health conditions (OECD, 2003). This would also explain why the overall sample is in good or fair health, as seen from Figure 8, and Figure 9 shows how health deteriorated in the higher age groups, however it is worth noticing that there was an improvement in health at age 90, which is a likely confounder of 'healthy survivors', as SRH is also a strong predictor of mortality (Heiss, 2011).

To minimise this bias, the oldest age groups were collapsed into the category for those aged 80+ (see also section 3.3.2.1). For the purpose of the binary regression good health was the reference, as being in good health was noted by other studies to be associated with a stronger likelihood of providing care (Norman and Purdam, 2013; Hiel *et al.*, 2015; O'Reilly *et al.*, 2008).

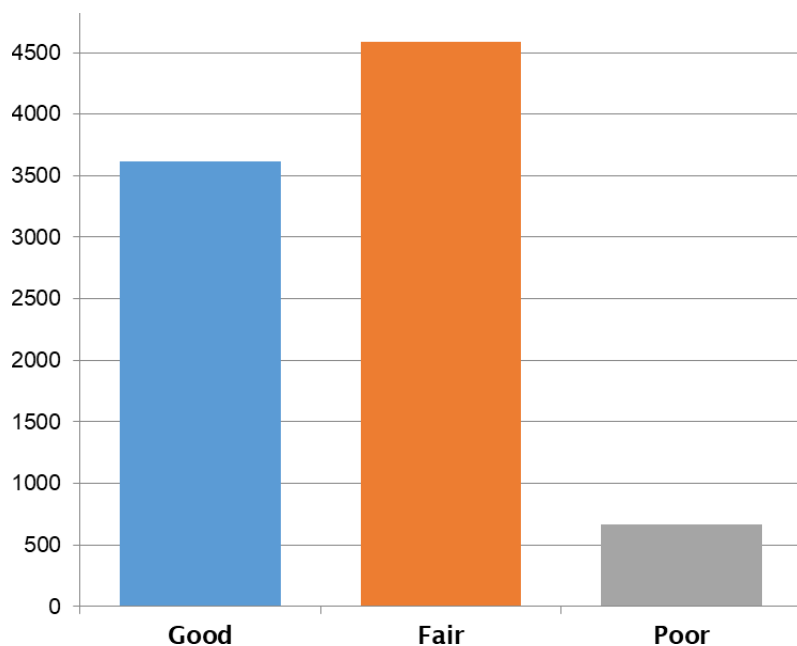


Figure 8 Self-reported health - three categorical derived variable, the ELSA wave 7

Source: Author’s analysis of ELSA Wave 7.

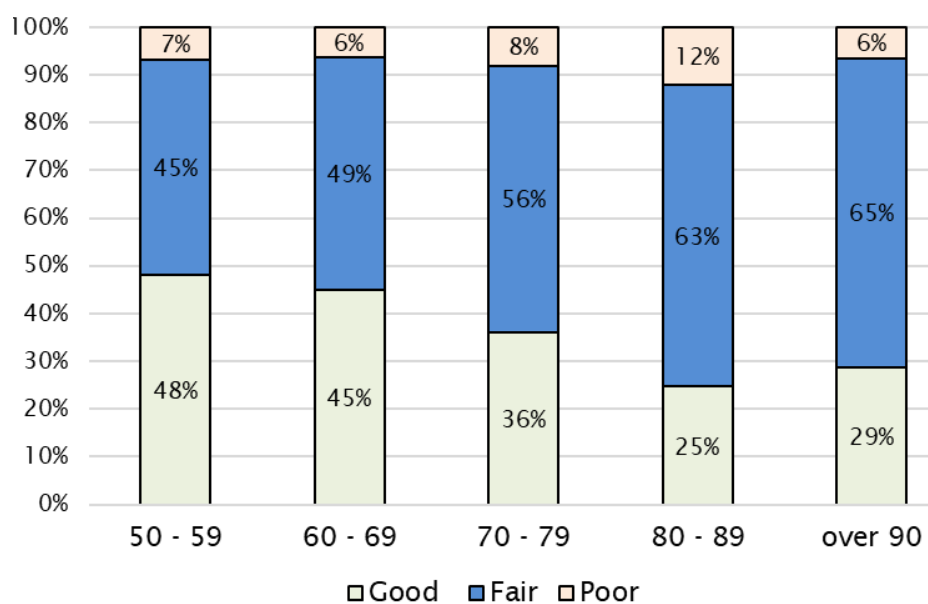


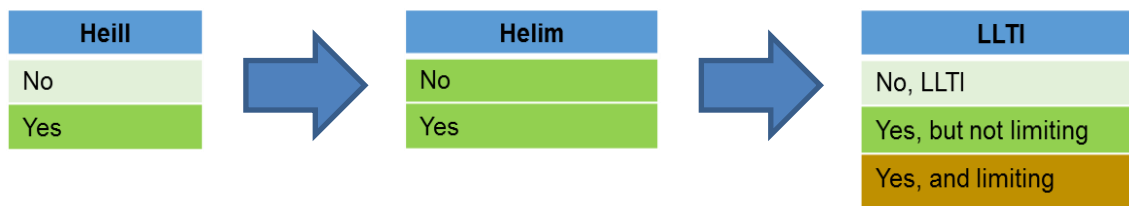
Figure 9 Self-reported health - three-category variable by age, the ELSA wave 7. The figure shows SRH by age before collapsing respondents aged over 90 into the over 80 age category. Source: Author’s analysis of ELSA Wave 7.

Limiting long-term illness (LLTI): Although there is a positive correlation between LLTI and SRH ($r=0.52$, $p<0.002$) (see section 4.4, Table 23), the variables measure different aspects of health. Whereas SRH is a subjective health measure, LLTI observes the functional limitation in activities caused by an illness, such as work and other daily activities, and these limitations may not be apparent in individuals’ SRH (Manor *et al.*, 2001). Thus from the perspective of informal care,

one could rate themselves to have fair health and a long-term illness, but the latter may not be limiting the individual’s ability to provide care.

For the purpose of this research, LLTI was derived from a two-part question. The first question was: ‘Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time’ (HEILL). If the respondent answered ‘yes’. A subsequent question was asked: ‘Does this/do these illness(es) or disability(ies) limit your activities in any way?’ (HELIM). A three-category variable was derived (see Table 11) by combining the two questions, into one variable noting whether the respondent had a long-term illness and if the illness was limiting. For the binary regression having no LLTI was used as the reference, as literature had noted most carers did not report having a LLTI (O’Reilly *et al.*, 2008; Rafnsson *et al.*, 2015). Additionally, preliminary exploration of the data showed that the highest proportion of respondents, and carers in the sample did not report having an LLTI.

Table 11 Derived variable: Limiting Long-Term Illness



Source: Author’s own

Activities of Daily Living (ADLs) & Instrumental Activity of Daily Living (IADLs):

The Katz index was developed in 1963 and measures difficulties with basic tasks of everyday life (Katz *et al.*, 1963). The report of difficulty with such tasks is a good measure of independence and functional capabilities of an individual, as it measures the practical dimensions of everyday life, as a reflection of a person’s functional status (Katz *et al.*, 1963; Wiener *et al.*, 1990). As seen from Table 12, having a LLTI may not equal to also having difficulties with an ADL and vice versa. Carers tend to have fewer difficulties with ADLs and IADLs than non-carers, however providing care, especially at a higher intensity, is associated with a decline in the carer’s ADL functions (Jenkins *et al.*, 2009; Lyon *et al.*, 2015; Glauber *et al.*, 2016). Although both ADLs and IADLs measure difficulties with dimensions of everyday living, each measure different aspects of this. ADLs can be seen as more physical tasks, such as walking, getting dressed etc. on the other hand, IADLs include more cognitive and practical tasks such as handling personal finances, meal preparation, and making a telephone call (Graf, 2008).

In the ELSA dataset the question related to difficulties with ADLs (HEADLB) was asked as such: ‘*Here are a few more everyday activities. Please tell me if you have any difficulty with these because of physical, mental, emotional or memory problems. Again exclude any difficulties you expect to last less than three months. Because of a health or memory problem do you have difficulties doing any of the activities on this card?*’ The options were: 1) dressing, including putting on shoes and socks; 2) walking across a room; 3) bathing or showering; 4) eating, such as cutting up your food; 5) getting in or out of bed and/or 6) using the toilet, including getting up or down. The options for IADLs were: 1) difficulties reading a map to figure out how to get around a strange place; 2) recognising when in physical danger; 3) preparing a hot meal; 4) shopping for groceries; 5) making a telephone call; 6) communication (speech, hearing or eyesight); 7) doing work around the house/garden; 8) managing money, such as paying bill and keeping track of expenses and/or 9) taking medication.

For the purpose of this research, the variables for ADLs or IADLs difficulties were collapsed into 2 separate variables (i.e. one for difficulties with ADLs and one for difficulties with IADLs), each with 3 categories, measuring the number of (I)ADLs which a person had difficulties with (i.e. None, 1 (I)ADL, >2 (I)ADLs). Having no difficulties with an (I)ADL was the reference category for the binary regression, as literature had noted that carers were less likely to have difficulties with ADLs/IADLs (Jenkins et al., 2009; Lyon *et al.*, 2015). Additional, preliminary exploration founded that majority of carers in the sample had no difficulties with (I)ADLs.

Table 12 Limiting Long-Term Illness by difficulties with ADLs, the ELSA Wave 7

<i>Number of difficulties with ADLs</i>	<i>Limiting long-term illness</i>		
	No, LLTI % (n)	LLTI, not limiting % (n)	LLTI, limiting % (n)
<i>None</i>	96% (3,831)	93% (1,698)	60% (1,835)
<i>1 ADL</i>	3% (139)	5% (99)	16% (485)
<i>2 or more ADLs</i>	1% (40)	2% (29)	24% (681)
<i>Total</i>	100% (4,010)	100% (1,826)	100% (3,001)

(N)=sample number in brackets are unweighted. $\chi^2=1714.79$ (df 4, $p<0.001$); $R_s=0.395$, $p<0.001$. ADL: activities of daily living.

Source: Author’s analysis of ELSA Wave 7.

3.3.2.4 Informal care variables

Variables directly related to informal care provision were only asked of the respondents, who had answered yes to having *looked after* other people last week (ERCAA), (see section 3.3.1).

Intensity of care (hours): As explored in section 2.3.2, the intensity level of the care provision is associated with the outcomes of providing informal care (Carmichael and Ercolani, 2016; Kim *et al.*, 2016). Furthermore, the intensity of care is related to the direction of care and residential status (Beesley, 2006), see also section 2.3.1.1 and 2.3.1.2.

The number of hours of care per week (ERCAC) was initially entered as a continuous variable, ranging from 1 to 168 hours. If care was provided ‘round-the-clock’ this was entered as 168 hours per week. Due to the nonparametric nature of this variable (see Figure 10), the intensity level was transformed to a four-level variable (i.e. 1 to 19, 20 to 49, 50 to 167 and 168), consistent with other studies analysing care provision using the ELSA data (Vlachantoni, 2010) and with other studies examining the effect of intensity on the carer (O'Reilly *et al.*, 2008; Carmichael and Ercolani, 2014; Drinkwater, 2015; Robards *et al.*, 2015).

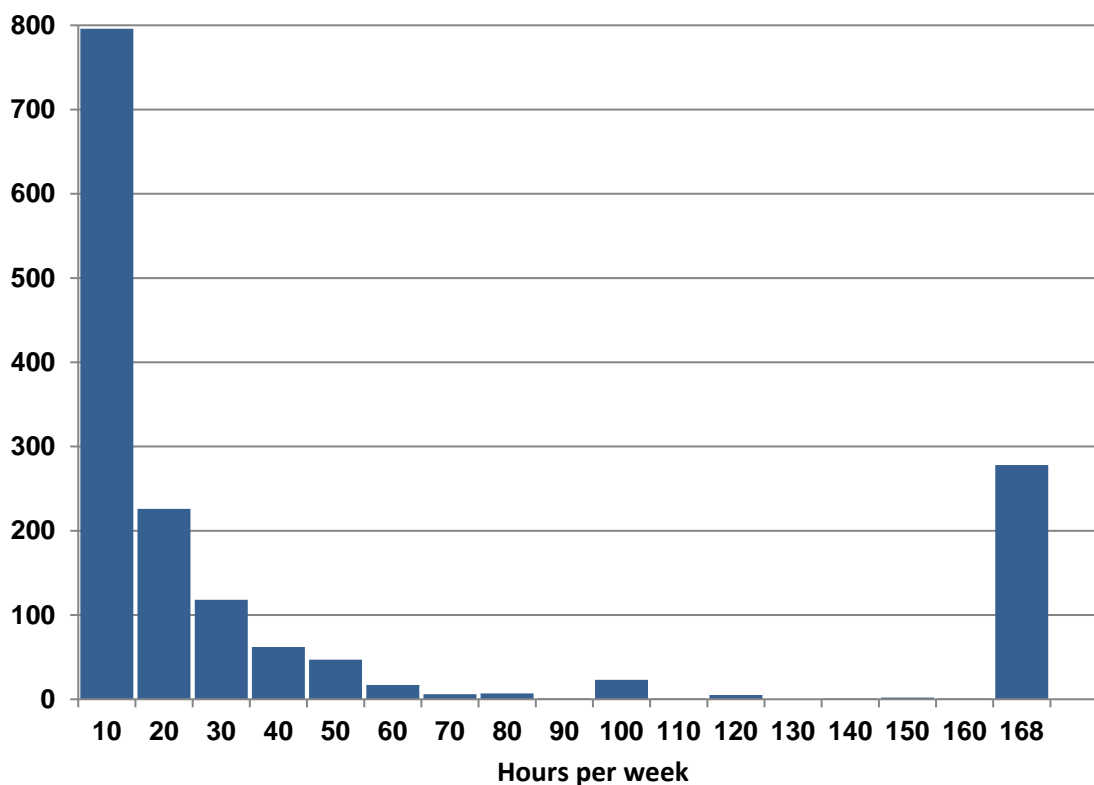


Figure 10 Hours spent looking providing care last week, the ELSA Wave 7
Mean = 42.4 hrs/wk., SD=60.8, and median= 10 hrs/wk.

Source: Author's analysis of ELSA.

Number of people cared for: The number of people one carer provided care for in the past week (ERCANTT) ranged from 1 to 42 people. Similar to the caring intensity, the number of people cared for was associated with the direction of care, see Table 13.

Preliminary analysis of the distribution of the number of people cared for in the ELSA Wave 7 found that most carers cared for only 1 or 2 people, as also noted by Henz (2004). For this reason, the variable was transformed from a continuous variable to a 4-level categorical variable (i.e. 1,2,3, ≥ 4). For the purpose of the binary regression caring for 1 person was the reference, as research has shown that most carers only provide care to 1 person (Henz, 2004). Moreover, the preliminary analysis, also showed the highest proportion of carers provided care to 1 person.

Table 13 Number of people cared for by direction of care, the ELSA Wave 7

Number of people cared for	Direction of care					
	Spouses/partners - ONLY	Parents & parents-in-law - ONLY	Other(s) - ONLY Inc. other relatives/friends/neighbours	Grandchildren - ONLY	Children - ONLY	Combinations
Minimum	1	1	1	1	1	2
Maximum	1	5	42	7	3	17
Total	480	315	294	270	87	158

The tables show the range of people cared for last week according to the direction of care. Unweighted data.

Source: Author's analysis of ELSA Wave 7.

Direction of care: As highlighted by the literature, the motivations, as well as rewards and burden of care, vary according to the relationship to the care-recipient (Bonsang, 2009, Carmichael and Ercolani, 2014), see also section 2.2.3.

The direction of care (ERCAB) was a multiple responses question ('select all that apply') with 8 possible answers (i.e. spouse/partner, child, grandchild, parent, parent-in-law, other relative, friend or neighbour, and other person). The eight directions of care can, in theory, produce as many as 255 combinations of caring directions (Miller *et al.*, 2002). The actual number of unique combinations for this variable was 44, and the most common circumstance was caring for one "direction" only (e.g. a spouse). The two most common combinations were looking after a parent AND a grandchild (n=23); or spouse AND a grandchild (n=15). For a complete list of possible circumstances and combinations, see Appendix A.

Chapter 3

To reduce the number of unique combinations a simpler variable of the direction of care was derived, see Table 14. This was divided into ‘ONLY’ and ‘combinations’ categories. As this thesis included care to grandchildren this category was kept as a separate category. The analysis was done excluding grandchildren for sensitivity and the results can be seen in Appendix D. The end result was a seven category variable (i.e. Spouse ONLY, Parent(s)/parent(s)-in-law ONLY, children ONLY, Grandchildren ONLY, Other ONLY and combinations). Due to a limited number of respondents providing care for other relatives, friends and neighbours a category of ‘others ONLY’ was created.

As caring for a spouse is more commonly witnessed in older age for the purpose of the binary regression this acted as the reference category (Pickard *et al.*, 2007; Vlachantoni, 2010; Glauber, 2016).

Table 14 Derived variable: Direction of care provided

ERCAB	Direction of care
Spouse/Partner	Spouse/Partner ONLY
Child	Child(ren) ONLY
Grandchild	Grandchild(ren) ONLY
Parent	Parent(a) & Parent(s)-in-law ONLY
Parent-in-law	Other(s) ONLY
Other relative	Combinations
Friend or neighbour	
Other person	

Source: Author’s own

Co-residential or extra-residential care: As also noted in section 2.3.1.1, the living arrangements of the carer and the care-recipient work as an indicator for both the caring intensity and the direction of care. Co-residential care tends to involve a higher intensity of care and is often associated with spousal care. This study made the assumption that all spousal care is co-residential care, see also section 4.3.3.1, Figure 17. Extra-residential care is often less intense and associated with caring for a parent or others (Arber and Ginn, 1990; Pickard, 2002; Del Bono *et al.*, 2009; Mentzakis *et al.*, 2009; Norman and Purdam, 2013; Ramsay *et al.*, 2013; Carmichael and Ercolani 2014; Caputo *et al.*, 2016). The variable (ERCALIVE) remained dichotomous (yes or no).

3.3.3 Change variables, *Phase II* and *III*

The answer Research Question 2 and 3 (see also section 1.2), change variables were derived including changes to caring status, caring intensity, direction of care and changes to SRH and economic activity.

3.3.3.1 Change to caring status

A new variable and was created to examine how respondents had transited between caring statuses between waves. The variable used responses from the informal care variable 'ERCAA' (see also section 3.3.1), and if a respondent had not provided care in any waves, they were classified as a *non-carer*; if they answered yes to providing care for someone in all analysed waves, they were classified as a '*repeating carer*'.

For the purpose of *Phase II*, carers who had provided care for two waves were separated into having provided care for either two consecutive waves or for non-consecutive waves, for further details see section 5.1.2.

For the purpose of *Phase III*, if the carer had provided care in Wave 6, but not in Wave 7, the carer were classified as a '*discontinued carer*'. Lastly, if an individual had not cared for someone in Wave 6, but had answered yes in Wave 7, they were classified as a '*new carer*'; similar classifications were used in other studies (Carmichael *et al.*, 2010; King and Pickard, 2013; Gomez-Leon *et al.*, 2017).

It should be noted that a non-carer may still have provided care between waves at time points not captured by the ELSA, likewise '*repeating carers*' may have had breaks from their caring role.

3.3.3.2 Changes to the caring intensity

To explore the trajectories of caring intensity, a variable was created to track the changes between light and heavy intensity care provision. Light intensity was classified as under 20 hours per week, and heavy as over 20 hours per week, as also used in *Phase I*, see section 3.3.2.4.

Respondents were classified, in accordance with other studies (Berecki-Gisolf *et al.*, 2008; Robards *et al.*, 2015; Vlachantoni *et al.*, 2016) as follows:

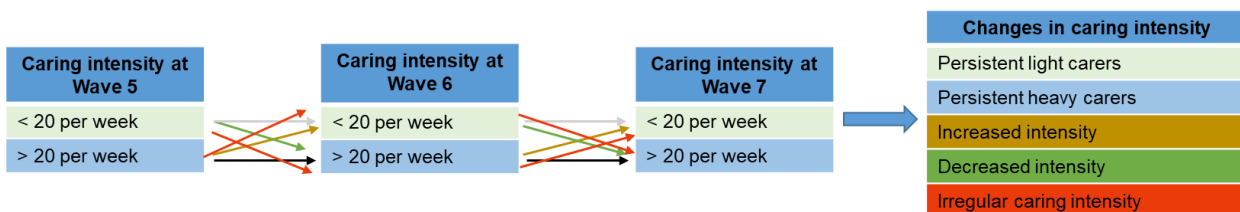
- 1) Non-carers (no care provided in all analysed waves)
- 2) '*Repeating carers*' (care provided in all analysed waves)

Chapter 3

- a. Persistent low intensity
 - b. Persistent high intensity
 - c. Increased intensity
 - d. Decreased intensity
- 2) Irregular caring intensity (*Phase II* only)
 - 3) 'New carers' (*Phase III* only)
 - a. Entry at low intensity
 - b. Entry at high intensity
 - 4) 'Discontinued carers' (*Phase III* only)
 - a. Exit at low intensity
 - b. Exit at high intensity

Carers were identified as 'persisting light' or 'persisting heavy' carers, when they had provided care at the same intensity at all measured points. Increased intensity (or decreased intensity) was classified as a carer who had increased their caring intensity at any point and sustained this increase. If the increase was not sustained the carers were classified as having 'irregular caring intensity' (i.e. light care in Wave 5, heavy care in Wave 6 and light care in Wave 7). The latter classification was only observed for 'repeating carers' in *Phase II*, see Table 15 as an example.

Table 15 Derived variable: Caring intensity, ELSA Waves 5 to 7



Source: author's own

3.3.3.3 Changes to the direction of care

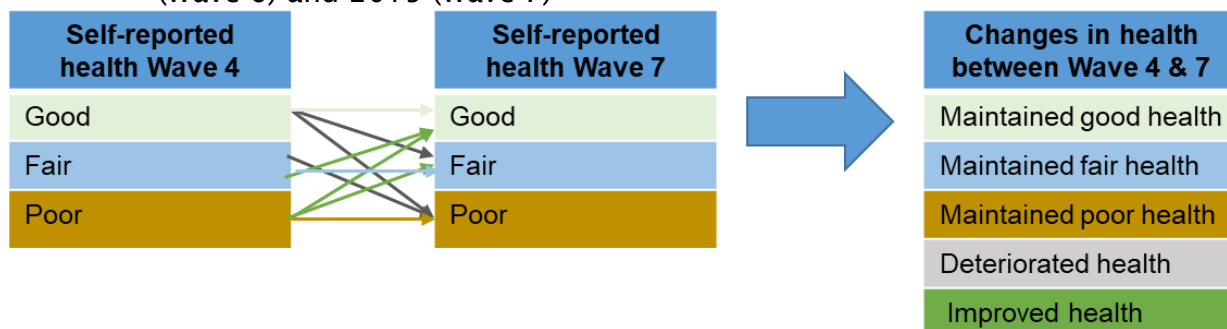
A further variable was created to observe the transitions between the directions of care (see section 3.3.2.4 for the groupings of the directions of care). If a carer provided care for the same direction of care in all the analysed waves, the carer was classified as a 'persistent (...) carer', otherwise the carer was classified as a 'transitional carer', as follows:

1. Persistent spousal carer - carers provided care for a spouse only at all points
2. Persistent parental carer - carers provided care for a parent or parent-in-law only at all points
3. Persistent 'other' carer - carers provided care for others only at all points
4. Persistent grandchild carer - carers provided care for a grandchild only at all points
5. Persistent child carer - carers provided care for a child only at all points
6. Persistent combination carer - carers provided care for a combination of people at all points
7. Transitional carer - the carers transitioned between care-recipients over the waves

3.3.3.4 Change to Self-reported health status

To assess changes to SRH a new variable was constructed to measure change between Waves 4 and 7 (*Phase II*) and between Waves 6 and 7 (*Phase III*), (see also section 3.3.2.3 for details on the SRH variable). Respondents whose SRH health status was the same in all analysed waves were classified as having 'maintained good health', 'maintained fair health', or 'maintained poor health'. Respondents whose SRH changed from good to fair/poor, or from fair to poor were classified as having 'deteriorated health', while those whose SRH changed from poor/fair to good, or from poor to fair were classified as having 'improved health' (see Table 16 for an example of the new variable). A similar approach was used by Jenkins *et al.* (2009).

Table 16 Derived variable for the change to self-reported health status in 2013 (Wave 6) and 2015 (Wave 7)



Source: Author’s own analysis.

For the purpose of *Phase II*, the health change was measured in Wave 4 prior to any caring episode and again at Wave 7 to allow for the comparison of a longer-term effect of repeated exposure to care provision, compared to a shorter-term exposure and no exposure. It is, however, acknowledged that 6 years between the measures may have allowed the respondents to have recovered from any potential health-shocks, and these would therefore not be detected in this research.

3.3.3.5 Changes to Economic Activity

Changes to economic activity (economic activity) was only analysed in *Phase III*, as the sample size in *Phase II* was too low.

A new variable was derived to show how respondents had changed economic activity between Waves 6 (2013) and 7 (2015), see Table 17 (see also section 3.3.2.2).

Table 17 Economic Activity in Wave 6 (2013) by Economic Activity in Wave 7 (2015), the ELSA

		2015 (Wave 7)				Total
		Retired	Full-time	Part-time	Economic inactive	
2013 (wave 6)	Retired	93.8% (4,183)	0.3% (15)	1.6% (72)	4.3% (188)	100% (4,458)
	Employed (full-time)	10.6% (158)	73.8% (1,102)	13.8% (207)	1.8% (27)	100.0% (1,494)
	Employed (part-time)	22.1% (282)	7.4% (94)	66.7% (850)	3.8% (48)	100.0% (1,274)
	Economic inactive	36.0% (275)	1.6% (12)	4.6% (35)	57.8% (442)	100.0% (764)
Total		4,898	1,223	1,164	705	7,990

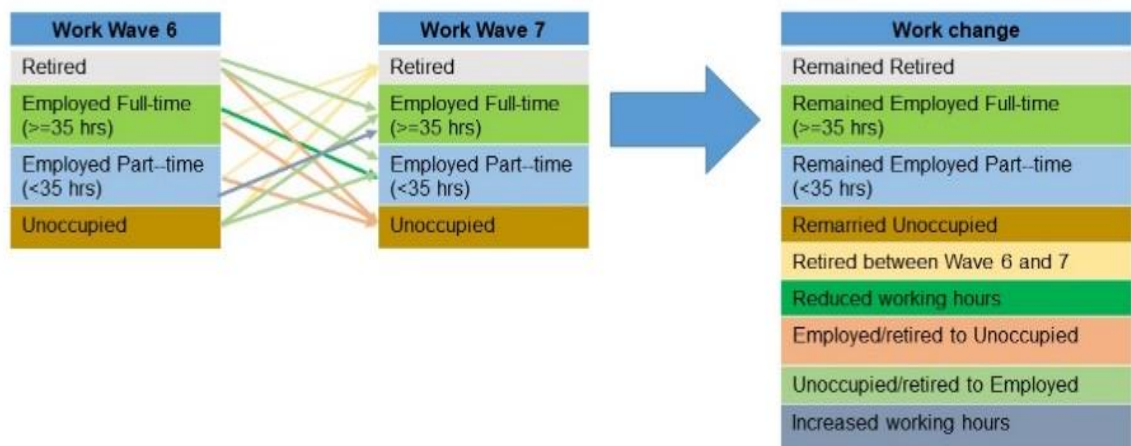
Pearson Chi-Square 11183.22 (df:9), p<0.001. Unweighted data.

Source: Author’s own analysis of the ELSA. Wave 6 and 7.

If respondents had remain retired or in employment (i.e. part-time or full-time), the categories ‘remained retired’, ‘remained employed part-time’ or ‘remained

employed part-time' were used, see Table 18. Respondents who by Wave 7 (2015) had retired, regardless of previous economic activity were categorised as 'retired', and respondents who had changed from full-time to part-time or vice versa were categories as either 'reduced hours' or 'increased hours', similar methodological strategy has been used by other studies (Henz, 2004; Berecki-Gisolf *et al.*, 2008; Gomez-Leon *et al.*, 2017). In order to minimise the numbers of categories in this change variable, and to ensure an acceptable cell count (see Table 18), some transitions were combined (see Table 18).

Table 18 Derived variable: Transition of Economic Activity in Wave 6 (2013) & Wave 7 (2015)



Source: Author's own analysis.

3.3.4 Summary

This concludes the description and justification of the independent and dependent variables, which used across all three stages of the analysis. All analysis was conducted using the Statistical Package for the Social Science (SPSS), version 24, unless otherwise mentioned.

The next section provides the other aspects of the methodology used including: binary and multinomial logistic regression modelling, weighting and a critical evaluation of data quality.

3.4 Binary logistic regression analysis design

Binary logistic regression was used to explore the effects of the dependent variables on the probability of providing informal care. In the binary regression the dependent variable is dichotomous (i.e. providing informal care: yes or no). The likelihood was presented in terms of odds ratios, which express the likelihood of an event occurring relative to the likelihood it not occurring (NCRM, 2011). The odds ratios from 0 to just below 1 indicate an event is less likely to happen in comparison to the reference category, whereas odds ratios above 1 to infinity indicate that the event is more likely to happen in comparison to the reference category (Ibid).

If $\beta_j > 0$, then $\exp(\beta_j) > 1$, and the odds increase

If $\beta_j < 0$, then $\exp(\beta_j) < 1$, and the odds decrease

For the binary regression model the variables were entered using the forced entry method (i.e. 'enter' command in SPSS). The variables (with the exception of block 1 and final model) were added to the block one at a time.

This decision was based on literature recommending a forced entry approach and due to the strong theoretical reasoning for each of the selected variables in the model (Field, 2005). As part of the preliminary exploration 'backward' elimination (likelihood ratio) was carried out. This method removes the variables based on the probability of the likelihood-ratio statistic, based on the maximum partial likelihood estimation (Ibid). A description of how each model was created is provided prior to the results of the regression models (see Chapter 4 and Chapter 5).

The odds ratio, statistical significance level and 95% confidence interval (CI) were reported in the tables. All models were tested for the overall good-of-fit statistics, and variables were omitted if noted not to be statistically significant or if the variable did not improve the overall good-of-fit of the model. The tables depicting the models were each presented with the -2 log-likelihood (-2LL) deviance and the difference between each step in the model, as well as the statistical significance of this change.

The significance of the change was obtained from the omnibus tests of the model coefficients produced by SPSS. The -2LL estimates how much unexplained variation was displayed in each model and a reduction in -2LL equals a better predictive power of the model (NCRM, 2011). The table also displayed the results

of the Hosmer and Lemeshow's goodness-of-fit test, which tests the hypothesis that the observed data are significantly different from the predicted values of the model (Field, 2005). Therefore, a non-significant p-value indicates that the model is a good fit (ibid). The model presented in Chapter 4 and Chapter 5 will only show 4 blocks of the model, the full model containing all blocks can be found in Appendix T to Appendix W including results of further statistical tests, such as the Cox and Snell R-Squared test (Field, 2005; Argyrous, 2014).

Multicollinearity is a statistical problem in which two or more dependent variables in the binary logistic regression model are highly correlated (Midi *et al.*, 2010). To check for multicollinearity between the independent variables used, a correlation matrix using the Spearman Rank correlation coefficient, assessed the strength of the relationship. The Spearman Rank correlation coefficient is based on the ranks of the data, rather than the actual data, and is therefore more appropriate when examining the relationship between categorical variables (Ibid). The correlation matrix produces correlation coefficients, which laid between -1 and +1. Any value at 1, negative or positive indicates a perfect correlation, whilst a value of 0 indicates a lack of correlation, as a general rule of thumb, if the correlation between two independent variables is greater than 0.8, then multicollinearity is a serious problem (Field, 2005; Midi *et al.*, 2010).

3.5 Weighting

Most national surveys provide pre-calculated weights. A survey weight is a value assigned to each case (respondent) in the data file and normally used to make the data representative of the population (UKDS, 2014). Weights can for example be used to compensate for the over- or under-sampling of cases with specific characteristics or for the disproportionate stratification and to adjust for survey non-response, for instance general population surveys tend to sample substantially more females than male respondents (Ibid).

The weights used in the ELSA were constructed to adjust for non-response and the process of combining Cohorts 1,3,4,6 and 7 (Littleford *et al.*, 2016). The cross-sectional weight was derived by the ELSA team to be used in the analysis of all core members responding to Wave 7; the cross-sectional sample at Wave 7 aimed to be representative of those living in England in 2014 (Ibid).

Chapter 3

The cross-sectional weight combines four complex calculation from: a) non-response across the 5 core waves; b) population estimated (education, tenure, ethnicity and marital status) for core members aged 63 and over; c) non-response rates for 63 and over at wave 7 (to calibrate these to population estimates of age/gender and region from 2014 household population estimates) and d) non-response weights for all core members aged 50-62 (at Wave 7) for calibration purposes (Littleford *et al.*, 2016). The variable used for the cross-sectional weight is named 'W7XWGT'.

In *Phase 1* all models were run with and without cross-sectional weights for comparison of sensitivity.

3.6 Data Quality

As previously mentioned, the ELSA has been running for numerous years with highly trained and respected researchers collecting the data. Nevertheless, even in a well-designed study missing data and attrition may occur. Missing data can lead to reduced statistical power and introduce biased estimates leading to invalid conclusions (Kang, 2013). However, the ELSA's comparably large national sample size enhances the reliability and validity of the data as well as limits the effect of potential missing data.

Due to a lack of survey information some research questions concerning the pathways into informal care provision could not be considered. These include the association between informal care and urban or rural settings, as the ELSA dataset has limited regional information due to concerns of disclosure. Additionally, by its very nature, the study was confined to England, and certain nuances in the population diversity may have been missed (Steptoe *et al.*, 2013). These nuances and diversity in care provision were also lost among ethnic minority, as the ELSA deemed oversampling of ethnic minority groups prohibitively expensive (Ibid). Therefore, the analysis was limited to focussing on broad geographical setting and white and non-white respondents only.

The ELSA may also suffer from a responder bias associated with longitudinal surveys, such as the 'learnt component' whereby respondents become more accustomed to the questions over time (Young *et al.*, 2007). In addition, there is evidence that individuals become 'conditioned' by repeated surveys, meaning that responses given in one wave may be influenced by those given in previous waves (Young *et al.*, 2007; Lugtig, 2014).

The consequences of these data limitations are further discussed in section 6.4.

3.6.1 Sensitivity analyses

Sensitivity analysis is defined as ‘a method to determine the robustness of an assessment by examining the extent to which results are affected by changes in methods, models, values of unmeasured variables, or assumptions’ (Thabane *et al.*, 2013, p.2).

In order to assess the robustness and ensure appropriate interpretation, a separate analysis was carried out excluding all carers who had provided care to a grandchild. This was to ensure that the characteristics of these carers was not vastly different from those who provided care to other care-recipients (i.e. a spouse, parent, others or combinations). The results found the carer’s characteristics not to be different whether grandchild carers were included or not, the results can be found in Appendix D.

Twenty hours of care per week was used as the threshold for high intensity (see also section 3.3.2.4). A sensitivity analysis was carried out to test alternative thresholds of the intensity of care (i.e. 10, 20 or 35 hours of care per week). The results can be seen in Table 19 and Appendix E, and showed that the alternative thresholds had little influence on the effect of higher intensity of care provision. Other studies have used 10 hours of care per week (King and Pickard, 2013; Carr *et al.*, 2016). Carr and colleagues also carried out a sensitivity test using 10, 15 and 20 hours of care per week, and also noted that alternative thresholds of caring intensity did not influence the strength of the statistical significance of the analysis. A threshold of 35 hours per week was tested, as this is the criteria for receiving the Carer’s Allowance (see also 1.1.2, Table 1). The results of the sensitivity test are interpreted in section 4.4.1.3.

Table 19 Comparison of outcomes for different caring intensity level cut-off points

	Over 10 hours per week	Over 20 hours per week	Over 35 hours per week
Variables			
Gender	NS	NS	NS
Age	NS	SS	SS
Ethnicity	NS	NS	NS
Marital status	NS	NS	NS
Household type	SS	SS	SS
Self-reported health	SS	SS	SS
Long-standing illness	NS	NS	NS
Difficulties with ADL	NS	NS	NS
Difficulties with IADL	NS	NS	NS
Economic activity	SS	SS	SS
Education	NS	NS	NS
Wealth	NS	SS	SS
Housing tenure	SS	SS	NS
Access to car	NS	SS	SS

NS: not statistically significant; SS: Statistically significant. The significant variable had the same effect unless indicated by the comparison of the odd ratios. For detailed results, please refer to Appendix E. Source: Author's own analysis of the ELSA Wave 7

3.6.2 Non-response and Attrition of the ELSA

The data quality is greatly affected by non-response and attrition. Non-response is the failure to collect the required information from a sample member, and can be either unit non-response (sample member not responding) or item non-response (missing data for a particular question) (Kang, 2013).

For instance, data may be missing for individual items within the survey (item non-response); an example is the variable wealth which is known to have a higher item non-response, compared to other socio-economic status variables, as wealth is considered to be more sensitive information (Westermeier and Grabka, 2015). In the ELSA Wave 7 almost 14% (unweighted data) of the respondents had missing data of Net Total Wealth. This may lead to a bias in the interpretation of how wealth is related to the probability of providing care.

There are generally three types of missing data, based on the assumption for the missingness 1) missing completely at random (MCAR), referring the missing data not being related to either the specific value which is supposed to obtain, ideal as the analysis remains unbiased, 2) missing at random (MAR), when the responses missing depends on the set of observed responses, but is not related to the

specific missing values, which are expected to be obtained and 3) missing not at random (MNAR) (Kang, 2013).

MNAR is the worst case scenario as the only way to obtain an unbiased estimate of the parameters is to model the missing data, by incorporating a more complex estimation of the missing values (Ibid). A common solution to deal with item non-response is either a) imputation for missing items, single imputation replaces each missing value with a plausible guess or b) by omitting those cases with the missing data and analysis the remaining data, this approach is known as the complete case analysis or listwise deletion or by c) pairwise deletion, which eliminates information only when the particular data-point needed to test a particular assumption is missing (Young *et al.*, 2007; Deng *et al.*, 2013; Kang, 2013).

The analysis used a mix between both listwise deletion and pairwise analysis. This decision was based on SPSS procedures performing listwise deletion of more advanced modelling procedures, however for the purpose of the univariate descriptive analysis pairwise deletion was used. The advantage of using pairwise deletion is that it maximises all the data available, which increases the power of the analysis, however it assumes that the missing data are MCAR. Furthermore, pairwise deletion can produce a standard of error, which is either under or overestimated (Kang, 2013).

The associated predictors of attrition in the ELSA was the level of education held by the respondent, and lower education was associated with higher attrition, but only for those aged 50-64 (Banks *et al.*, 2011). Among the older ELSA respondents no strong evidence of a correlation between attrition and education, income, housing tenure or wealth was noted (Ibid). It was argued that the lack of association between housing tenure and attrition was due to the relatively low internal mobility of the older population in England. In addition, association between health factors and attrition was also examined, however no associations were noted here either (Banks *et al.*, 2011).

In a longitudinal context missing data occurs from either wave non-response or attrition, the latter refers to initially cooperative sample member dropping out of the study before the study ends (Lugtig, 2014). Panel studies typically suffer from attrition, which reduces the sample size and can result in biased inferences (Deng *et al.*, 2013; Lugtig, 2014). Banks *et al.* (2011) demonstrated how attrition was a far greater problem in ELSA (Waves 1 to 3) than in the American HRS, with

Chapter 3

attrition rates nearly four times higher in the ELSA. It should, however, be noted that the attrition rates are not higher than the standard of other ageing panels in Europe, such as for example SHARE (Börsch-Supan *et al.*, 2013). The effects of attrition are discussed in section 6.4.

3.7 Summary

Chapter 3 described the overall methodology used for this study, including details on the dataset and the how the variables were derived. Ethical approval was granted on the 10/06/2016 by the Ethics committee of the University of Southampton. The ELSA dataset was chosen due to its depth and breadth of information in relation to informal care provision, moreover this dataset allowed for a detailed analysis of the direction of care provision, including care provided to grandchildren, which other survey ordinarily omit.

Chapter 4 and Chapter 5 is divided in accordance with the methodology used (i.e. cross-sectional and longitudinal) and provides details of the particular methodology used for each phase (i.e. *Phase I, II* and *III*) of the data analysis and presents the finding.

Chapter 4 Phase I: Methodology and Results of the cross-sectional analysis

4.1 Introduction

Phase I aims to answer Research Question 1 '*Who are the informal carers in England?*' This phase is the descriptive cross-sectional analysis of the ELSA Wave 7 (2015), which at the time of analysis the most recent wave available (Marmot *et al.*, 2017) (see also section 2.5). The phase utilises descriptive bivariate analysis and binary logistic regression analysis to predict the likelihood of individuals providing care, as well as to highlight any gender differences in care provision, as the literature review consistently noted a marked difference between the caring characteristics of males and females, such as age, employment and the intensity of care (Vlachantoni 2010; Glauber, 2016; Haberkern *et al.*, 2015) (see also sections 2.3.1.1 and 2.3.1.2). The chapter further explores the within-carer patterns, such as the intensity of care provided and to whom the care is being provided, also separately analysed by sex.

4.2 The sample population of ELSA Wave 7

The fieldwork for Wave 7 was completed in 2015 and the data became accessible in 2016. The wave consisted of a total of 9,666 respondents and included a refreshment sample of 301 who became core members. The refreshment sample was at the time of fieldwork (2014/2015) aged between 50-51 years. The response rate for this wave was for the core members: 61% for Cohort 1, 65% for Cohort 3, 75% for Cohort 4 and 82% for Cohort 6 (Littleford *et al.*, 2016) (see also Box 1, p. 71).

Figure 11 depicts a flowchart of the final sample used for *Phase I* after excluding respondents who had completed the interview by proxy (full or partial) and all institutional interviews. As this study solely focuses on factors associated with informal care provision among individuals within the household, any respondents living in an institutional setting were excluded, based on the Office for National Statistics' (ONS) definition of non-household groups, which includes health and care establishments, access restricted establishments and managed residential establishments (Joloza, 2009), see also section 1.1. After the exclusion, 9,059 respondents remained.

Chapter 4

Respondents aged under 50 were also deleted (n=147). Although the ELSA is a study of people aged over 50, the sampling method includes partners living in the same household as a core member who may have been younger than 50 at the time of the data collection, see also section 3.2.1. Likewise, respondents residing in Scotland (n=15) and Wales (n=23) were excluded (see section 3.3.2.1, for justification). To ensure consistency in the caring activities (also referred to as caring pattern), a further 35 cases that had either refused to reply or replied 'Don't know' in the variable 'ErCAA': '*Have you cared for anyone in the past week?*' were deleted. This was done as 'ErCAA' acts as a filter question to other questions related to informal care provision, (see also section 3.3.1). This led to a total sample consisting of 8,839 respondents.

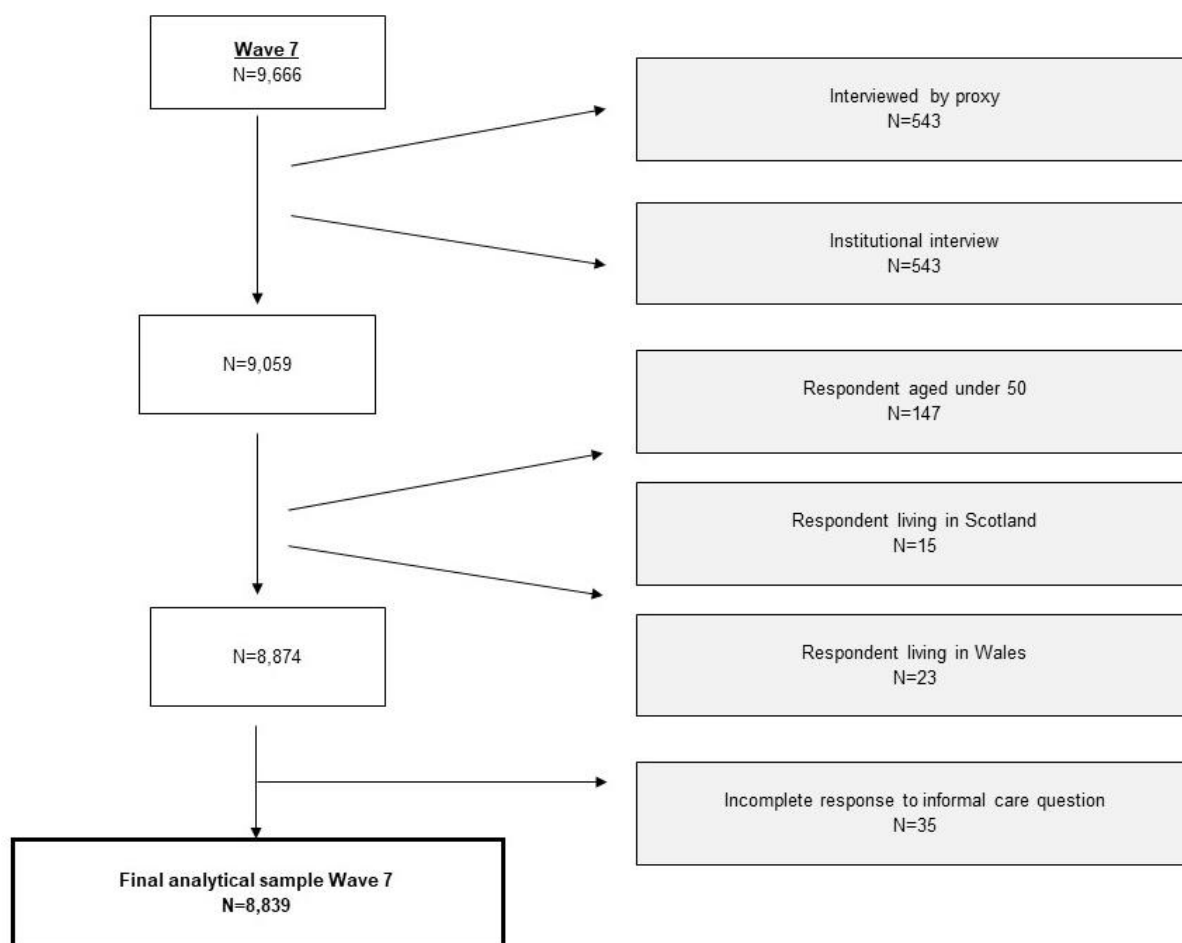


Figure 11 Flow chart of excluded respondents, the ELSA Wave 7
Source: Author's analysis of the ELSA

The gender and age distribution of the sample can be seen in Figure 12. Females represented more than half of sample and the majority of the sample were aged between 50 to 59 years. It should be noted that the Wave 7 refreshment sample was this age-group (Box 1), which may have contributed to the younger age-structure of the sample. The younger age-structure seen in Figure 12 was to be

expected from this kind of panel study and is representative of the general population (Steptoe *et al.*, 2013).

Out of the 8,839 respondents used for this data analysis, 4,933 were females and 3,906 males. There was a total of 1,604 informal carers (1,017 female and 587 male carers).

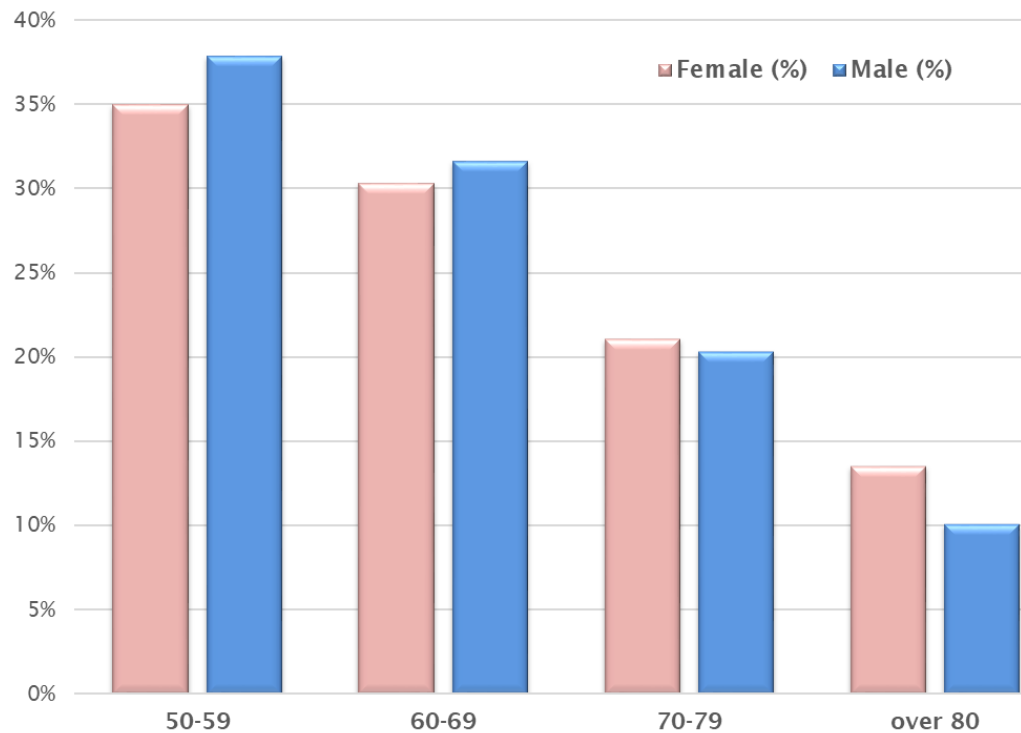


Figure 12 Age by sex, the ELSA Wave 7

Source: Author's analysis of the ELSA Wave 7

4.3 Descriptive statistical data analysis design

The respondents' demographic, health and socio-demographic characteristics, in addition to their informal care activities and who was the care-recipient, were summarised using descriptive statistics (frequencies and percentages) (Argyrous, 2014). Percentages were calculated using cross-sectional weights and excluded missing data, unless otherwise stated (see also sections 3.4 and 3.6.2).

The results of the bivariate analyses are displayed in tables created to capture the relationship between carers and non-carers, and any difference both between and within the genders. The total sample number presented in the tables are column percentages, unless otherwise specified, and it should be noted that the totals may differ due to item non-responses. The Pearson's Chi-Square (χ^2) test was used to assess the independence between respondents providing informal care and those who did not. A statistical significance at $p < 0.05$ was assumed (Argyrous, 2014).

4.3.1 The demographic and socio-economic characteristics of the all respondents, by non-carers and carers, the ELSA Wave 7

To establish who the carers were in Wave 7 (2015) (Research Question 1.a.) Table 20 provides a descriptive summary of the sample by caring status. For a description of the overall sample, please refer to Appendix P

The sample population of informal carers in Wave 7 represented 17.6% (1,604) of the overall sample. Most carers were female (63%) and younger (mean age 64 years) than non-carers (mean age 66 years). The largest proportion of carers were aged between 50 and 59 (40%) and only 7% were aged over 80, in comparison 36% of the non-carers were aged between 50 and 59 and 13% aged over 80. Any differences in the caring characteristics between the genders are further explored in sections 4.3.2 and 4.3.3.

Most carers were married (76%), 7% were single, 11% divorced and 6% were widowed. This compared with 63% of non-carers who were married and 8% were single, 15% were divorced and 14% were widowed. Widowhood could imply that one no longer has a partner to provide care for, hence the lower proportion of carers in this group. Furthermore, other scholars noted a positive correlation between widowhood and age, and therefore widowers may themselves be likely to be in need of care, rather than to provide care (Del Bono *et al.*, 2009; Carmichael and Ercolani, 2014). The differences between carers and non-carers were further reflected in the household structure, and only 11% of carers lived in single households, 56% in couple households, 20% in coupled households with children and 5% in extended families. Among non-carers, nearly half lived in coupled households (47%), 25% in single households, 18% lived in coupled households with children and 4% with extended families (4%). This is further discussed in section 6.2.1.3.

Due to the over-representation of respondents from a white ethnic background, no statistical significance in ethnic background was observed between the carers and non-carers. This is a limitation of the analysis, discussed in sections 3.6 and 6.4.

Among carers, 41% reported good SRH, 53% fair health and 6% poor health. Among the non-carers, 42% had good SRH, 50% fair health and 9% poor health. No statistically significant difference was observed in the report of a LLTI between carers and non-carers. Among carers, 89% had no ADLs difficulties, 6% had difficulty with 1 ADL and only 5% of carers reported difficulty with 2 or more ADLs. Among non-carers, 83% had no difficulties with ADLs, 8% had difficulty with 1 ADL and 9% of non-carers had difficulties with more than 2 ADLs. A similar pattern was

seen for IADLs (see also Table 20). This may suggest a '*healthy carer effect*' (Arrighi and Hertz-Picciotto, 1994) and as discussed in section 2.3.1.3 and 2.3.2.1 and further discussed in section 6.3.4.

Table 20 shows that 46% of the carers were retired, 18% worked full-time, 21% worked part-time and 15% were economically inactive. This was different among the non-carers, where 49% were retired, 27% worked full-time, but only 15% worked part-time and 9% were economically inactive (see section 3.3.2.2 for the classification of economically inactive). The potential of a causal relationship between working part-time and the provision of care is further analysed in section 5.2.4.2, and discussed in section 6.3.5.

Among the SES measures, only education and having access to a car showed a statistically significant difference between informal carers and non-carers. Most carers had NVQ3/GCE/A-levels or equivalent (23%) or no education (23%), and the smallest proportion of carers had NVQ1/GSE/O-level or equivalent (3%), as seen in Table 20. The majority of carers had access to a car or van (89%), compared to 84% of non-carers, which may reflect a necessity of having readily available transportation to provide care, rather than a factor of SES. As this is a cross-sectional analysis, it is not possible to conclude whether those providing care already had access to a car, or whether they obtained access to transportation as a consequence of providing care.

Most carers owned their house outright (60%) or with a mortgage (22%), and a smaller amount were social renters (14%), however there was no statistically significant difference between carers and non-carers and their housing tenure. Wealth was distributed almost equally between the poorest and wealthiest quintiles, however wealth was not found to be statistically significant within or between carers and non-carers. As discussed in section 3.3.2.2, wealth reflects a stock of resources accumulated over a lifetime (Searle and Köppe, 2014), which may help to explain the distribution of wealth in this sample. Furthermore, as discussed in section 3.6 wealthier respondents are overrepresented in the ELSA dataset.

The regions of residence varied between carers and non-carers by approximately 1 percentage point with the exception of the North East, Yorkshire and the Humber and London, where little variation was noted. In the subsequent binary logistic regression analysis, the region is reduced to a three-category variable, see also section 3.3.2.2.

Table 20 Descriptive statistics: Total sample by non-carers and carers

	Total sample	Non carers	Carers	p-value ^c
Sex	100% (8,839)	82.4%	17.6%	p<0.001
Male	47.5%	49.6%	37.3%	
Female	52.5%	50.4%	62.7%	p<0.001
	100% (8,839)	100% (7,235)***	100% (1,604)***	
Mean Age (years) (SD)^{a,b}	65.4 (± 10.9)	65.7 (± 11.1)***	64.0 (± 9.5)***	p<0.001
Age Group (years)				
50-59	36.4%	35.7%	39.5%	
60-69	31.0%	30.4%	34.1%	
70-79	20.7%	20.9%	19.7%	p<0.001
Over 80	11.9%	13.0%	6.7%	
	100% (8,839)	100% (7,235)***	100% (1,604)***	
Marital Status				
Single, never married	8.0%	8.2%	6.7%	
Married or partnered	65.0%	62.7%	75.9%	
Divorced, or separated	14.5%	15.3%	11.1%	p<0.001
Widowed	12.5%	13.8%	6.3%	
	100% (8,837)	100% (7,233)***	100% (1,604)***	
Household Type				
Single	22.4%	24.9%	10.9%	
Lone plus children	5.3%	4.9%	6.5%	
Couple	48.5%	46.8%	56.3%	
Couple plus children	18.5%	18.3%	20.1%	p<0.001
Extended family	3.9%	3.7%	5.0%	
Other households	1.4%	1.4%	1.2%	
	100% (8,839)	100% (7,235)***	100% (1,604)***	
Ethnicity				
White	94.3%	94.2%	94.9%	
Non-white	5.7%	5.8%	5.1%	P=0.526
	100% (8,838)	100% (7,234) [#]	100% (1,604) [#]	
Self-reported Health				
Good	41.6%	41.6%	41.4%	
Fair	50.4%	49.9%	52.9%	
Poor	8.0%	8.5%	5.7%	p<0.010
	100% (8,836)	100% (7,232)**	100% (1,604)**	
Longstanding Illness				
No	48.1%	48.2%	47.7%	
Yes, but not limiting	19.5%	19.2%	20.7%	
Yes and limiting	32.4%	32.6%	31.6%	P=0.403
	100% (8,837)	100% (7,233) [#]	100% (1,604) [#]	
Difficulties with ADLs				
None	83.9%	82.9%	88.5%	
1 ADL	7.6%	7.9%	6.4%	
2 or more ADLs	8.5%	9.3%	5.1%	p<0.001
	100% (8,839)	100% (7,235)***	100% (1,604)***	
Difficulties with IADLs				
None	81.4%	80.9%	83.5%	
1 IADL	8.9%	8.7%	10.1%	
2 or more IADLs	9.7%	10.4%	6.4%	p<0.001
	100% (8,839)	100% (7,235)***	100% (1,604)***	

^a weighted mean (67.7 years unweighted); ^b Independent-samples Mann Whitney U, ^c between non-carers and carers. *** p<0.001, ** p<0.01, * P<0.05, # no statistical significance. SD: standard deviation, ADL: activities of daily living, IADL: instrumental activities of daily living

Source: Author's analysis of the ELSA Wave 7.

Table 20 (continued) Descriptive statistics: Total sample by non-carers and carers

	Total sample	Non carers	carers	p-value ^c
Economic Activity				
Retired	48.2%	48.7%	45.6%	
Employed: Full-time(>=35hrs)	25.2%	26.8%	18.2%	
Employed: Part-time(<35hrs)	16.1%	15.1%	21.0%	p<0.001
Economic inactive	10.5%	9.4%	15.2%	
	100% (8,808)	100% (7,210)***	100% (1,598)***	
Mean Working Hours –hrs (SD) (2,327)^{a,b}	33.97 (±13.3)	34.5 (±12.8)***	31.2 (±15.4)***	P=0.117
Education Level				
NVQ4/NVQ5/Degree or equiv	15.8%	15.9%	15.5%	
Higher education below degree	12.5%	12.3%	13.6%	
NVQ3/GCE/A-level or equiv	9.1%	8.9%	9.7%	
NVQ2/GCE/O-level or equiv	20.6%	20.1%	23.2%	
NVQ1/GSE or grade equiv	4.1%	4.3%	2.9%	p<0.010
Foreign/other	12.7%	12.7%	12.4%	
No qualification	25.2%	25.8%	22.7%	
	100% (8,615)	100% (7,053)**	100% (1,562)**	
Housing Tenure				
Own, outright	58.7%	58.4%	59.7%	
Own with mortgage or loan	22.4%	22.6%	21.6%	
Private renting	4.4%	4.4%	4.6%	
Social renting	13.6%	13.6%	13.7%	P=0.229
Live rent free	0.9%	1.0%	0.4%	
	100% (8,825)	100% (7,222) [#]	100% (1,603) [#]	
Access to Car or Van				
Yes	84.7%	83.8%	89.1%	
No	15.3%	16.2%	10.9%	p<0.010
	100% (8,838)	100% (7,234)***	100% (1,604)***	
Non-Pension Wealth Quintiles				
Poorest	20.1%	20.1%	19.8%	
2 nd Quintile	20.0%	20.2%	19.9%	
3 rd Quintile	20.0%	20.1%	19.3%	
4 th Quintile	20.0%	19.5%	22.1%	P=0.302
Wealthiest	19.9%	20.1%	18.9%	
	100% (7,653)	100% (6,316) [#]	100% (1,337) [#]	
Region				
North East	5.3%	5.1%	5.9%	
North West	13.4%	13.6%	12.7%	
Yorkshire and the Humber	10.2%	10.1%	10.3%	
East Midlands	9.0%	8.8%	10.4%	
West Midlands	10.7%	10.8%	9.9%	
East of England	11.7%	11.3%	13.9%	P<0.050
London	11.5%	11.5%	11.7%	
South East	16.9%	17.1%	16.0%	
South West	11.3%	11.7%	9.3%	
	100% (8,839)	100% (7,235) [*]	100% (1,604) [*]	

^a Weighted mean (SD); ^b independent-samples Mann Whitney U test; ^c independent Samples T-test *** p<0.001, ** p<0.01, * P<0.05, # no statistical significance. SD: standard deviation.

Source: Author's analysis of the ELSA wave 7

4.3.2 The demographic and socio-economic characteristics by gender, in the ELSA Wave 7

The characteristics of informal carers and non-carers are strongly associated with gender (Pickard, 2015; Robards *et al.*, 2015; Glauber, 2016), see also sections 2.3.1.2 and 3.3.2.1. Therefore, in order to evaluate if gender has an effect on the caring characteristics measured, and to answer Research Question 1.a, the descriptive analysis of caring status was divided by sex. This section highlights the key differences noted and the results are displayed in Table 21.

There was an approximately two-year difference in mean age between male (65 years) and female carers (63 years). The proportion of male carers was spread more evenly across the age ranges compared to the female carers. Additionally, more male carers were aged between 70-79 years (24%) or over 80 (9%) compared to female carers (17% and 5% respectively). These results correspond to evidence noted in the literature review, section 2.3.1.2.

More male (81%) than female carers (73%) were married and more female carers than male carers were divorced (13% and 8%, respectively) or widowed (8% and 3%, respectively). The difference between the genders is likely associated with the direction of care. Male carers are more likely to provide care for a spouse, whereas female carers tend to have a broader range of care-recipients, such as parents, other relatives and grandchildren (Vlachantoni, 2010, Glauber, 2016), this is further analysed in section 4.3.3.

Unexpectedly, there were significantly more non-white male carers (7%) compared to non-white female carers (4%). This is not in accordance with the evidence found in the literature (Young *et al.*, 2006) (see section 2.3.1.2). It should, however, be noted that the cell count for the male non-white carers was relatively low (n=22), thus the analysis was less robust. This limitation is discussed in sections 3.6 and 6.4.

A higher proportion of male carers had no difficulties with IADLs (86%) compared to female carers (82%), moreover only 4% of male carers had difficulties with more than 2 IADLs, compared to 8% of female carers. No statistically significant difference was otherwise observed in the health measures between male and female carers.

Finally, as seen from Table 21, more male carers were retired (50%) compared to female carers (43%), which is likely due to male carers on average being older than female carers. For those who were employed, the mean working hours for male carers were 36 hours per week, compared to 28 hours per week for female carers,

potentially due to 25% of female carers worked part-time compared to only 14% of male carers. Only 11% of male carers were economically inactive compared to 18% of female carers. As these results are cross-sectional, it is not possible to say whether carers worked part-time prior to providing care or whether providing care led to them to reduce their hours. The causal effect of informal care provision on employment is further explored in *Phase III* (see section 5.2.4.2).

The majority of the SES measures did not show statistically significant differences between the male and female carers, with the exception of housing tenure and education. More male carers were social renters (15%) compared to female renters (13%), and more female carers were private renters (6%) compared to only 3% of male carers. However, as mentioned previously these findings should be interpreted with caution, as the cell counts are low, particularly for the male carers.

The next part of the analysis concentrates on the caring patterns, including gender differences in the caring intensity, the relationship with the care-recipient and the living arrangement between the carer and recipient (i.e. extra-residential care or co-residential care).

Table 21 Descriptive statistics: Non-carers and carers, by sex, the ELSA Wave 7

	Male n= 3,906 (100%)		Female n=4,933 (100%)		p-value
	Non-carers n= 86.2%	Carers n= 13.8%	Non-carers n= 79.0%	Carers n= 21.0%	
Mean Age – in years (SD)^{a,b}	64.7 (±10.5) [#]	65.3 (±10.1) [#]	66.8 (±11.6) ^{***}	63.1 (±9.0) ^{***}	p<0.001
Age Group					
50-59	38.3%	35.5%	33.2%	41.9%	
60-69	31.7%	31.5%	29.0%	35.6%	
70-79	19.8%	23.9%	22.1%	17.3%	P<0.005
Over 80	10.2%	9.1%	15.7%	5.2%	
	100% (3,319) [#]	100% (587) [#]	100% (3,916) ^{***}	100% (1,017) ^{***}	
Marital Status					
Single, never married	10.2%	8.3%	6.4%	5.8%	
Married or partnered	69.8%	81.0%	55.6%	72.9%	
Divorced, incl. separated	13.2%	7.7%	17.3%	13.1%	P=0.106
Widowed	6.8%	3.0%	20.7%	8.2%	
	100% (3,317) ^{***}	100% (587) ^{***}	100% (3,916) ^{***}	100% (1,017) ^{***}	
Household Type					
Single	20.1%	8.9%	29.6%	12.1%	
Lone plus child	3.0%	5.3%	6.8%	7.1%	
Couple	50.2%	60.6%	43.5%	53.7%	
Couple plus child	22.2%	19.9%	14.5%	20.3%	P=0.090
Extended family	4.5%	5.3%	5.6%	6.8%	
	100% (3,319) ^{***}	100% (587) ^{***}	100% (3,916) ^{***}	100% (1,017) ^{***}	
Ethnicity					
White	93.7%	93.3%	94.6%	95.9%	
Non-white	6.3%	6.7%	5.4%	4.1%	P<0.050
	100% (3,318) [#]	100% (587) [#]	100% (3,916) [#]	100% (1,017) [#]	

Weighted percentages, unweighted frequencies. Please note that the p-value on the right hand side of the table represents the statistical significance between male and female carers.

^a Weighted mean (SD); ^b independent-samples Mann Whitney U test; ^c Mean working hours were derived from respondents, who had reported being employed or self-employed. *** p<0.001, ** p<0.01, * P<0.05, Chi-Square test, # no statistically significance.

Source: Author's analysis of the ELSA Wave 7

Table 21 (continued): Descriptive statistics: Non-carers and carers, by sex, the ELSA Wave 7.

	Male		Female		p-value
	Non-carers	Carers	Non-carers	Carers	
Self-reported Health					
Good	44.6%	37.8%	38.7%	43.5%	P=0.065
Fair	48.0%	55.3%	51.8%	51.4%	
Poor	7.4%	6.9%	9.5%	5.1%	
	100% (3,316)**	100% (587)**	100% (3,930)***	100% (1,017)***	
Long-term Illness					
No	50.4%	46.9%	46.1%	48.1%	P=0.200
Yes, but not limiting	20.7%	23.2%	17.6%	19.2%	
Yes and limiting	28.9%	29.9%	36.3%	32.7%	
	100% (3,318)#	100% (587)#	100% (3,915)#	100% (1,017)#	
Difficulties with ADLs					
None	85.0%	88.6%	80.8%	88.4%	P=0.965
1 ADL	7.5%	6.2%	8.2%	6.6%	
2 or more ADLs	7.5%	5.2%	11.0%	5.0%	
	100% (3,319)#	100% (587)#	100% (3,916)***	100% (1,017)***	
Difficulties with IADLs					
None	85.4%	85.7%	76.5%	82.2%	P<0.050
1 IADL	7.3%	10.1%	10.1%	10.1%	
2 or more IADLs	7.3%	4.2%	13.4%	7.7%	
	100% (3,319)**	100% (587)**	100% (3,916)***	100% (1,017)***	
Economic Activity					
Retired	44.7%	49.5%	52.7%	43.3%	p<0.001
Employed: full time (≥35hrs)	38.3%	26.1%	15.4%	13.5%	
Employed: Part time (≤35hrs)	10.0%	13.5%	20.1%	25.4%	
Economic inactive	7.0%	10.9%	11.8%	17.8%	
	100% (3,305)***	100% (587)***	100% (3,905)***	100% (1,011)***	
Mean Working Hours – hrs (SD)^{a, b, c}	38.9 (±11.3)*	36.4 (±14.1)*	29.5 (±12.6)#	28.3 (±15.4)#	p<0.001

Weighted percentages, unweighted frequencies. Please note that the p-value on the right hand side of the table represents the statistical significance between male and female carers.

^a Weighted mean (SD); ^b independent-samples Mann Whitney U test; ^c Mean working hours were derived from respondents, who had reported being employed or self-employed. *** p<0.001, ** p<0.01, * P<0.05, Chi-Square test, # no statistical significance.

Source: Author's analysis of the ELSA Wave 7.

Table 21 (continued): Descriptive statistics: Non-carers and carers, by sex, the ELSA Wave 7

	Male		Female		p-value
	Non-carers	Carers	Non-carers	Carers	
Education Level	20.2%	17.4%	11.7%	14.3%	
NVQ4/NVQ5/Degree or equiv	15.1%	16.8%	9.6%	11.7%	
Higher education below degree	9.1%	9.0%	8.8%	10.3%	
NVQ3/GCE/A-level or equiv	16.8%	22.0%	23.2%	23.8%	P<0.010
NVQ2/GCE/O-level or equiv	5.9%	4.1%	2.8%	2.2%	
NVQ1/GSE or grade equiv	11.9%	11.9%	13.5%	12.7%	
No qualification	20.9%	18.8%	30.4%	24.9%	
	100% (3,213) [#]	100% (569) [#]	100% (3,840) [*]	100% (993) [*]	
Housing Tenure					
Own outright	57.8%	58.9%	59.0%	60.2%	
Own with mortgage or loan	24.6%	23.3%	20.7%	20.7%	
Private renting	4.9%	2.6%	3.9%	5.7%	P<0.050
Social renting	11.9%	15.1%	15.3%	12.8%	
Live rent free	0.8%	[-]	1.1%	0.5%	
	100% (3,313) [*]	100% (587) [*]	100% (3,909) [*]	100% (1,016) [*]	
Access to Car or Van					
Yes	87.6%	90.8%	80.0%	88.0%	
No	12.4%	9.2%	20.0%	12.0%	P=0.113
	100% (3,318) [*]	100% (587) [*]	100% (3,916) ^{***}	100% (1,017) ^{***}	
Non-pension Wealth Quintiles					
Poorest	18.4%	21.6%	21.7%	18.7%	
2 nd Quintile	19.3%	18.1%	21.0%	21.0%	
3 rd Quintile	20.0%	18.5%	20.2%	19.7%	P=0.242
4 th Quintile	20.3%	24.3%	18.8%	20.8%	
Wealthiest	21.9%	17.5%	18.3%	19.8%	
	100% (2,878) [*]	100% (482) [*]	100% (3,438) [#]	100% (855) [#]	
Region					
South of England	40.0%	38.7%	40.3%	39.6%	
London	12.3%	13.1%	10.8%	10.9%	P=0.469
North of England	47.7%	48.2%	48.9%	49.6%	
	100% (3,319) [#]	100% (587) [#]	100% (3,916) [#]	100% (1,017) [#]	

Weighted percentages, unweighted frequencies. Please note that the p-value on the right hand side of the table represents the statistical significance between male and female carers.

*** p<0.001, ** p<0.01, * P<0.05, Chi-Square test, # no statistical significance

Source: Author's analysis of the ELSA

4.3.3 Caregiving patterns by gender, the ELSA Wave 7

This section focuses solely on the carers identified in Wave 7. Table 22 provides a descriptive summary of the carers (n=1,604) and their caring patterns. The analysis is divided by gender, as evidence has shown a difference in the patterns of care provided by gender, such as women providing more hours of care per week (see sections 2.3.1.1 and 2.3.1.2). The next section presents the results and highlights the key gender differences.

Approximately 60% of carers provided care between 1 and 19 hours per week (light care), 17% provided care for between 20 and 49 hours per week (moderate care), 5% provided care for over 50 hours per week (heavy care) and 18% provided 24-hour care (168 hours per week). Female carers represented 63% of the light carers, 68% of the moderate carers, 69% of the heavy carers and 56% of 24-hour care providers. This lower difference between women and men providing 24-hour care might be due to men higher likelihood of being spousal carers and provide co-residential care, both which are associated with a higher intensity of care (see also section 4.3.3.1).

The majority of carers cared for one person (74%), and 16% provided care for 2 persons, 7% for 3 persons and 4% for over 4 persons. There was no statistically significant difference between the genders in the numbers of the persons cared for. This is contradictory to other studies, which have noted a significant difference between the gender and number of care-recipients (Vlachantoni, 2010).

The majority of carers provided extra-residential care (59%) and among co-residential carers 56% were female. Co-residential care was more prevalent among spousal carers and for high intensity carers (Carmichael and Ercolani, 2014) (see also section 2.3.1.1 and Figure 13). The interpretation and implications of these results are critically discussed in section 6.2.2.

Over a quarter (27%) of the carers provided care to a spouse or partner, and 23% provided care to a parent or parent-in-law, 15% to a grandchild and 6% to a dependent or independent child. 18% of the carers provided care to 'others', which included other relatives, friends and neighbours. The remaining 11% of the respondents cared for a combination of individuals simultaneously, for example a parent and a grandchild, see also Appendix C. There was no pronounced gender difference among those caring for a spouse or partner, however female carers provided the highest proportion of care to all the additional directions of care, see Table 22.

Table 22 Descriptive statistics: Informal carers, by sex, the ELSA wave 7

	All carers 100% (1,604)	Female carers 62.7% (1,017)	Male carers 37.7% (587)	P-value between sex
	% (N)	% (n)	% (n)	
Intensity of care				
1-19	59.7	59.8	59.3	
		62.9	37.1	100% (958)
20-49	17.1	18.4	14.9	
		67.5	32.5	100% (268)
50-167	5.2	5.7	4.4	P<0.050
		69.0	31.0	100% (81)
168	18.0	16.0	21.4	
		55.7	44.3	100% (277)
	100% (1,584)	100% (1,003)*	100% (581)*	
Number of people cared for				
1	73.9	72.5	76.2	
		61.6	38.4	100% (1,197)
2	15.8	16.4	14.8	
		65.1	34.9	100% (250)
3	6.5	6.3	6.7	P=0.111
		61.4	38.6	100% (96)
Over 4	3.8	4.7	2.3	
		77.4	22.6	100% (61)
	100% (1,604)	100% (1,017)#	100% (587)#	
Co-residing with care-recipient				
Yes	41.4	37.4	48.1	
		56.8	43.2	100% (669)
No	58.6	62.6	51.9	P<0.001
		67.0	33.0	100% (934)
	100% (1,603)	100% (1,017)***	100% (586)***	
Direction of care				
Spouse or partner	27.0	23.2	33.5	
		53.9	46.1	100% (480)
Parent(s) ¹	22.8	24.5	20.1	
		67.2	32.8	100% (315)
Child(ren)	5.9	5.7	6.3	P<0.001
		60.5	39.5	100% (87)
Grandchild(ren)	15.4	17.1	12.7	
		69.3	30.7	100% (270)
Others	18.0	18.5	17.2	
		64.4	35.6	100% (294)
Combinations	10.8	11.1	10.3	
		64.6	35.4	100% (158)
	100% (1,604)	100%** (1,017)	100%** (587)	

Weighted percentages, (unweighted frequencies). *** p<0.001, ** p<0.01, Chi-Square test, * P<0.05# no statistical significance; based on a Chi-Square test. ¹ or Parent-in-law(s).

Source: Author's analysis of the ELSA Wave 7

4.3.3.1 Caring characteristics by age, direction of care and the intensity of care, the ELSA Wave 7

Figure 13 shows the direction of care by the intensity of care (hours of care per week). The highest intensity of care was provided to a spouse (or partner), and 43% of spousal carers provided 24-hour care. Contrastingly, the lowest intensity of care (1-19 hours per week) was mainly provided to others (91%), parents/parents-in-law (76%) and to grandchildren (75%).

Evidence suggests that increased caring intensity is a risk factor for adverse effects on the carer's health (ONS, 2013c; Carmichael and Ercolani, 2016), see also section 2.3.1.3. This may place spousal carers at a higher health risk, furthermore as noted from Figure 14, spousal carers tend to be older. This is further explored in the following section and its significance is discussed in section 6.5.2.2.

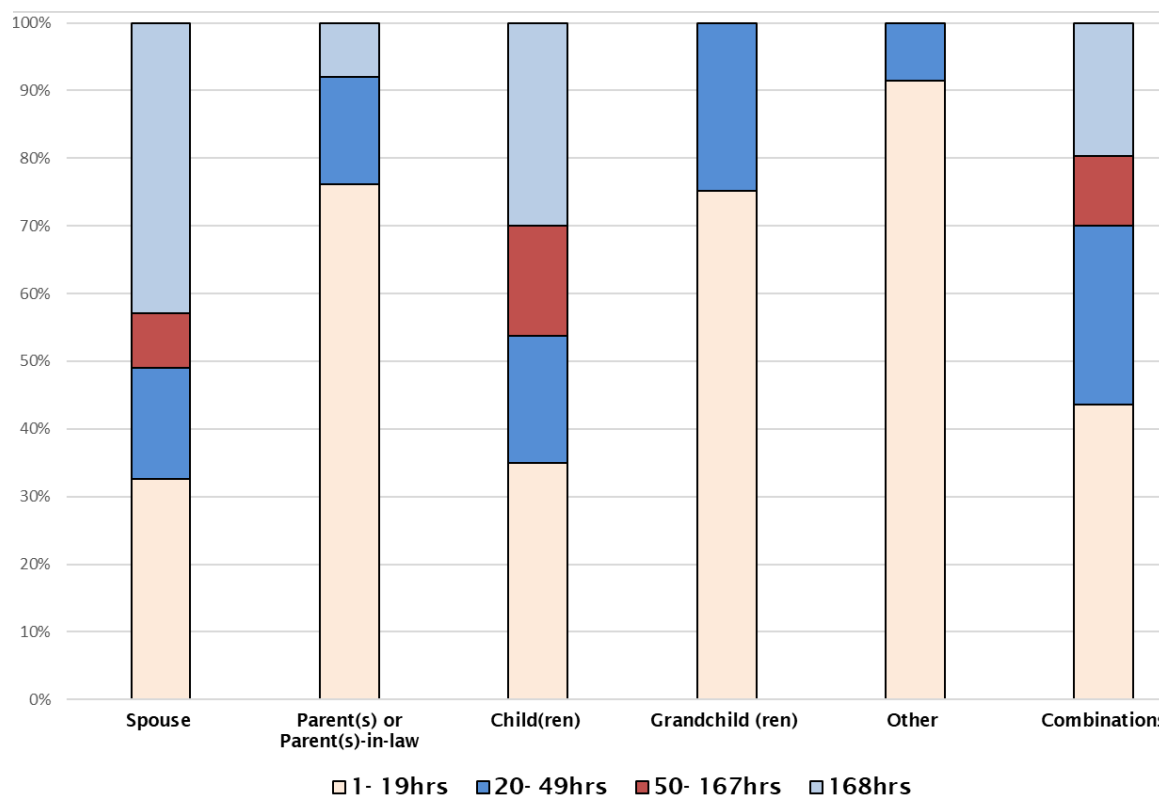


Figure 13 Percentage of carers by hours of care provided per week and direction of care, the ELSA Wave 7

Please note that the data was weighted and categories less than 5% were collapsed. $\chi^2=386.72$, $p<0.001$.

Source: Author's analysis of the ELSA.

Chapter 4

As noted in the literature review (section 2.3.1.2), there is an association between the carer's age and the direction of care (Vlachantoni, 2010). Figure 14 shows the distribution of the direction of care according to the age of the carer.

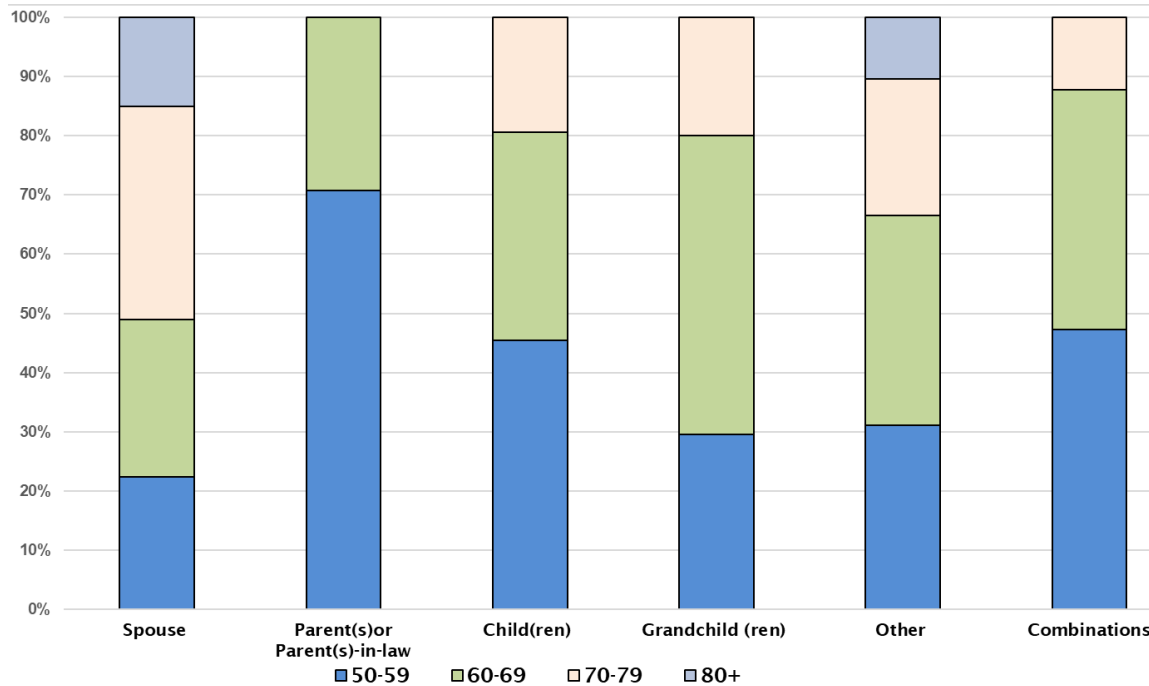


Figure 14 Percentage of carers by age and direction of care, the ELSA Wave 7 Please note weighted data was used and categories less than 5% were collapsed. $\chi^2=342.60$, $p<0.001$.

Source: Author's analysis of the ELSA.

Spousal carers were typically aged between 70 and 79 years, nevertheless, 15% of spousal carers were aged over 80. The lower proportion of spousal carers over 80, compared to those aged 70-79, is likely due to the passing of the care-recipient.

The largest proportion of parental carers was found among those aged between 50 and 59 (71%). As expected, no parental carers were aged over 70, as the likelihood of one's parent being alive is limited.

Among the carers of grandchildren, the majority were aged 60 to 69, likely associated with the carers' retirement, as well as the timing of other life-events over the life-course, see also sections 2.2.1 and 2.3.2.3. Further analysis of the transitions into and out of care and transitions between directions of care is conducted in *Phase II and III*.

The analysis of the direction of care by the intensity and age, revealed that among carers providing 24-hour care for a spouse, 18% were aged 50-59, 23% were aged 60-69, 39% were aged 70-79 and 20% were aged over 80. It was also noted that among the younger carers who provided 24-hour care, the distributed between providing spousal, child and parental care was more evenly, although spousal care was still remained the highest proportion. This again highlights the intensity of

spousal care, especially among the oldest carers. The implication of this is critically discussed in section 6.2.1.2. The detailed cross-tabulation of the direction of care by intensity can be found in Appendix S.

Seen from Figure 15 all spousal carers were married, this was similar for all other caring directions. For carers of 'others' although 53% were married, 10% were single, 20% divorced and 17% widowed. This finding give rise to support the theory that being married allows for the support to provide care (see also section 2.3.1.2). This is further discussed in section 6.2.1.3.

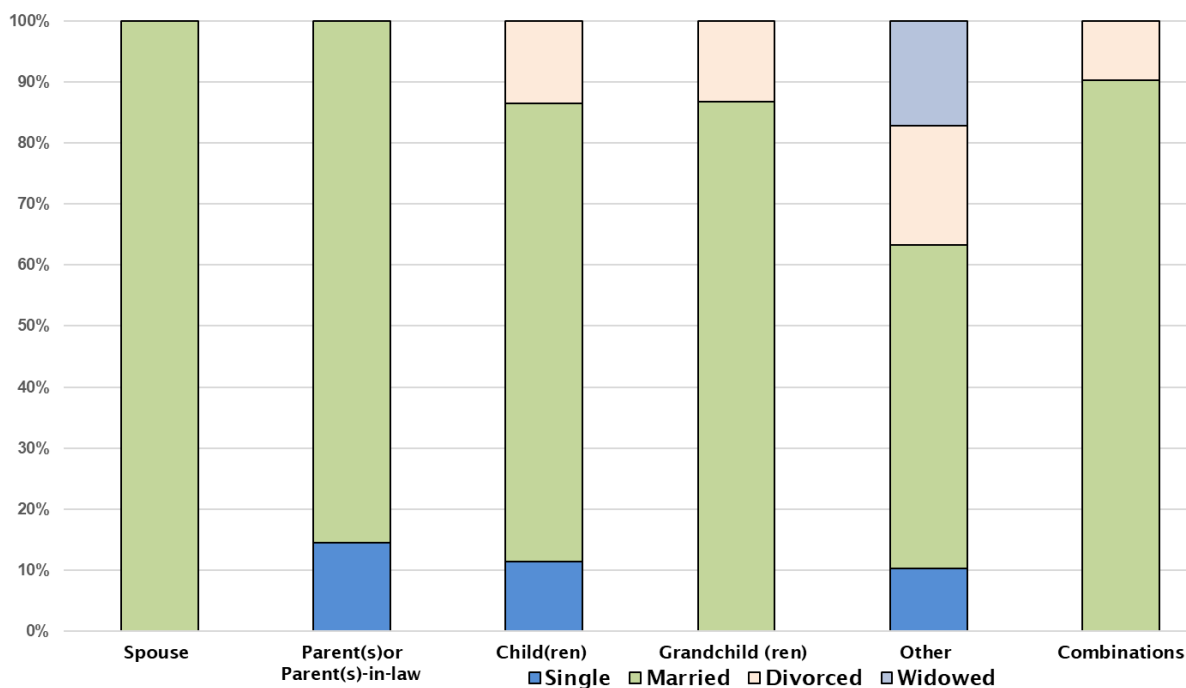


Figure 15 Percentage of carers by marital status and direction of care, the ELSA Wave 7

Please note weighted data was used and categories less than 5% were collapsed. $\chi^2=300.32$, $p<0.001$. Source: Author's analysis of the ELSA

Chapter 4

The living arrangements are associated with both the direction of care and its intensity (Carmichael and Ercolani, 2014). Figure 16 shows that the majority of light and moderate care was extra-residential. This was contrasted by co-residential care, which was associated with heavy care provision and 24-hours care. This may not be surprising, as Figure 13 showed that spousal care made up the majority of the heaviest intensity of care provided.

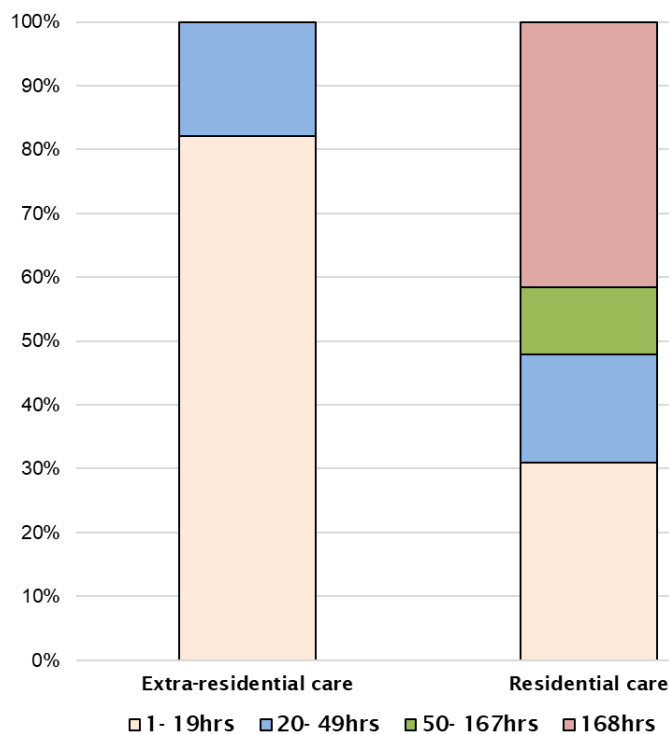


Figure 16 Percentage of carers providing either extra-residential care or co-residential care by the intensity of care, the ELSA Wave 7

Weighted data and categories less than 5% were collapsed. $\chi^2=466.23$, $p<0.001$.

Source: Author's analysis of the ELSA Wave 7

Figure 17 depicts the direction of care by living arrangement. The majority of the co-residential care was spousal care (66%), while most extra-residential care was provided to a parent or parents-in-law (46%) and others (38%). Among carers providing co-residential and light care (1 to 19 hours/week), 62% provided this to a spouse (partner). The majority of carers providing care to co-residing parents or parents-in-law did so for 24-hours a-day (53%), followed by a sizable proportion who provided light care (31%). This could indicate that co-residential parental care may only be provided when the need of the parent becomes the highest, see also section 2.3.1.1.

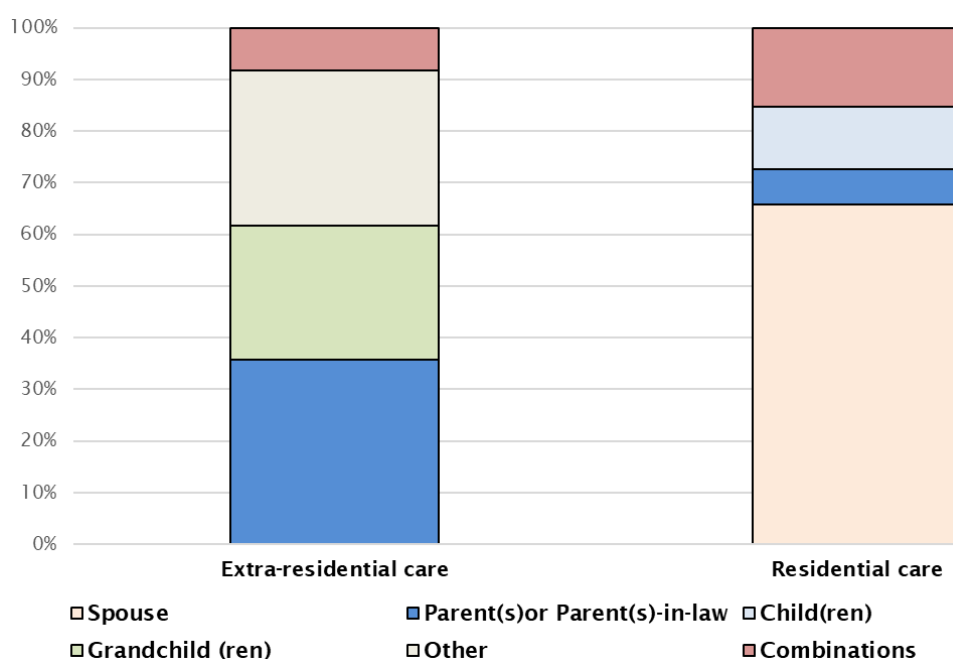


Figure 17 Percentage of carers providing either extra-residential care or co-residential care by direction of care, the ELSA Wave 7

Please note weighted data was used and categories less than 5% were collapsed.

$\chi^2=875.00$, $p<0.001$.

Source: Author's analysis of the ELSA.

An analysis of the difference in carer's health by direction of care and by sex (see the graph in Appendix F) and it was found that parental carers reported better health, compared to carers of all other individuals. Spousal carers were seemingly in poorer health, than carers of all others, whereas no carers of grandchildren reported poor health. Male compared to female carers generally reported their health to be fair or poor, with the exception of providing care to a child, it is however important to remember, that the chart was not been controlled for age³, which may have confounded the results (see also section 3.3.2.3).

³ The mean age of spousal carers was 70 years, parental carers 60 years, carers for others 68 years, carers for grandchildren 65 years, carers for children 64 years, and for carers for a combination it was 63 years old.

4.3.4 Summary of the descriptive statistical *Phase I* analysis of the ELSA population Wave 7

The descriptive analysis aimed to answer Research Question 1 '***Who are the informal carers in England?***' The sample of the ELSA Wave 7 consisted of 8,839 individuals, 18% of whom answered yes to having provided care for someone in the previous week. The mean age of the carers was 64 years and the majority of carers were females. Most carers were married, retired and living in their own house, which they had paid for outright. Most of the SES measures did not show statistically significant differences between carers and non-carers. The carers were in better overall health than non-carers, which may suggest a '*healthy carer effect*'.

Research Question 1.a asked '***How do the socio-demographic, socio-economic and health characteristics of respondents in the ELSA differ between carers and non-carers, and between women and men?***' and gender differences in the characteristics of the carers were in fact observed. Female carers were younger than male carers, and more female carers lived in either single households or with extended family, whereas most male carers were married and lived in coupled households. Among carers who were employed, male carers worked longer hours than female carers. Research Question 1.b asked about gender differences in the carers' characteristics. This analysis showed that female carers provided more hours of care, compared to male carers, with the exception of 24-hour care. Care provided to a spouse was associated with a higher intensity of care, whereas care provided to a parent (parent-in-law) was of lower intensity. Moreover, spousal carers were older than carers providing for any other directions of care, which may imply that spousal care poses a relatively heavy burden on the care provider (Wanless *et al.*, 2006).

The following section presents the binary logistic regression analysis, which explores the predictors of informal care provision.

4.4 The predictors of care provision, *Phase I*

This section presents the binary logistic regression analysis of the ELSA Wave 7. A total of 4 models are shown; 1) the overall sample, 2) female respondents only, 3) male respondents only and 4) informal carers only.

Research Question 1.c explores the differences in the determinants of care provision between men and women, in accordance with evidence, see examples of this in sections 1.2 and 2.3.1.2. For example, Glauber (2016) and Vlachantoni (2010) noted that women were more likely to provide care at a higher intensity than men. Moreover, the same two authors noted that women were more likely to provide care for a range of care-recipients, whereas men were more likely to provide care for a spouse. In order to ensure gender does not confound the results, the analysis was divided with a separate model for male and female respondents.

In addressing Research Question 1.d, Model 4 only included carers and explored the factors associated with providing more than 20 hours of care per week, the methodology is explained in section 4.4.1.3. The literature review highlighted that the intensity of care is associated with the different characteristics of the carer (O'Reilly *et al.*, 2008; Carmichael and Ercolani, 2014; Drinkwater, 2015) (see also section 2.3.1.1). As also discussed in sections 3.3.2.4 and 4.3.3.1, providing care for over 20 hours per week, compared to less hours may increase the adverse effect for the carer (Carmichael and Ercolani, 2016). Furthermore, providing over 20 hours could require more time availability of the carer, including working less hours (Drinkwater, 2015), have fewer family commitments (Brandt *et al.*, 2009) and finally be in better health (Carmichael and Ercolani, 2014), than providing care for less than 20 hours per week.

A correlation matrix of the overall sample was produced to check for multicollinearity and the results indicated mostly a weak correlations between most of the independent variables, see Table 23. However, a strong negative correlation was observed between work status and age ($r=-0.57$, $p<0.001$), this indicates an interaction between being retired and older age. There was also a strong positive correlation between housing tenure and wealth ($r= 0.58$, $p<0.001$), which suggests an association between owing one's house outright and being in the wealthiest quintile. A strong positive correlation was noted between SRH and LLTI. This suggests that individuals are more likely to rate their poor SRH if also suffering a LLTI, and vice versa. Lastly, a strong correlation was observed between the report

Chapter 4

of difficulties with ADLs and IADLs ($r= 0.60$, $p<0.001$), see also section 3.3.2.3. All of the above-mentioned correlations were statistically significant.

The results of the correlations matrix for females and males respondents separately and for carers only (see Appendix I, Appendix J and Appendix K), showed a similar pattern as for the combined sample. However, female respondents had a strong negative correlation between household type and marital status ($r= -0.51$, $p<0.001$).

The binary regression results tables presents the odds ratio (OR), the 95% confidence interval (CI) and the p-values for each of the independent variables. Below each block, the -2LLR, the change in -2LLR between each block and the statistical significance thereof, as well as the Hosmer & Lemeshow goodness-of-fit test, the chi-square and p-value of the overall model are presented (see also section 3.4).

Table 23 Correlation matrix: All respondents, the ELSA Wave 7

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Age	1.00															
2. Sex	.036**	1.00														
3. Ethnicity	-.123**	-.027**	1.00													
4. Marital status	.201**	.188**	-.021*	1.00												
5. Household type	-.272**	-.107**	.115**	-.407**	1.00											
6. Work status	-.565**	.029**	.117**	-.136**	.201**	1.00										
7. Education	-.126**	-.130**	.000	-.123**	.102**	.027*	1.00									
8. Tenure	-.306**	.000	.112**	.043**	.000	.286**	-.129**	1.00								
9. Wealth	-.089**	.053**	.039**	.151**	-.132**	.133**	-.322**	.582**	1.00							
10. Access to car	.085**	.095**	.038**	.158**	-.262**	-.026*	-.181**	.236**	.313**	1.00						
11. Region	-.010	.010	.010	.020	-.010	.020	-.069**	.030**	.243**	.055**	1.00					
12. SRH	.150**	.044**	.057**	.113**	-.109**	-.031**	-.172**	.130**	.260**	.186**	.053**	1.00				
13. LLTI	.195**	.054**	-.023*	.104**	-.124**	-.094**	-.127**	.063**	.202**	.170**	.051**	.512**	1.00			
14. Difficulties with ADLs	.150**	.042**	.000	.126**	-.102**	-.043**	-.127**	.091**	.187**	.167**	.043**	.367**	.406**	1.00		
15. Difficulties with IADLs	.144**	.103**	-.006	.160**	-.145**	-.045**	-.154**	.091**	.201**	.220**	.054**	.387**	.445**	.596**	1.00	
16. Care provided	-.030**	.092**	-.010	-.083**	.090**	.053**	.030**	-.010	-.000	-.054**	.000	-.010	.000	-.056**	-.026*	1.00

0.5-1.0	Strong correlation
0.3-0.4.9	Moderate correlation
0.1-0.2.9	Weak correlation
0-0.99	Very weak or no correlation
	Not statistically significant

*. Correlation significant p< 0.05, ** Correlation significant p<0.01 level. See Appendix H for label values. SHR: Self-reported health, LLTI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living. Source: Author’s own analysis of the ELSA Wave 7.

4.4.1.1 Phase I MODEL 1: Predictors of care provision

Model 1 included all respondents and the dependent variable was whether the respondent was a carer or not (non-carers acted as the reference). This section provides further description of the modelling strategy of Model 1 and how the independent variables were chosen.

Table 24 shows the comparison of the ‘forced entry’ and ‘backward elimination’ method (see also section 3.4 for more information of these methods). The forced entry model was selected, as this performed better based on the -2LLR. Moreover, the backwards elimination omitted gender, however the literature review reiterated the importance of gender in informal care provision and it was therefore judged that this variable needed to be included in the model.

Table 24 Method comparison **Model 1**: All respondents, the ELSA Wave 7

Variables (final model)	Forced entry	‘Backward’ elimination
Gender	√	Omitted
Age	√	√
Marital status	√	√
Household type	√	√
SRH	√	√**
Difficulties with ADLs	√	√
Difficulties with IADLs	√	√
Education	√	√*
Wealth	√	√
Housing tenure	Omitted	√
Access to car	√	√
-2LLR	6257.47	6586.40

√: kept in the model. * only one category was significant ** only good health (the reference category was statistically significant).

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living.

Source: Author’s own analysis of the ELSA Wave 7.

Ethnicity was excluded from all blocks, due to a lack of statistically significant results in the preliminary analysis tests, moreover the correlation matrix showed ethnicity was not statistically significant correlated with care provision (Table 23, Appendix I, Appendix J and Appendix K). Region was also excluded from the analysis, as it was found not to be statistically significant in preliminary test models or in the correlation matrices. Lastly, a strong positive correlation between LLTI and SRH was noted. Pre-tests showed LLTI to have no statistical significance, whereas SRH did, therefore LLTI was excluded from the model.

The model was also tested for various interactions (see also section 3.4). The interaction effect is the combined effect that the two dependent variables have on the independent variable, and adding an interaction term can greatly expand the understanding of any associations noted (Field, 2005). Interactions between SRH and age; work status and age; housing tenure and wealth were tested, however none of these were found to be statistically significant and were therefore not included in the model. The interaction between SRH and age was based on a theoretical reason of the known negative association between the two variables (i.e. health is likely to deteriorate with age (OECD, 2003)) (see also section 3.3.2.3). Therefore, any effect of health may be amplified due to the age of the sample population used in this study. The interaction between work status and age was based on results from the correlation matrix, which noted a strong negative correlation between the two ($r = -0.57$, $p < 0.01$), see also Table 23. The interaction between housing tenure and wealth was also based on the results of the correlation matrix ($r = 0.82$, $p < 0.01$), which implied that an individual who owned their house outright, would also be wealthier. The interaction may therefore wrongly estimate the effect of home ownership on the likelihood of providing care, see also section 3.3.2.2.

The final model (see Table 25) used forced entry and excluded housing tenure, as this variable was not statistically significant, furthermore housing tenure was noted to be strongly positively correlated with wealth, which raised concerns of multicollinearity.

Table 25 Modelling strategy **Model 1**: Informal care provision – all respondents, the ELSA Wave 7

Block 1	Block 2	Block 3	Block 4	Block 5	Block 6	Block 7	Block 8	Block 9	Final model
Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender
Age	Age	Age	Age	Age	Age	Age	Age	Age	Age
Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status
	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type
		SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH
			ADLs*	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs
			IADLs**	IADLs	IADLs	IADLs	IADLs	IADLs	IADLs
			Work status	Work status	Work status	Work status	Work status	Work status	Work status
			Education	Education	Education	Education	Education	Education	Education
				Wealth	Wealth	Wealth	Wealth	Wealth	Wealth
					Housing tenure	Housing tenure	Housing tenure	Housing tenure	Omitted
						Access to car	Access to car	Access to car	Access to car

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living. *Difficulties with ADL, ** Difficulties with IADL.

Source: Author's own

Table 26 provides a summary of Model 1: block 2, which contained all the demographic variables; block 5, which added the health variables; and block 10, which contained all the socio-economic variables and the refined model. The full model displaying all blocks can be found in Appendix T (see section 3.4 for general description data analysis strategy).

The final model contained 11 independent variables: gender, age, marital status, household type, SRH, numbers of ADLs and IADLs, work status, education, wealth quintiles and access to car. The model was statistically significant ($\chi^2 = 438.10$, $p < 0.001$) with a 3.4% change to the -2LLR from the base block. This indicates that the independent variables significantly predicted the dependent variable of providing care.

The final model confirmed the relationship between gender and caring noted in the literature review (Pickard, 2015; Robards *et al.*, 2015; Glauber, 2016) (section 2.3.1.2), as the odds of male providing care were lower than for females (OR 0.66, $p < 0.001$). As expected, as the age ranges increased the odds of providing care decreased, and respondents aged over 80, had the lowest odds of providing care (OR 0.51, $p < 0.001$), compared to those aged 50-59.

Those who were divorced or widowed also had reduced odds of providing care, compared to the reference category (OR 0.55, $p < 0.01$, equally). The odds of providing care were reduced if living in a single household compared to a coupled household (OR 0.56, $p < 0.01$), whereas living in a single household with a child (i.e. no other adult) increased the odds of providing care (OR 1.48, $p < 0.05$). Living in an extended household also increased the odds of care provision (OR 1.40, $p < 0.05$, block 2), however this was no longer significant once controlled for health and socio-economic characteristics. The relationship of both marital status and family structure with care provision is critically discussed in section 6.2.1.3.

Being in poor SRH decreased the odds of providing care compared to being in good health (OR 0.71, $p < 0.05$), and likewise respondents who had difficulties with more than 2 ADLs compared to none, also had lower odds of providing care (OR 0.51, $p < 0.001$). Respondents who had difficulty with 1 IADL had higher odds of providing care (OR 1.36, $p < 0.01$) compared to having no IADL difficulties. The complex relationship between care provision and health is discussed in section 6.3.4.

The economic activity was introduced in block 6 (see also Appendix T), and this made the age variable become statistically significant. Moreover, respondents

Chapter 4

who were employed full-time, compared to retired persons, had decreased odds of providing care (OR 0.44, $p < 0.001$). Being economically inactive significantly increased the odds of providing care compared to being retired (OR 1.54, $p < 0.001$). The influence on age, may be due to the association between work and age, as younger age groups are more likely to work (ONS, 2017b), see also section 2.3.1.4.

Higher education levels increased the odds of providing care, for example the odds of someone with higher than an A-level education compared to no education providing care was 1.23 times higher. *Ceteris paribus*, those in wealthier quintiles had decreased odds of providing care, compared to those belonging to the poorest quintile. Not having access to a car or van decreased the odds of providing care, compared to having such access (OR 0.75, $p < 0.01$). This may imply the necessity of transportation in order to provide care, rather than as a proxy of SES (see also section 3.3.2.2).

Table 26 Logistic regression **Model 1**: Predictors of care provision – all respondents, the ELSA Wave 7

	Block 2	Block 5	Block 10	Final Model
Sex				
Female (Ref.)	1.00***	1.00***	1.00***	1.00***
Male	0.55*** (0.50 - 0.64)	0.56*** (0.50 - 0.64)	0.66*** (0.58 - 0.76)	0.66*** (0.58 - 0.76)
Age				
50-59 (Ref.)	1.00***	1.00**	1.00***	1.00***
60-69	0.99 (0.85 - 1.18)	0.98 (0.84 - 1.15)	0.80* (0.66 - 0.96)	0.82* (0.68 - 0.98)
70-79	0.89 (0.74 - 1.07)	0.88 (0.73 - 1.06)	0.67** (0.53 - 0.85)	0.68** (0.54 - 0.86)
>80	0.60*** (0.46 - 0.78)	0.62*** (0.47 - 0.81)	0.51*** (0.37 - 0.69)	0.51*** (0.38 - 0.70)
Marital Status				
Married (Ref.)	1.00***	1.00***	1.00***	1.00**
Single	0.78 (0.56 - 1.08)	0.8 (0.58 - 1.12)	0.78 (0.56 - 1.10)	0.78 (0.56 - 1.10)
Divorced	0.54*** (0.40 - 0.73)	0.55*** (0.41 - 0.74)	0.56*** (0.41 - 0.76)	0.55*** (0.40 - 0.75)
Widowed	0.50*** (0.35 - 0.71)	0.50*** (0.35 - 0.72)	0.56** (0.39 - 0.81)	0.55** (0.38 - 0.80)
Household Type				
Couple (Ref.)	1.00***	1.00***	1.00***	1.00***
Couple plus children	0.85 (0.71 - 1.02)	0.85 (0.71 - 1.02)	0.85 (0.71 - 1.03)	0.84 (0.70 - 1.02)
Single	0.60** (0.44 - 0.83)	0.59** (0.43 - 0.81)	0.55*** (0.39 - 0.76)	0.56** (0.40 - 0.78)
Single plus children	1.66** (1.12 - 2.40)	1.63** (1.13 - 2.36)	1.46 (1.00 - 2.14)	1.48* (1.01 - 2.17)
Extended Family	1.40* (1.04 - 1.88)	1.41** (1.05 - 1.90)	1.38* (1.01 - 1.87)	1.32 (0.97 - 1.79)
Self-reported Health				
Good (Ref.)		1.00*	1.00**	1.00*
Fair		1.16* (1.02 - 1.33)	1.08 (0.94 - 1.24)	1.08 (0.94 - 1.25)
Poor		0.89 (0.66 - 1.20)	0.70* (0.51 - 0.96)	0.71* (0.52 - 0.97)
Difficulties with ADLs				
None (Ref.)		1.00**	1.00***	1.00***
1 ADL		0.87 (0.67 - 1.12)	0.81 (0.62 - 1.05)	0.81 (0.62 - 1.05)
Over 2 ADLs		0.56*** (0.40 - 0.77)	0.50*** (0.36 - 0.70)	0.51*** (0.36 - 0.70)
Difficulties with IADLs				
None (Ref.)		1.00**	1.00**	1.00**
1 IADL		1.45** (1.15 - 1.82)	1.36** (1.08 - 1.71)	1.36** (1.08 - 1.72)
Over 2 IADLs		1.01 (0.75 - 1.37)	0.87 (0.64 - 1.18)	0.88 (0.64 - 1.19)

Table 26 (Continued)	Block 2	Block 5	Block 10	Final Model
Economic Activity				
Retired (Ref.)			1.00***	1.00***
Employed (Full-time ≥ 35)			0.45*** (0.36 - 0.57)	0.44*** (0.35 - 0.55)
Employed (Part-time < 35)			0.94 (0.77 - 1.15)	0.93 (0.76 - 1.13)
Economic inactive			1.54*** (1.22 - 1.93)	1.54*** (1.22 - 1.93)
Education				
Less than O-level or equivalent (Ref.)			1.00**	1.00**
O-level or equivalent			1.23 (1.05 - 1.44)	1.22** (1.05 - 1.42)
Higher than A-level			1.25 (1.06 - 1.48)	1.23** (1.04 - 1.46)
Wealth Quintiles				
Poorest (Ref.)			1.00*	1.00**
2nd Quintile			1.01 (0.72 - 1.41)	0.86 (0.70 - 1.06)
3rd Quintile			0.91 (0.63 - 1.30)	0.78* (0.63 - 0.97)
4th Quintile			0.87 (0.61 - 1.25)	0.76* (0.60 - 0.95)
Wealthiest			0.72 (0.50 - 1.04)	0.62*** (0.49 - 0.79)
Housing Tenure				
Own outright (Ref.)			1.00	
Own with mortgage			0.87 (0.72 - 1.06)	
Renting, social			1.13 (0.75 - 1.72)	Omitted
Renting, private			1.22 (0.85 - 1.75)	
Live rent free			0.50 (0.20 - 1.27)	
Access to Car or Van				
Yes (Ref.)			1.00***	1.00***
No			0.74 (0.59 - 0.92)	0.75** (0.60 - 0.93)
-2LLR	6421.77	6385.22	6249.40	6257.47
% Change -2LLR		0.16%**	0.12%**	3.37%** #
Hosmer & Lemeshow Test	$\chi^2=16.51, p=0.036$	$\chi^2=18.20, p=0.020$	$\chi^2=14.52, p=0.069$	$\chi^2=8.74, p=0.365$
Chi-square overall model	$\chi^2=271.67, p<0.001$	$\chi^2=308.25, p<0.001$	$\chi^2=444.07, p<0.001$	$\chi^2=438.10, p<0.001$

Weighted data. # Percentage change from base (block 1), see Appendix T. *Significant at the 0.05 level, ** Significant at the 0.01 level, *** Significant at the 0.001 level. ADL: Activities of daily living, IADL: Instrumental activities of daily living. Source: Author's own analysis of the ELSA Wave 7

4.4.1.2 *Phase I* MODELS 2 and 3: Predictors of care provision by sex

Models 2 and 3 added each variable to the block one at a time (with the exception of block 1 and final model). Table 27 shows the preliminary tests results compared forced entry to backwards entry. The forced entry approach was used for both genders, as it was judged to have the best overall fit. For the male sample ethnicity was excluded from the model, but it was included for females, as it was noted to be statistically significant.

The final model for females (see Table 27 and Table 28) excluded household type, wealth, access to car and LLTI. As there is a strong correlation between household type and marital status (see also Appendix I), it was decided to include only marital status to avoid concerns of multicollinearity. Similarly wealth and housing tenure were correlated, and as only housing tenure was noted to be statistically significant in the preliminary test, this variable was maintained in the model. The report of a LLTI was excluded based on similar reasons explained in the overall model, and concerns of multicollinearity with SRH. The variable 'access to a car' showed no statistical significance and the effect of this variable (based on the -2LLR) was minimal; the variable was therefore excluded. An interaction term was included between SRH and age, and although a statistically significant effect was noted, this was only for the categories 'good' and 'fair' health. When compared to the model without the interaction term, the odds of people in different health states providing care, remained in the same direction (negative). Moreover, the strength of the odds ratios for the two models was comparable, it was therefore decided not to include the interaction term, in order to have a simpler model which is easier to interpret.

The final model for males excluded: age, SRH and housing tenure due to a lack of statistical significance (Table 27 and Table 29). Furthermore, housing tenure was noted to be strongly positively correlated with wealth, raising concerns of multicollinearity (see Appendix J), as a result, housing tenure was excluded.

Table 27 Method comparison **Model 2**: Female and male respondents, the ELSA Wave 7

Variables (final model)	Female		Male	
	Forced entry	'Backward' elimination	Forced entry	'Backward' elimination
Age	√	√	Omitted	Omitted
Ethnicity	√	Omitted	Not included	Not included
Marital status	√	√ [#]	√	√
Household type	√	√	√	√
SRH	√	√	Omitted	Omitted
LLTI	Omitted	Omitted	Not included	Not included
Difficulties with ADLs	√	√	√	√
Difficulties with IADLs	Omitted	Omitted	√	√
Work status	√	√	√	√
Education	Omitted	Omitted	√	√
Wealth	Omitted	Omitted	√	√
Housing tenure	√	√	Omitted	√
Access to car	Omitted	√	√	√
-2LLR	3943.16	3635.52	2564.97	2546.30

√: kept in the model. [#]Not statistically significant.

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living. The variable 'not included' was never included in the model due to either multicollinearity with other variables or found in preliminary analysis not to have an effect.

'Omitted variable were included, but excluded in the final model, due to lack of statistical significance.

Source: Author's own analysis of the ELSA Wave 7.

Table 28 Modelling strategy **Model 2**: Informal care provision - female respondents, the ELSA Wave 7

Block 1	Block 2	Block 3	Block 4	Block 5	Block 6	Block 7	Block 8	Block 9	Block 10	Block 11	Final model
Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age
Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity
Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status
	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type
		SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH
			LLTI	LLTI	LLTI	LLTI	LLTI	LLTI	LLTI	LLTI	Omitted
				ADLs*	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs
					IADLs**	IADLs	IADLs	IADLs	IADLs	IADLs	Omitted
						Work status	Work status	Work status	Work status	Work status	Work status
							Education	Education	Education	Education	Omitted
								Wealth	Wealth	Wealth	Omitted
									Housing tenure	Housing tenure	Housing tenure
										Access to car	Omitted

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living. *Difficulties with ADL, ** Difficulties with IADL.

Source: Author's own

Table 29 Modelling strategy **Model 2**: Informal care provision – male respondents, the ELSA Wave 7

Block 1	Block 2	Block 3	Block 4	Block 5	Block 6	Block 7	Block 8	Block 9	Block 10	Block 11	Final model
Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Omitted
Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status
	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type
		SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH	Omitted
		ADLs*	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs
		IADLs**	IADLs	IADLs	IADLs	IADLs	IADLs	IADLs	IADLs	IADLs	IADLs
			Work status	Work status	Work status	Work status	Work status	Work status	Work status	Work status	Work status
				Education	Education	Education	Education	Education	Education	Education	Education
					Wealth	Wealth	Wealth	Wealth	Wealth	Wealth	Wealth
						Housing tenure	Housing tenure	Housing tenure	Housing tenure	Housing tenure	Omitted
							Access to car	Access to car	Access to car	Access to car	Access to car

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living. *Difficulties with ADL, ** Difficulties with IADL.
Source: Author's own

Figure 18 and Figure 19 show little difference between the genders in the likelihood of providing care in terms of marital status, employment and education. However, there were key differences in the determinants of care provision between female and male carers in terms of age, SHR, difficulties with IADLs and wealth. For men, neither age, SRH nor wealth were statistically significant determinants of care provision, whereas these variables were significant for women. Men who had difficulty with 1 IADL had increased odds of care provision, whereas for women having difficulty with 1 IADL decreased such odds.

As seen from the change in the -2LLR of the two models, the included variables fitted the male respondents better than the variable included did for females, and as discussed in section 4.4.1.2. This could imply that for women other factors than those analysed, are more important in predicting informal care provision. As also seen from Figure 18 and Figure 19, some categories had relatively wide CIs, and particularly for the categories 'lone, plus children', 'extended families', and for females 'live rent free' and males 'economic inactive'. This suggests a small cell count (see also Table 21) and caution should be taken when interpreting the results. This limitation is discussed in section 6.4.

The next binary logistic regression only includes the informal carers identified in the ELSA Wave 7 and aims to determine the odds of providing over 20 hours of care per week.

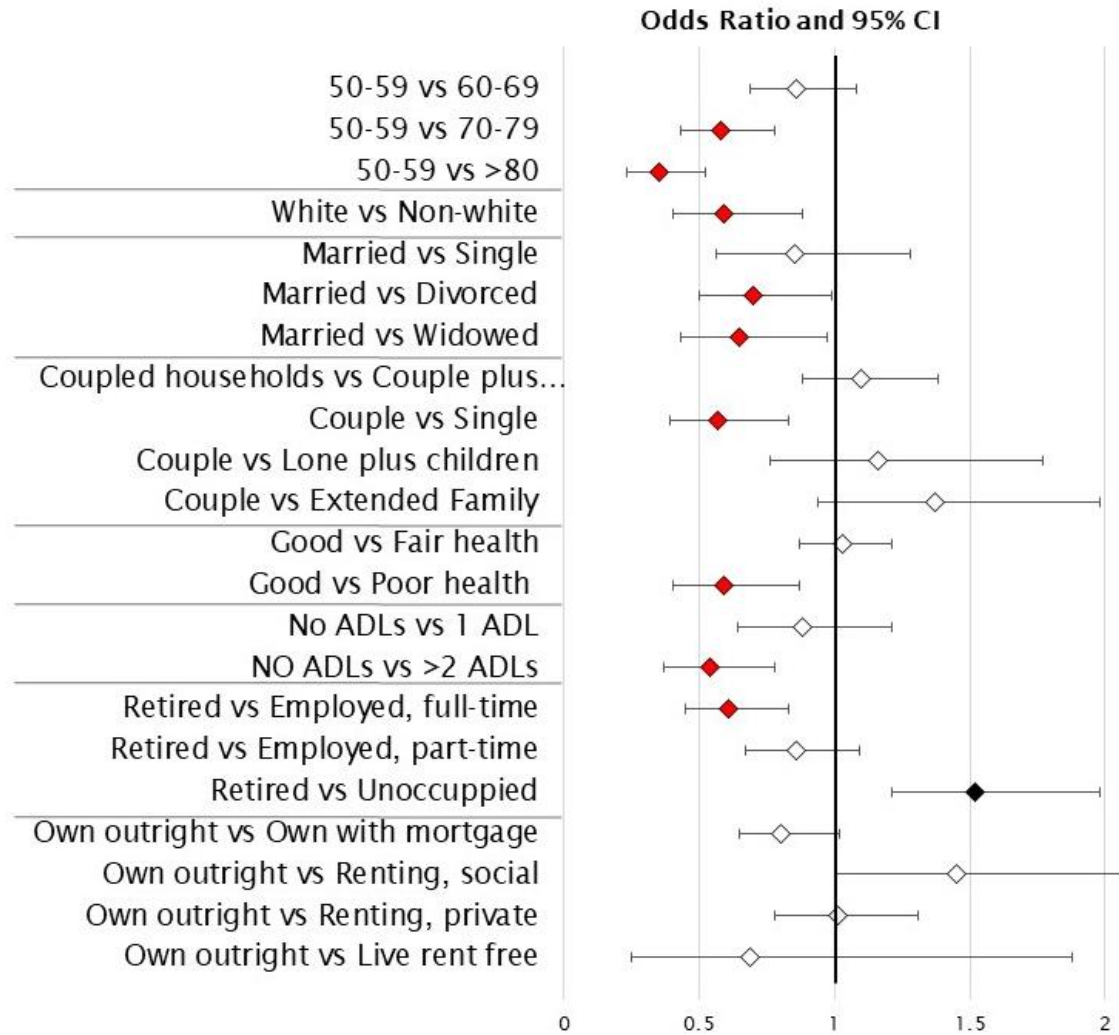


Figure 18 Forest plot of the predictors of care provision – female respondents, the ELSA Wave 7.

Red diamond: lower statistically significant odds; Black diamond: higher statistically significant odds; white diamond: not statistically significant. - 2LLR=3943.16, -5.05% change from base model, overall model: $X^2=254.67$, $p<0.001$. See Appendix U for full model.

Source: Author’s own analysis of the ELSA Wave 7.

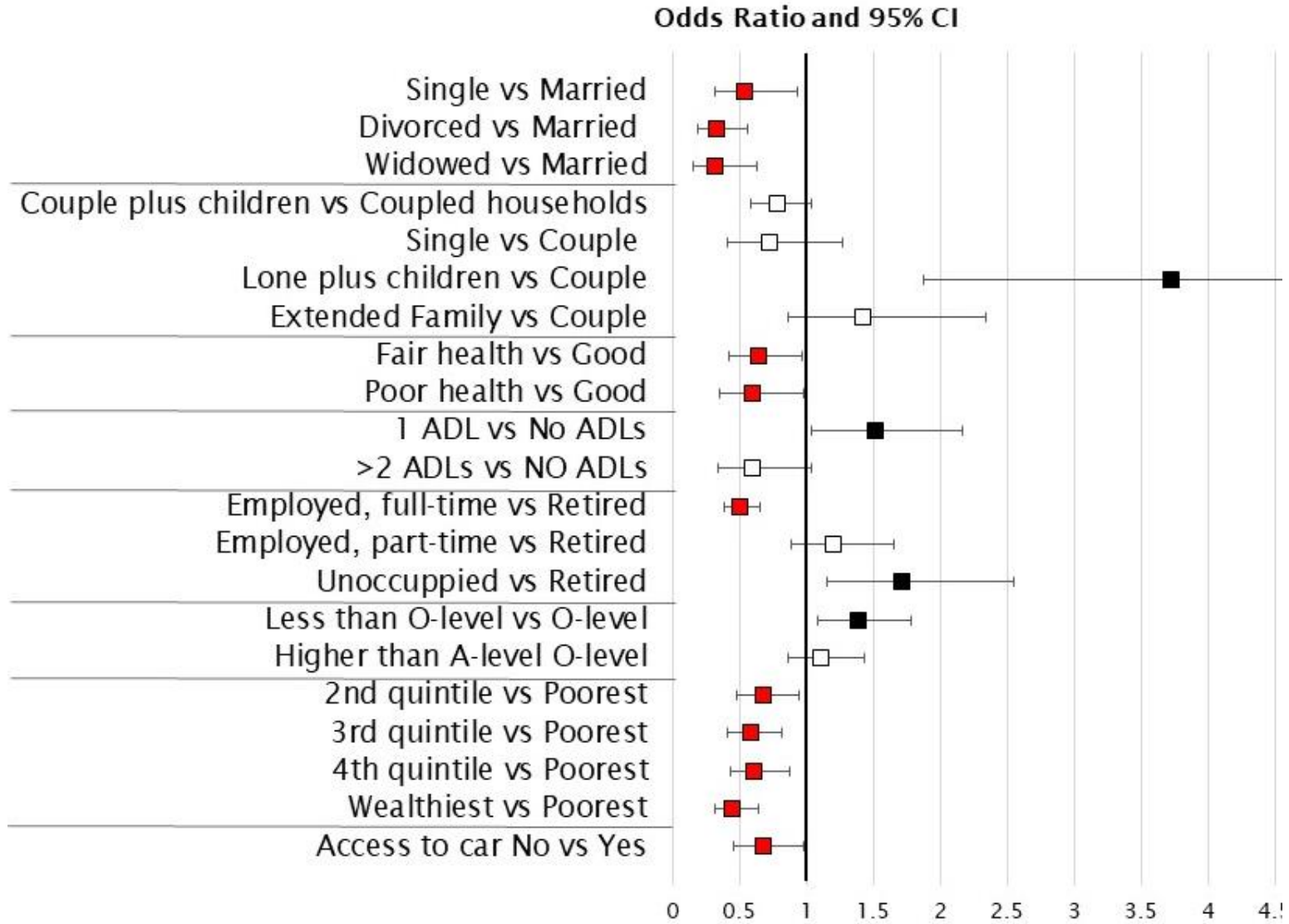


Figure 19 Forest plot of the predictors of care provision – male respondents, the ELSA Wave 7

Red squares: lower statistically significant odds; Black squares: higher statistically significant odds; white squares: not statistically significant. -2LLR=2564.97, 4.73% change from base model, overall model: $\chi^2=167.27$, $p<0.001$. See Appendix V for full model.

Source: Author’s own analysis of the ELSA Wave 7.

4.4.1.3 *Phase I* MODEL 4: Predictors of higher intensity of care provision

Respondents who were informal carers in Wave 7 were selected for this binary regression model (both male and female). The binary outcome was whether the carer had provided care for 20 hours or more per week compared to 19 hours or less per week. The literature review highlighted that the intensity of care is associated with the different characteristics of the carer (O'Reilly *et al.*, 2008; Carmichael and Ercolani, 2014; Drinkwater, 2015) (see also sections 2.3.1.1 and 4.4). This model aimed to answer Research Question 1.b, exploring the differences in the care intensity in terms of gender, age, to who and where the care is provided (see also section 1.2 and section 2.3.1.1).

A sensitivity test was carried out to test the robustness of using 20 hours of care per week as the threshold. Alternative thresholds were explored, such as ≥ 10 hours/week and ≥ 35 hours/week, however the results did not influence the results or the statistical significance, which indicates that the results remain robust. See also section 3.6.1 for justification of the alternative threshold and Appendix E for results.

As with the three other models, each variable (with the exception of block 1 and the final model) was added to the block one at a time. The final model (Table 30) used forced entry and excluded gender, ethnicity, education and access to a car, as these were noted not to be statistically significant. Housing tenure was also excluded, as this variable was not statistically significant, furthermore housing tenure was strongly and positively correlated with wealth, which raised concerns of multicollinearity (see also Appendix K). The only statistically significant health variable was SRH. The full model contained 14 blocks, of which 13 introduced selected variables individually with a final refined block. Detailed results of all blocks and statistical tests carried out can be found in Appendix W.

Table 30 Modelling strategy **Model 4**: Providing care for more than 20 hours per week - carers, the ELSA Wave 7

Block 1	Block 2	Block 3	Block 4	Block 5	Block 6	Block 7	Block 8	Block 9	Block 10	Block 11	Block 12	Block 13	Final model
Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Gender	Omitted
Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age	Age
	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Ethnicity	Omitted
		Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Marital status	Omitted
			Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type	Household type
				SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH	SRH
					LLTI	LLTI	LLTI	LLTI	LLTI	LLTI	LLTI	LLTI	Omitted
						ADLs*	ADLs	ADLs	ADLs	ADLs	ADLs	ADLs	Omitted
							IADLs**	IADLs	IADLs	IADLs	IADLs	IADLs	Omitted
								Work status	Work status	Work status	Work status	Work status	Work status
									Education	Education	Education	Education	Omitted
										Wealth	Wealth	Wealth	Wealth
											Housing tenure	Housing tenure	Housing Tenure
												Access to car	Access to car

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living. *Difficulties with ADL,

** Difficulties with IADL.

Source: Author's own.

Table 31 is a summary of the main effects blocks, namely block 4, which contains the demographic variables; block 9, which contains the health variable; and block 13, which added socio-economic variables and the final model. The final model contained 7 independent variables: age, household type, SRH, work status, wealth quintiles, household type and access to a car/van. The model was statistically significant ($\chi^2 = 174.74$, $p < 0.001$) and resulted in a 7.4% change in -2LLR. This indicates that the independent variables significantly predicted the dependent variable of providing care. The following text presents a summary of the final model and highlighting changes between each block.

Gender was not found to be statistically significant. Other studies have noted a similar effect, particularly noting that after adjusting for marital status and household type, any gender differences in care provision disappear (Del Bono *et al.*, 2009). This is an important finding and is critically discussed in section 6.2.1.1.

The results show that the older age ranges had significantly greater odds of providing higher intensity care than those aged between 50 and 59. For example, carers aged between 70 and 79 had higher odds (OR 1.66, $p < 0.05$) of providing longer hours of care, than the reference category. Moreover, those aged over 80 had even higher odds of providing high intensity care (OR 1.97, $p < 0.05$) than the reference group. It should, however, be noted that the CI is very wide for both age categories, which suggests a low cell count. This is likely due to the association between age, the intensity of care and the direction of care, as also noted by other studies (Carmichael and Ercolani, 2014), this is further discussed in section 4.3.3.1.

Carers who lived in a coupled household with children had higher odds of providing longer hours of care compared to coupled households without children (OR 1.53, $p < 0.05$). Likewise, living in an extended household, compared to coupled households, increased the odds of providing care at a higher intensity care (OR 2.40, $p < 0.01$). On the other hand, living in a single household decreased the odds of providing higher intensity care, compared to living in coupled households (OR 0.35, $p < 0.001$). This may be due to the association between co-residential care and spousal care, which in turn is associated with higher caring intensity (see also section 4.3.3.1, Figure 17 and section 6.2.3 for the discussion).

The health predictors of SRH, LTLI and difficulties with ADLs and IADLs were added to the model in blocks 5 to 9. Carers with fair SRH had increased odds of providing higher intensity care, compared to carers with good SRH (OR 1.38,

$p < 0.05$). The change between the blocks was largest for carers reporting poor SRH; the odds of providing high intensity care when in poor SRH before controlling for socio-economic factors were OR 3.34, $p < 0.001$, however after adjusting for SES the odds of providing high intensity care decreased (OR 1.92, $p < 0.05$).

The carers who were economically inactive had greater odds of providing higher intensity care, compared to carers who were retired (OR 2.32, $p < 0.001$), this is further discussed in section 6.3.5.

Carers who owned their property with a mortgage, compared to owning it outright were less likely to provide care for ≥ 20 hours per week (OR 0.54, $p < 0.01$). Carers who did not have access to a car or a van had higher odds of providing ≥ 20 hours per week (OR 1.87, $p < 0.01$). Although one would think it necessary to have access to transportation in order to provide higher intensity care, this finding may be due to the majority of high intensity care being co-residential care and often provided by older carers (see also section 4.3.3.1).

Table 31 Logistic regression **Model 4**: predictors of care provided more than 20 hours per week, the ELSA Wave 7

	Block 4	Block 9	Block 13	Final model
Sex				
Female (reference)	1.00	1.00	1.00	-
Male	0.83 (0.65 - 1.06)	0.82 (0.64 - 1.05)	0.91 (0.70 - 1.18)	-
Age				
50-59 (reference)	1.00***	1.00***	1.00**	1.00**
60-69	1.25 (0.90 - 1.73)	1.28 (0.92 - 1.79)	1.17 (0.80 - 1.72)	1.14 (0.78 - 1.65)
70-79	2.12*** (1.48 - 3.03)	2.07*** (1.43 - 2.99)	1.80* (1.15 - 2.83)	1.66* (1.07 - 2.57)
>80	2.87*** (1.74 - 4.75)	2.68*** (1.60 - 4.48)	2.24** (1.24 - 4.04)	1.97* (1.12 - 3.48)
Ethnicity				
White (reference)	1.00	1.00	1.00	-
Non-white	1.30 (0.69 - 2.44)	1.15 (0.61 - 2.18)	1.15 (0.58 - 2.26)	-
Marital Status				
Married (reference)	1.00	1.00	1.00	-
Single	1.71 (0.89 - 3.27)	1.67 (0.86 - 3.22)	1.31 (0.65 - 2.63)	-
Divorced	1.19 (0.68 - 2.09)	1.13 (0.64 - 2.00)	1.13 (0.62 - 2.04)	-
Widowed	0.76 (0.40 - 1.46)	0.80 (0.41 - 1.56)	0.81 (0.41 - 1.63)	-
Household Type				
Couple (reference)	1.00***	1.00***	1.00***	1.00***
Couple plus children	1.48* (1.03 - 2.12)	1.49* (1.03 - 2.15)	1.54* (1.05 - 2.27)	1.53* (1.05 - 2.24)
Single	0.41** (0.22 - 0.74)	0.39** (0.22 - 0.72)	0.34** (0.18 - 0.64)	0.35*** (0.23 - 0.52)
Single plus children	1.23 (0.60 - 2.51)	1.05 (0.51 - 2.19)	0.70 (0.32 - 1.53)	0.77 (0.43 - 1.38)
Extended Family	2.34** (1.38 - 3.98)	2.20** (1.28 - 3.79)	2.35** (1.33 - 4.15)	2.40** (1.42 - 4.08)
Self-reported Health				
Good (reference)		1.00***	1.00**	1.00*
Fair		1.52** (1.16 - 1.98)	1.50** (1.13 - 1.99)	1.38* (1.07 - 1.77)
Poor		3.34*** (1.79 - 6.26)	2.52** (1.31 - 4.84)	1.92* (1.09 - 3.41)
Difficulties with ADLs				
None (reference)		1.00	1.00	-
1 ADL		0.95 (0.59 - 1.52)	0.84 (0.52 - 1.37)	-
Over 2 ADLs		0.91 (0.49 - 1.67)	0.75 (0.40 - 1.42)	-

ADL: Activities of daily living

Table 31 Continued	Block 4	Block 9	Block 13	Final model
Difficulties with IADLs				
None (reference)		1.00	1.00	-
1 IADL		1.17 (0.78 - 1.78)	1.05 (0.69 - 1.62)	-
Over 2 IADLs		1.52 (0.88 - 2.65)	1.47 (0.83 - 2.63)	-
Economic Activity				
Retired (reference)			1.00***	1.00***
Employed (Full-time >=35)			0.67 (0.41 - 1.09)	0.67 (0.42 - 1.08)
Employed (Part-time <35)			0.78 (0.53 - 1.14)	0.79 (0.55 - 1.15)
Economic inactive			2.28*** (1.50 - 3.49)	2.32*** (1.53 - 3.51)
Education				
Less than O-level or equivalent (reference)			1.00	-
O-level or equivalent			1.30 (0.96 - 1.74)	-
Higher than A-level			0.99 (0.73 - 1.35)	-
Wealth Quintiles				
Poorest (reference)			1.00*	1.00*
2nd Quintile			1.34 (0.66 - 2.71)	1.39 (0.70 - 2.76)
3rd Quintile			0.86 (0.41 - 1.82)	0.97 (0.47 - 2.00)
4th Quintile			0.68 (0.32 - 1.44)	0.72 (0.35 - 1.50)
Wealthiest			0.88 (0.41 - 1.89)	0.95 (0.46 - 1.98)
Housing Tenure				
Own outright (reference)			1.00*	1.00*
Own with mortgage			0.52** (0.35 - 0.78)	0.54** (0.36 - 0.80)
Renting, social			1.17 (0.50 - 2.76)	1.17 (0.51 - 2.69)
Renting, private			1.37 (0.64 - 2.93)	1.44 (0.69 - 3.03)
Live rent free			2.27 (0.39 - 13.36)	2.62 (0.45 - 15.18)
Access to Car or Van				
Yes (reference)			1.00**	1.00***
No			1.87** (1.21 - 2.90)	1.87*** (1.22 - 2.87)
-2LLR	1677.55	1649.17	1586.74	1602.33
% Change -2LLR	2.14%***	0.14%	0.51%**	7.4%
Hosmer & Lemeshow Test	$\chi^2=4.70$, p=0.781	$\chi^2=9.17$, p=0.328	$\chi^2=9.75$, p=0.284	$\chi^2=6.26$, p=0.618
Chi-square overall model	$\chi^2=69.87$, p<0.001	$\chi^2=98.25$, p<0.001	$\chi^2=178.68$, p<0.001	$\chi^2=174.75$, p<0.001

Weighted data. # Percentage change from base (model 1), see Appendix W.

Source: Author's own analysis of the ELSA

*Significant at the 0.05 level, ** Significant at the 0.01 level, *** Significant at the 0.001 level. IADL: Instrumental activities of daily living.

4.4.2 Summary of the logistic regression *Phase I*

The binary logistic regression confirmed the evidence also noted from previous studies, which showed that women have higher odds of providing care compared to men (O'Reilly *et al.*, 2008; Glauber, 2016). The older age groups had lower odds of providing care than those aged between 50 and 59. Conversely, among carers, the odds of providing higher intensity care (≥ 20 hours per week) were higher in the older age groups compared to the reference group; in fact, the odds of providing higher intensity care for respondents aged over 80 were 2.34 times higher than those among persons aged between 50 to 59.

Single, divorced or widowed persons had lower odds of providing care and provided care at a higher intensity compared to married respondents.

The health of the respondents showed an association with the odds of providing care and on the intensity of care provision. Overall, respondents in poor health had significantly lower odds of providing care, compared to those in good health. Contrastingly, the odds of providing care at high intensity when in poor health were significantly higher, than compared to being in good health. Lastly, having difficulties with more than 2 ADLs decreased the odds of providing care, compared to having no difficulties with ADLs.

All respondents who worked full-time had lower odds of providing care compared to retired persons, whereas being economically inactive increased the odds of providing care compared to being retired. Male respondents had slightly higher odds of providing care if working part-time, compared to being retired. All respondents in the wealthiest quintile had significantly decreased odds of providing care compared to those in the poorest quintile.

4.5 Summary of *Phase I*

The results in *Phase I* set out to answer Research Question 1: ‘**Who are the informal carers of ELSA Wave 7?**’ The results found in *Phase I* confirmed the evidence presented in the literature review and demonstrated that the majority of the informal carers were women aged between 50 and 59. For both women and men, the majority of carers were married, retired and had medium education levels. Most carers owned their house outright (i.e. had paid of their mortgage) and most carer belonged to the wealthier quintiles. Most carers reported good or fair SRH and the majority had no LLSI or difficulties with ADLs and IADLs.

The results from the logistic regression showed that the predictors of care provision included gender, age, marital status, household structure, health, economic activity and wealth. The main differences between women and men were that age and SHR were not significant predictors of providing care for men, whereas they were for females.

Among those who were caring, the determinants of providing care for a higher intensity included the age, marital status and health of the carers. Co-residential care increased the likelihood of providing high intensity care (≥ 20 hours/week). Likewise, the direction of the care was associated with the intensity, and the highest intensity of care was provided by spousal carers.

Phase I used a cross-sectional study design and focused solely on the ELSA Wave 7. Although this provided an important insight into the characteristics of the informal carers and the effects of caring, it cannot offer any insights to changes in caring states over time, nor can it provide causal conclusions on the effect of care provision on the carer’s circumstances. Therefore the analysis in *Phase II* takes a longitudinal approach, examining the associations between socio-demographic characteristics and entering into the caring role, using the ELSA Waves 4 (2009) to 7 (2015).

Chapter 5 *Phase II & III: Methodology and Results of the longitudinal analysis*

This chapter presents the results of the longitudinal data analysis Phase II and III, (see also section 2.5, Figure 6).

Phase II aims to answer Research Question 2 ‘**What are the longer-term trajectories into informal care provision?**’, this phase takes a longitudinal approach and uses the ELSA Waves 4 (2008/2009) to 7 (2015/2016) (Marmot *et al.*, 2017) to explore the predictors of becoming a future care and the effect of the timing of the care provision. In addition case studies of how carers adjusted to the role over the 6 years are presented.

Phase III examines the transitions of caring types between Wave 6 (2013) and 7 (2015). The analysis intends to answer Research Question 3 ‘**Between 2013 and 2015 how did respondents transition between caring statuses (i.e. non-carers, ‘repeating carers’, ‘discontinued caring’ and ‘new carers?’**’ This phase also takes a longitudinal approach, but by only including two waves, it provides a more detailed picture of how carers change between caring statuses, directions of care, intensity of the care provided, as well as how their caring status is associated with changes to their employment and health.

5.1 *Phase II: Results of the longer-term trajectories of informal care provision between 2009 (Wave 4) and 2015 (Wave 7)*

Phase II examine the trajectories into informal care provision and the effects when the caring episodes took place on the carer’s SRH (see also section 2.5, Figure 6). The advantages of exploring informal carers and their caring trajectories over four waves are that it provides an understanding of the causal pathways and the longer-term effects of care provision. A caring episode is classified as the number of waves the care was provided, it is however important to bear in mind the limitations of the care provision variable. As the respondents are asked if they ‘*looked after anyone last week*’, the carer may not have provided care for the full two years between the ELSA interview. In addition, the disadvantage of using multiple waves of the ELSA dataset is increased attrition rate, see also section 3.6.2.

The ELSA Wave 4 acted as the baseline measure, as literature has shown that many carers will have provided care for an estimated 5 years by the time they reach the age of 65 (Seltzer and Li, 2000; Henz, 2004; Plaisier *et al.*, 2015). Therefore, after excluding

Chapter 5

respondents who were providing care in Wave 4, Waves 5 to 7 provided a total of 6 subsequent years of potential caring episodes. The inclusion of Wave 3 was tested, however the response rate was lowered by a further 34% and leaving a total sample of 3,858 respondents (see Appendix L), which was deemed too low for a robust analysis.

It should be noted that the caring variable ErCAA was routed via a filter question in Waves 4 and 5 (NatCen, 2012). More specifically, only respondents who had answered 'yes' to the question WPACTca: '*Did you provide care for someone during the last month*', were eligible to answer ErCAA (Ibid), (see section 3.3.1). As a consequence, the prevalence of carers prior to Wave 6 was potentially underestimated, as fewer respondents were identified as carers. Nonetheless, to ensure consistency in the sample, the filter was replicated and applied to Waves 6 and 7. All caring related variables used in *Phase II* of the analysis (i.e. care direction and intensity) were also derived with the filter applied to ensure consistency. A similar strategy has been used by other studies (King and Pickard, 2013). Applying the filter excluded 1,003 carers from Wave 6 and 851 carers from Wave 7. Appendix M provide details of the caring characteristics of the excluded carers, and it showed that the majority of excluded carers provided low intensity care (i.e. ≤ 20 hours per week), and primarily extra-residential care.

It is important to remember that the results only show aggregated patterns, where individual cases are counted and summed up by type into totals and this creates a limitation when explaining individual caring provision behaviours (Garrett, 2003). Using aggregate data can provide conclusions regarding the relations between socio-demographics characteristics and care provision, which may be different from a group level to an individual level (Ibid). For example, the results could show that carers as a group are wealthier, but that does not mean that all individual carers are wealthy. The issues of aggregated data is critically discussed in section 6.4.

The section provides the descriptive analyses of the caring statuses, the bivariate analysis comparing the socio-demographic of carers and non-carers between Wave 4 and Wave 7; and the multivariate analysis of the predictors of being a future carer, based on socio-demographic characteristics in Wave 4. The section also examines whether the timing of when the care was provided had an impact on changes of the carer's health status between Wave 4 and Wave 7. In addition, the analysis exploring how carer's transition between different care intensities and caring directions. *Phase II* concludes by presenting the case studies, these aims to aid the understanding of the possible causal links in real-life scenarios that are too complex for the quantitative

analysis to ascertain, and secondly to explain a more real-life context of care provision (Yin, 2003).

5.1.1 The sample population of ELSA Wave 4 to Wave 7

The fieldwork for Wave 4 was completed in 2009 and included a total of 11,050 respondents, Wave 4 had a refreshment sample of respondents aged 50-74 at the time of fieldwork (2008/2009) (Bridges *et al.*, 2014). The fieldwork for Wave 5 was completed in 2011 and this wave included a total of 10,274 respondents and had no refreshment sample (Ibid). The fieldwork for Wave 6 was completed in 2013 and included a total of 10,632 respondents, in addition to a refreshment sample of 826 individuals aged between 50 and 54 at the time of fieldwork (2011/2012) (Bridges *et al.*, 2014), see also Box 1. For details of the structure of the ELSA Wave 7, please refer to section 4.2.

In order to distinguish the true effect of the pathways into caring, the sample was further restricted to respondents who did not provide care in Wave 4, also done by Carmichael *et al.* (2010). As discussed in section 3.6, including care provision at the baseline (Wave 4) may underestimate the impact of caring on the carer's circumstances, as the effect may already have occurred. Although no carers were included in Wave 4, respondents may nevertheless have provided care in a previous wave, which may affect the results. It was nevertheless judged that further exclusions would cause too great an attrition for a robust analysis.

Figure 20 depicts a flowchart of the composition of the final sample (Waves 4 to 7) after exclusions (see also section 4.2), leading to a total analytical sample consisting of 5,916 respondents.

Wave 4 N=11,050	Wave 5 N=10,274	Wave 6 N=10,601	Wave 7 N=9,666
Excluded: n=807	Excluded: n=826	Excluded: n=929	Excluded: n=827
Interviewed by proxy (n=392)	Interviewed by proxy (n=477)	Interviewed by proxy (n=614)	
Partial interviewed (n=58)	Partial interviewed (n=102)	Partial interviewed (n=52)	
Institutional interview (n=68)	Institutional interview (n=72)	Institutional interview (n=12)	
Aged under 50 (n=265)	Aged under 50 (n=149)	Aged under 50 (n=189)	
Not living in England (n=21)	Not living in England (n=25)	Not living in England (n=30)	
Incomplete ERCAA response (n=3)	Incomplete ERCAA response (n=1)	Incomplete ERCAA response (n=32)	
Total remaining=10,243	Total remaining=9,448	Total remaining=9,672	Total remaining =8,839^a

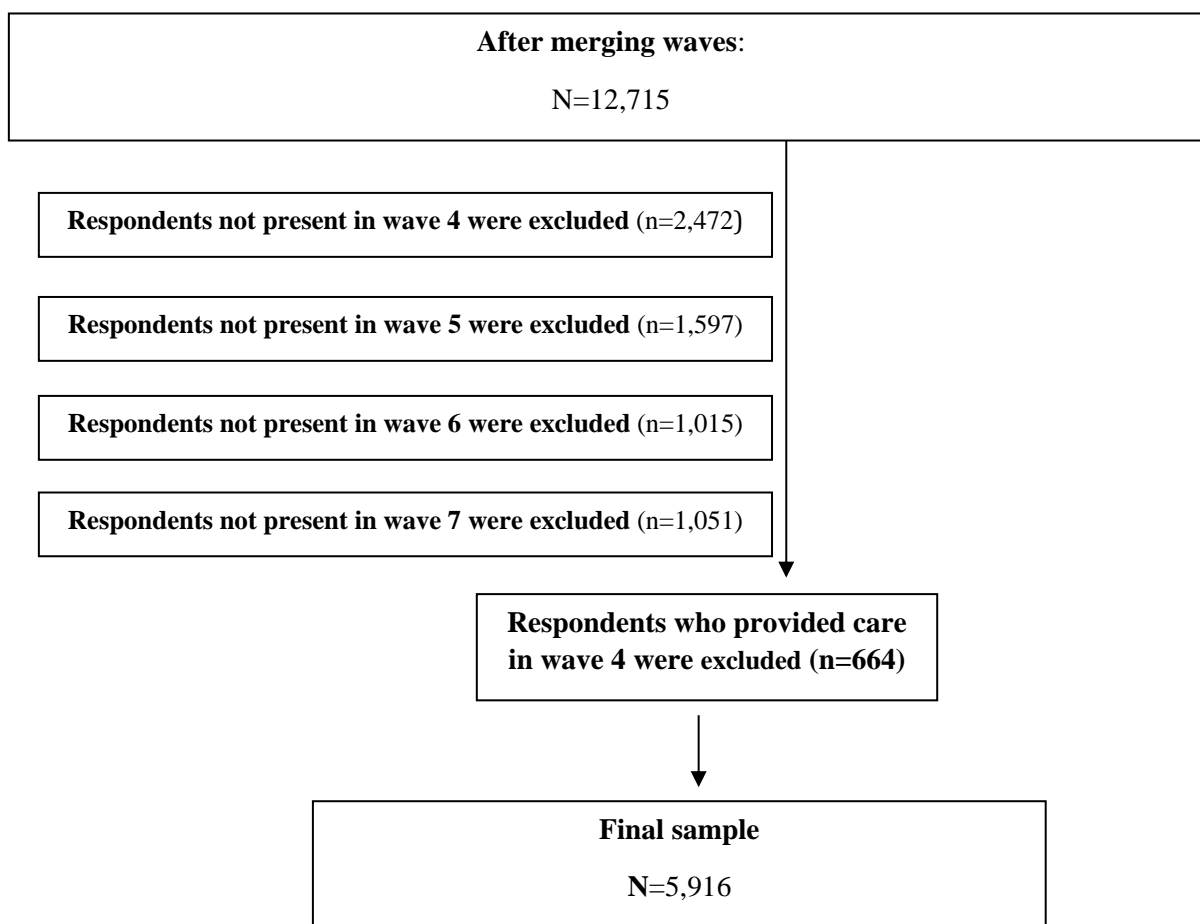


Figure 20 Flowchart of the composition of the study sample, the ELSA Waves 4 to 7.

^aSee section 4.2 for a detailed account of exclusions.

Each wave followed the same exclusion criteria, as set in section 4.2. After the waves were merged respondents not present in all 4 waves were excluded. In addition, respondent who had provided care in wave 4 were also excluded.

Source: the author's own.

5.1.2 The longitudinal statistical data analysis design of longer-term transition in Phase II

The demographic and socio-economic characteristics of future carers were analysed in order to answer Research Question 2.a: '*what are the main socio-demographic differences between the caring statuses in Wave 4 (2009) (i.e. future non-carers 'repeating carers', 'intermittent carers')* and how do these differ between caring statuses in 2015?', see section 1.2.

The construction of the caring statuses was guided by literature showing that continuous caring may have a greater adverse impact on the carer's health and attachment to the labour market (Leopold *et al.*, 2014; Lyons *et al.* 2015). A distinction was made between 'repeating carers', who provided care at each measured wave (i.e. Waves 5, 6 and 7); and carers providing care for two consecutive waves (i.e. Waves 5 & 6 or 6 & 7) and caring for non-consecutive waves (i.e. provided care in one wave only or Waves 5 & 7). The 'non-consecutive waves' status was included, as Rafnsson *et al.* (2015) noted that two-years after discontinuing care provision, the carer's health was no longer affect by the caring episode. The caring exposure for carers providing care for either one wave or for non-consecutive waves may be lower, and any effect of care provision therefore missed. Moreover, carers providing care for two non-consecutive waves, may have greatly benefitted from the two-year break. Therefore, using an accumulation measure (i.e. grouping all carers who had provided care for two waves regardless of the timing) may have masked the impact of providing continuous care. Table 32 displays the distribution of the respondents caring episodes.

Table 32 Distribution of the caring episodes

The timing of the care provision	Frequency
Non-carers in all waves:	5,006
Cared in Wave 5 only:	256
Cared in Wave 6 only:	202
Cared in Wave 7 only:	202
Cared in Waves 5 & 6 only	75
Cared in Waves 6 & 7 only	76
Cared in Waves 5 & 7	47
Cared in Waves 5,6 & 7	52

Source: author's own analysis of ELSA Waves 4, 5, 6 & 7

All variables used across the four waves were derived as described in section 3.3. The ELSA Wave 4 (2009) acted as a baseline measure to examine the differences in

Chapter 5

demographic, health and socio-economic characteristics prior to care provision between the four caring status groups. To explore the impact of the care provision, the four groups' characteristics were analysed at baseline (Wave 4) and compared to the characteristics at Wave 7.

The results of the bivariate analyses were displayed in tables created to capture the differences between non-carers and carers, as well as between waves (years) within caring statuses (i.e. non-carers, 'repeating carers', provided care for two consecutive waves, provided care for non-consecutive waves). The tables presented the column percentages and frequencies, unless otherwise specified, and it should be noted that the totals may differ due to non-responses in the independent variables.

The Pearson's Chi-Square (χ^2) test was used to assess the independence between caring statuses within the same wave (year), and the results are shown below the independent variables representing each wave (i.e. Wave 4 and Wave 7). The McNemar-Bowker's test was used to assess the statistical significance within the caring statuses between the waves, as this test is better equipped to test the difference in changes to responses between the related groups, moreover the McNemar-Bowker's test can assess independence of multiple categories in nominal variables, unlike the McNemar's test (Field, 2005; IBM, 2013b). The result of the McNemar-Bowker's test is presented above the results of each variable, between the years. The statistical significance at $p < 0.05$ was assumed (Argyrous, 2014).

5.1.3 A demographic and socio-economic comparison of carers and non-carers between 2009 and 2015

The results of the descriptive analysis can be seen in Table 33 and show the comparison of respondents' characteristics between Wave 4 (2009) and Wave 7 (2015) by their future caring status. More women than men provided care for 2 and 3 consecutive waves (70% and 30%, respectively). Although there were also more women providing care for non-consecutive waves, the split between the woman and men was smaller (61% and 39%, respectively). All carers, independent of the duration of their care provision, were younger at baseline (Wave 4).

Future carers were more likely to be married than single, divorced or widowed. Within the caring statuses changes were observed between Wave 4 (2009) and Wave 7 (2015). For example, among the non-carers, the proportion of respondents who were married decreased by 2015, while the proportion of those who were widowed increased by 2015, which was also similar for those providing care for either 2 consecutive waves or

non-consecutive waves. Among the 'repeating carers' 75% were married in both Wave 4 and Wave 7, which is likely due to high proportion of spousal carer. Indeed, a cross-tabulation of the 'repeating carers' between care direction and marital status revealed 21% were also 'persistent spousal carers'. These results mirrored results from the cross-sectional analysis in *Phase I*, which also noted that the majority of carers were married, and which is likely associated with spouses being the primary care-recipients (see sections 4.3.1 and 4.3.3).

All caring statuses reported better SRH than non-carers in Wave 4. Among, the 'repeating carers' 60% reported good health in Wave 4 compared to 45% of non-carers, however the cell count was not sufficient to measure the proportion of 'repeating carers' in poor health. 4% of carers who provided care for 2 consecutive waves and 3% caring for non-consecutive waves reported poor health compared to 6% of non-carers.

Among the non-carers, the proportion of those reporting good health decreased by 6.1 percentage points between 2009 and 2015, whereas the proportion of non-carers reporting poor health increased by 1.9 percentage points. Among carers providing care for 2 consecutive waves, the decrease in the proportion reporting good SRH was 5.9 percentage points, and no change was noted in the prevalence of those reporting poor health in 2009 and 2015. Similar patterns in SRH were observed for carers who provided care for non-consecutive waves and among the non-carers. The changes in SRH are further explored in section 5.1.6 and in *Phase III*, section 5.2.4.1.

At baseline (Wave 4), there was a significant difference between non-carers and all future caring statuses reporting none or some difficulties with ADLs, however by 2015 there was no longer a statistical difference. A higher proportion of future carers had no difficulties with ADLs compared to non-carers at baseline and a smaller proportion of those providing care for non-consecutive waves had difficulties with more than two ADLs. Within the non-carers, the proportion with no ADL difficulties fell by 2.6 percentage points between 2009 and 2015, whereas the proportion with 2 or more ADL difficulties rose by 2.7 percentage points. Among those caring for non-consecutive waves, the percentage with no ADL difficulties fell by 4.8 points between 2009 and 2015, whereas the proportion with more than 2 ADL difficulties rose by 3.4 percentage points. This could suggest that caring for non-consecutive waves has a greater adverse effect on health (reflected in difficulties with ADLs), than not providing care.

Half of the non-carers were retired in 2009, 43% caring for two-consecutive waves and 40% of those caring non-consecutive waves, whereas 54% of 'repeating carers' were retired in 2009. Independent of caring statuses, the proportion of respondents who

Chapter 5

were retired by 2015 increased. This is due to the age structure of the sample and is to be expected, as the sample would have aged 6 years, thereby increasing the proportion of the sample at retirement age. 23% of non-carers were employed full-time in 2009, compared to only 15% of the future 'repeating carers'. Interestingly, there was no difference in the proportion of non-carers and future 'repeating carers' who were employed part-time (17%) in 2009, whereas the proportion caring for two-consecutive waves was 21% and 25% for those caring for non-consecutive waves. By 2015, the proportion of 'repeating carers' working part-time had remained the same, whereas both the non-carers and the 'intermittent carers' had a decreased proportion of respondents working part-time. Changes to economic activity are further explored in section 5.2.4.2.

There was no statistically significant difference between caring statuses and housing tenure, however within the four caring statuses a difference was noted. All caring statuses observed an increase in respondents who own their house outright and a decline in respondents who owned their home with a mortgage by 2015. This suggested that over time the respondents' mortgage payments may have been completed. For all caring statuses, the proportion renting either from a private or social landlord stay relatively stable. There was no difference in the wealth quintiles between caring statuses both between years and within caring statuses.

Table 33 Comparison of characteristics future caring status at 2009 (Wave 4 baseline) and 2015 (Wave 7)

YEAR	Non-carers n=5,006		'Repeating carers' (3 waves) n=52		Provided care for 2 consecutive waves n=151		Provided care non- consecutive waves n=707	
	2009	2015	2009	2015	2009	2015	2009	2015
Gender								
Male	47.4%		30.8%		29.8%		38.6%	
Female	52.6%		69.2%		70.2%		61.4%	
	100% (5,006)***		100% (52)		100% (151)		100% (707)	
Age Group	***		***		***		***	
50-59	32.5%	8.1%	38.5%	9.6% (-)	44.4%	12.6%	41.7%	12.6%
60-69	37.6%	41.8%	44.2%	55.8%	32.5%	49.7%	38.8%	49.2%
70-79	24.0%	33.2%	15.4%	30.8%	19.2%	25.8%	16.7%	28.7%
Over 80	5.8%	16.8%	1.9% (-)	3.8% (-)	4.0%	11.9%	2.8%	9.5%
	100% (5,006)***		100% (52)		100% (151)		100% (707)	
Marital Status	***		***		***		***	
Single	6.2%	6.0%	5.8% (-)	3.8% (-)	4.0%	4.0%	5.1%	4.4%
Married	66.5%	63.7%	75.0%	75.0%	76.2%	72.8%	78.9%	73.4%
Divorced	12.8%	12.9%	7.7% (-)	5.8% (-)	11.3%	12.6%	10.2%	10.2%
Widowed	14.2%	17.5%	11.5%	10.1%	8.6%	10.6%	5.8%	12.0%
	100% (5,006)***		100% (52)		100% (151)		100% (707)	
Self-reported Health	***		#		#		***	
Good	45.3%	39.2%	59.6%	50.0%	45.0%	39.1%	52.8%	42.4%
Fair	49.0%	53.2%	36.5%	46.2%	51.0%	57.0%	44.6%	51.5%
Poor	5.8%	7.7%	3.8% (-)	3.8% (-)	4.0%	4.0%	2.7%	6.1%
	100% (5,005)***		100% (52)		100% (151)		100% (707)	

The statistical significance levels presented above the variable is within carer status, between the years, based on the McNemar-Bowker's test. The significant levels presented underneath the variables for the non-carers is a Chi-square Test of the statistical significant levels of the between carer statuses, within each year, see also section 0 for further information. ^a computed only for a PxP table were P must be greater than 1, means that the McNemar-Bowker test not possible.*** p<0.001, **p<0.01, *p<0.05, # not statistically significant, (-) cell count below 5. Source: author's own analysis of ELSA Waves 4,5,6 & 7

Chapter 5

Table 33 (continued) Comparison of characteristics future caring status at 2009 (Wave 4 baseline) and 2015 (Wave 7)

YEAR	Non-carers		'Repeating carers' (3 waves)		Provided care for 2 con. waves		Provided care non-con. waves	
	2009	2015	2009	2015	2009	2015	2009	2015
Longstanding Illness	***		#		#		*	
No	47.4%	43.6%	53.8%	44.2%	45.0%	44.4%	51.6%	44.0%
Yes, not limiting	22.1%	20.8%	25.0%	30.8%	24.5%	19.9%	20.8%	22.5%
Yes, limiting	30.5%	35.6%	21.2%	25.0%	30.5%	35.8%	27.6%	33.5%
	100% (5,005) #	100% (5,004) #	100% (52)	100% (52)	100% (151)	100% (151)	100% (707)	100% (707)
Difficulties with ADLs	***		#		#		***	
None	84.6%	82.0%	96.2%	82.7%	86.1%	85.4%	88.7%	83.9%
1 ADL	8.9%	8.9%	3.8% (-)	13.5%	7.9%	8.6%	6.6%	8.1%
2+ ADLs	6.5%	9.2%	(-)	3.8% (-)	6.0%	6.0%	4.7%	8.1%
	100% (5,006) *	100% (5,006) #	100% (52)	100% (52)	100% (151)	100% (151)	100% (707)	100% (707)
Difficulties with IADLs	***		a		#		*	
None	83.1%	79.4%	90.4%	86.5%	86.8%	84.1%	86.3%	82.2%
1 IADL	9.8%	10.1%	7.7% (-)	11.5%	10.6%	7.3%	8.8%	11.0%
2+ IADLs	7.1%	10.5%	1.9% (-)	1.9% (-)	2.6% (-)	8.6%	5.0%	6.8%
	100% (5,006) *	100% (5,006) **	100% (52)	100% (52)	100% (151)	100% (151)	100% (707)	100% (707)
Economic Activity	***		a		***		***	
Retired	49.9%	69.1%	53.8%	67.3%	43.3%	70.9%	39.7%	64.5%
Full-time	23.2%	11.6%	15.4%	(-)	22.0%	6.6%	23.9%	11.1%
Part-time	17.0%	12.3%	17.3%	17.3%	20.7%	11.3%	24.6%	15.9%
Economic inactive	9.9%	7.0%	13.5%	15.4%	14.0%	11.3%	11.8%	8.5%
	100% (4,890) ***	100% (4,987) ***	100% (52)	100% (52)	100% (150)	100% (151)	100% (687)	100% (704)

The statistical significance levels presented above the variable is within carer status, between the years, based on the McNemar-Bowker's test. The significant levels presented underneath the variables for the non-carers is a Chi-square Test of the statistical significant levels of the between carer statuses, within each year, see also section 0 for further information. ^a computed only for a PxP table were P must be greater than 1, means that the McNemar-Bowker test not possible. *** p<0.001, **p<0.01, *p<0.05, # not statistically significant, (-) cell count below 5. Source: author's own analysis of ELSA Waves 4,5,6 & 7

Table 33 (continued) Comparison of characteristics future caring status at 2009 (Wave 4 baseline) and 2015 (Wave 7)

N=5,916 YEAR	Non-carers		'Repeating carers' (3 waves)		Provided care for 2 con. waves		Provided care non-con. waves	
	2009	2015	2009	2015	2009	2015	2009	2015
Education Level	***		#		*		***	
< O-level	38.8%	42.5%	32.7%	34.6%	43.7%	48.3%	29.5%	35.9%
O-level	27.5%	26.5%	28.8%	28.8%	29.1%	25.8%	31.2%	29.1%
> A-level	33.7%	31.0%	38.5%	36.5%	27.2%	25.8%	39.3%	35.0%
	100% (4,996)	100% (4,990)	100% (52)	100% (52)	100% (151)	100% (151)	100% (705)	100% (705)
	***	**						
Housing Tenure	***		a		a		***	
Own, outright	63.6%	73.6%	58.8%	75.0%	67.5%	80.0%	64.1%	77.7%
Own with mortgage	21.8%	10.8%	23.5%	7.7% (-)	19.9%	10.7%	23.9%	10.9%
Private renting	2.8%	2.9%	2.0% (-)	(-)	3.3% (-)	2.0% (-)	2.1%	2.0%
Social renting	10.8%	11.3%	15.7%	17.3%	8.6%	7.3%	8.7%	8.9%
Live rent free	1.0%	1.3%	(-)	(-)	0.7% (-)	(-)	1.3%	0.6% (-)
	100% (4,996)	100% (5,001)	100% (51)	100% (52)	100% (151)	100% (150)	100% (704)	100% (707)
	#	#						
Non-pension Wealth Quintiles	#		#		#		#	
Poorest	15.8%	15.9%	18.8%	16.7%	13.6%	9.9%	13.0%	12.1%
2 nd Quintile	18.0%	17.0%	16.7%	20.8%	21.4%	19.0%	17.4%	14.6%
3 rd Quintile	20.2%	22.0%	16.7%	20.8%	24.3%	29.6%	20.7%	22.5%
4 th Quintile	21.5%	21.9%	22.9%	18.8%	18.6%	22.5%	23.7%	26.6%
Wealthiest	24.6%	23.2%	25.0%	22.9%	22.1%	19.0%	25.3%	24.2%
	100% (4,617)	100% (4,609)	100% (48)	100% (48)	100% (140)	100% (142)	100% (633)	100% (636)
	#	*						

The statistical significance levels presented about the variable is within carer status, between the years, based on the McNemar-Bowker's test. The significant levels presented underneath the variables is a Chi-square Test of the statistical significant levels of the between carer statuses, within each year, see also section 0 for further information. ^a computed only for a PxP table were P must be greater than 1, means that the McNemar-Bowker test not possible. *** p<0.001, **p<0.01, *p<0.05, # not statistically significant, (-) cell count below 5.

Source: author's own analysis of ELSA Waves 4,5,6 & 7

5.1.4 Introduction to the longer-term predictors of becoming a future carer

Research Question 2.b addressed the predictors of becoming a future care, based on the socio-demographic characteristics in 2009. A future carer was classified as someone who provided care at some point between Waves 4 to 7, independent of the duration of the care provision.

This section presents the predictors of becoming a future carer using binary logistic regression analysis. A total of three models are shown: 1) the overall sample, 2) female respondents and 3) male respondents. A separate regression model was analysed by sex, as results from *Phase I* and literature have consistently evidenced that women are more like to provide care (Glauber, 2016). The regression models were presented with OR, the 95% CI and p-values for each of the independent variables.

5.1.4.1 *Phase II* MODEL 5: Predictors of becoming a future carer

The binary regression modelling strategy followed a similar approach to *Phase I* (see section 4.4). Models 5 aimed to predict the determinants of being a future carer, based on the respondents' socio-demographic characteristics at Wave 4.

A correlation matrix was created to examine the strength of correlations between the independent variables, measured at baseline (Wave 4, 2009). As seen from Table 34, age and work were strongly correlated ($r=-0.55$, $p<0.001$), indicating an interaction between increasing age and the increased likelihood of being retired. There was also a strong correlation between housing tenure and wealth ($r=0.50$, $p<0.001$). For the independent health variables, there was a strong correlation between difficulties with ADLs and IADLs ($r=0.51$, $p<0.001$), which suggests that an increase in ADL difficulties is likely to occur at the same rate as an increase in IADL difficulties.

Table 34 Correlation matrix: All respondents, the ELSA Wave 4

	1	2	3	4	5	6	7	8	9	10	11
1. Gender	1.00										
2. Age	.001#	1.00									
3. Marital status	-.182***	.195***	1.00								
4. SRH	-.027*	.107***	.108***	1.00							
5. ADLs	-.019#	.130***	.116***	.337***	1.00						
6. IADLs	-.068***	.131***	.156***	.334***	.506***	1.00					
7. LLSI	-.027*	.120***	.105***	.485***	.373***	.397***	1.00				
8. Work	-.052***	-.550***	-.120***	-.029**	-.032*	-.027*	-.028*	1.00			
9. Education	.150***	-.176***	-.129***	-.188***	-.128***	-.143***	-.117***	.043***	1.00		
10. Tenure	.005#	.247***	-.127***	-.133***	-.106***	-.100***	-.091***	-.206***	.121***	1.00	
11. Wealth	.067***	-.032*	-.303***	-.245***	-.188***	-.201***	-.189***	-.038***	.344***	.505***	1.00
0.5-1.0	Strong correlation										
0.3-0.4.9	Moderate correlation										
0.1-0.2.9	Weak correlation										
0-0.99	Very weak or no correlation										
	Not statistically significant										

* Correlation significant $p < 0.05$, ** Correlation significant $p < 0.01$ level, *** Correlation significant $p < 0.001$ level.

SHR: Self-reported health, LLI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living.

Source: author's own analysis of the ELSA Wave 4

Chapter 5

The independent variables were entered into the model by forced entry method and by backward elimination (Field, 2005). Both were then compared for best fit, see Table 35 (the data analysis strategy can be found in section 3.4).

As *Phase II* had a relatively low sample size, the number of independent variables were kept to a minimum. Moreover, results from *Phase I* noted that ethnicity, region and access to a car were not statistically significant and showed no effect on the predictions of care provision, these variables were therefore not included in the analysis. Likewise, the variable LLSI was excluded, as the preliminary test showed no statistical significance. Lastly, ADLs and IADLs difficulties were excluded as they interacted with each other, as seen from the correlation matrix (Table 34). Moreover, neither was found to be statistically significant in predicting being a future carer.

The model using backward elimination had a lower -2LLR than the forced entry method, as the backward elimination omitted more variables from the model. Nevertheless, the forced entry model was used, because it was judged to be more suitable due to retain wealth as a control (see Table 34).

Table 35 Method comparison **Model 5: All future carers, ELSA Wave 4**

Variables (final model)	Forced entry	'Backward' elimination
Gender	√	√
Age	√	√
Marital status	√	√
Self-reported health	√	√
Limiting Long Standing Illness	Omitted	Omitted
Difficulties with ADLs	Omitted	Omitted
Difficulties with IADLs	Omitted	Omitted
Work	√	√
Education	√	√
Housing tenure	Omitted	Omitted
Wealth	√	Omitted
-2LLR	4336.52	4331.97

Source: author's own analysis of ELSA Waves 4, 5, 6 & 7

Table 36 shows the results of the binary regression in the determinants of becoming a future carer (i.e. providing care in either Wave 5, 6 or 7).

As expected, men were less likely than women to become a future carer (OR 0.61, $p < 0.001$), as also evidenced in *Phase I* (section 4.3.1). The odds of being a future carer decreased as the age ranges of the respondents increased. This is likely associated with the high proportion of spousal carers and with increased age of the carer, there was an increased risk of becoming widowed (i.e. no longer providing care). This can also be seen from the results, as the odds of becoming a future carer were lower for single (OR 0.56, $p < 0.001$), divorced (OR 0.61, $p < 0.001$) or widowed (OR 0.41, $p < 0.001$) respondents, compared to being married. This is further discussed in section 6.3.3

Being in fair or poor SRH compared to good health reduced the odds of becoming a future carer (OR 0.82, $p < 0.05$ and OR 0.44, $p < 0.001$, respectively). As seen from Table 36, respondents who went on to provide care were overall healthier in 2009 compared to those who never provided care, also discussed in section 6.3.4.

Being in full-time employment in 2009 reduced the odds of providing care in the future (OR 0.75, $p < 0.05$), compared to being retired. This was also noted by Carmichael et al. (2010), however the authors used a younger sample (aged 18 to 59). Respondents with higher education levels had increased odds of future care provision (OR 1.38, $p < 0.001$), compared to those with less than O-level education. Respondents who belonged to the poorest wealth quintiles, had higher odds of becoming future carers (OR 1.40, $p < 0.05$). This may be associated with more women in this sample belonging to the poorer wealth quintiles compared to men.

Table 36 **Model 5: Predictors of becoming a future carer (longer-term)**

	Block 1	Block 3	Block 7	Final Model
Gender				
Female (ref.)	1.00***	1.00***	1.00***	1.00***
Male	0.58 (0.50 - 0.68)***	0.58 (0.49 - 0.68)***	0.61 (0.51 - 0.72)***	0.61 (0.51 - 0.72)***
Age				
50-59	1.00***	1.00***	1.00***	1.00***
60-69	0.77 (0.65 - 0.92)***	0.78 (0.65 - 0.93)***	0.73 (0.59 - 0.90)***	0.75 (0.61 - 0.93)***
70-79	0.62 (0.50 - 0.77)***	0.64 (0.51 - 0.79)***	0.59 (0.44 - 0.78)***	0.62 (0.47 - 0.81)***
over 80	0.51 (0.33 - 0.79)***	0.54 (0.35 - 0.83)***	0.49 (0.31 - 0.79)***	0.51 (0.32 - 0.82)***
Marital Status				
Married (ref.)	1.00***	1.00***	1.00***	1.00***
Single	0.59 (0.41 - 0.84)***	0.60 (0.42 - 0.86)***	0.56 (0.39 - 0.80)***	0.56 (0.39 - 0.80)***
Divorced	0.62 (0.48 - 0.79)***	0.64 (0.50 - 0.82)***	0.60 (0.47 - 0.78)***	0.61 (0.48 - 0.79)***
Widowed	0.42 (0.31 - 0.56)***	0.42 (0.12 - 0.57)***	0.41 (0.30 - 0.55)***	0.41 (0.31 - 0.56)***
Self-reported Health				
Good (ref.)		1.00	1.00***	1.00***
Fair		0.85 (0.72 - 0.99)*	0.82 (0.70 - 0.97)*	0.82 (0.70 - 0.96)*
Poor		0.52 (0.32 - 0.82)***	0.47 (0.29 - 0.77)***	0.44 (0.28 - 0.69)***
Difficulties with IADLs				
None (ref.)		1.00	1.00	
1 IADL		1.19 (0.91 - 1.55)	1.17 (0.88 - 1.51)	
Over 2 IADLs		0.86 (0.58 - 1.25)	0.79 (0.53 - 1.16)	

Table 36 (continued) **Model 5: Predictors of becoming a future carer (longer-term)**

Economic Activity				
Retired (ref.)			1.00*	1.00***
Employed (Full-time >=35)			0.79 (0.59 - 1.02)	0.75 (0.58 - 0.98)*
Employed (Part-time <35)			1.09 (0.86 - 1.38)	1.07 (0.85 - 1.34)
Economic inactive			1.23 (0.93 - 1.63)	1.21 (0.91 - 1.60)
Education Level				
Less than O-level or equivalent (ref.)			1.00***	1.00***
O-level or equivalent			1.34 (1.10 - 1.64)***	1.33 (1.09 - 1.62)***
Higher than A-level			1.38 (1.13 - 1.69)***	1.38 (1.13 - 1.69)***
Housing Tenure				
Owned outright (ref.)			1.00	
Owned with mortgage			0.83 (0.67 - 1.03)	
Rent - private			0.84 (0.45 - 1.56)	
Rent - Social			1.02 (0.62 - 1.68)	
Live rent free			1.31 (0.62 - 2.74)	
Non-pension Wealth Quintiles				
Wealthiest (ref.)			1.00	1.00
4th Quintile			1.18 (0.95 - 1.48)	1.19 (0.95 - 1.48)
3rd Quintile			1.28 (1.01 - 1.62)*	1.27 (1.01 - 1.61)
2nd Quintile			1.39 (1.08 - 1.80)**	1.33 (1.04 - 1.71)*
Poorest			1.40 (0.86 - 2.27)	1.40 (1.04 - 1.87)*
-2LLR	4364.436	4351.154	4317.505	4336.524
% Change -2LLR		0.30 ^a %	1.08%	0.64%
Significance change to block	$\chi^2=129.81$ p<0.001	$\chi^2=2.56$, p=278	$\chi^2=7.62$, p<0.106	$\chi^2=171,027$ p<0.001
Hosmer & Lemeshow Test	$\chi^2=13.38$, p=0.037	$\chi^2=14.73$, p=0.065	$\chi^2=7.32$, p=0.057	$\chi^2=6.09$, p=0.638
Cox & Snell R squared	0.024	0.027	0.033	0.032
Chi-square overall model	$\chi^2=129.81$ p<0.001	$\chi^2=145.65$, p<0.001	$\chi^2=176.74$, p<0.001	$\chi^2=171.27$ p<0.001

^a change from base block. *** p<0.001, **p<0.01, *p<0.05. ADL: Activities of Daily Living, IADL: Instrumental Activity of Daily Living. Source: author's own analysis of ELSA waves 4, 5, 6 & 7

5.1.4.2 *Phase II* MODEL 6 and 7: Longer-term predictors of becoming a future carer – by sex

In order to answer Research Question 2.b, a regression analysis was conducted separately for female and male respondents.

The correlation matrix for each gender can be found in Appendix N and Appendix O. For both genders there were moderate to strong correlations between the different health variables. For example, for females having difficulties with ADLs was moderately correlated with having IADLs difficulties ($r=0.52$, $p<0.001$), and this was similar between SRH and ADLs difficulties ($r=0.35$, $p<0.001$), ADLs and IADLs difficulties ($r=0.35$, $p<0.001$), SRH and LLSI ($r=0.49$, $p<0.001$), ADLs difficulties and LLSI ($r=0.38$, $p<0.001$), and IADLs difficulties and LLSI ($r=0.42$, $p<0.001$). A comparable pattern was observed for the male respondents. The socio-economic variables for both gender also had correlations, for example between wealth and education ($r=0.31$, $p<0.001$), and housing tenure and wealth ($r=0.53$, $p<0.001$). For males respondents, there was a strong negative correlation between work status and age ($r=-0.56$, $p<0.001$), but this was not observed among females.

Table 37 shows the modelling strategy for predicting future carers. For both genders, only three variables were found to have a statistically significant influence on the outcome. For male future carers, these included marital status, education and wealth. For females, the variables included in the model were age, marital status and SRH. Results and discussion of the models can be found in 5.1.4.2.

Table 37 Method comparison **Model 6 and Model 7**: male and female future carers, the ELSA wave 4

Variables (final model)	Male (Model 6)		Female (Model 7)	
	Forced entry	'Backward' elimination	Forced entry	'Backward' elimination
Age	Omitted	Omitted	√	√
Marital status	√	√	√	√
Self-reported health	Omitted	Omitted	√	√
Limiting Long Standing Illness	Omitted	Omitted	Omitted	Omitted
Difficulties with ADLs	Omitted	Omitted	Omitted	Omitted
Difficulties with IADLs	Omitted	Omitted	Omitted	√ ^a
Work	Omitted	Omitted	Omitted	√ ^a
Education	√	√	Omitted	Omitted
Wealth	√	Omitted	Omitted	Omitted
Housing tenure	Omitted	√	Omitted	Omitted
-2LLR	1786.37	1743.15	2917.32	2562.53

^aOnly one category in this variable was statistically significant.

Source: author's own analysis of ELSA Waves 4, 5, 6 & 7

Figure 21 depicts a forest plot of the odds of becoming a future carer for both female and male respondents. For females, the only variables found to be significant of becoming a future carer were age, marital status and SRH. The direction of the odds was similar to that of the overall sample, however the effect size was greater for the age variable.

For males, only marital status, education level and wealth were found to be statistically significant in predicting becoming a future carer. Also here the direction of the odds was similar to that of the overall sample, however the effect size for marital status, education and wealth was higher, although education levels had lower statistical significance levels.

These gender differences in the determinants of becoming a future carer are discussed in section 6.3.3.

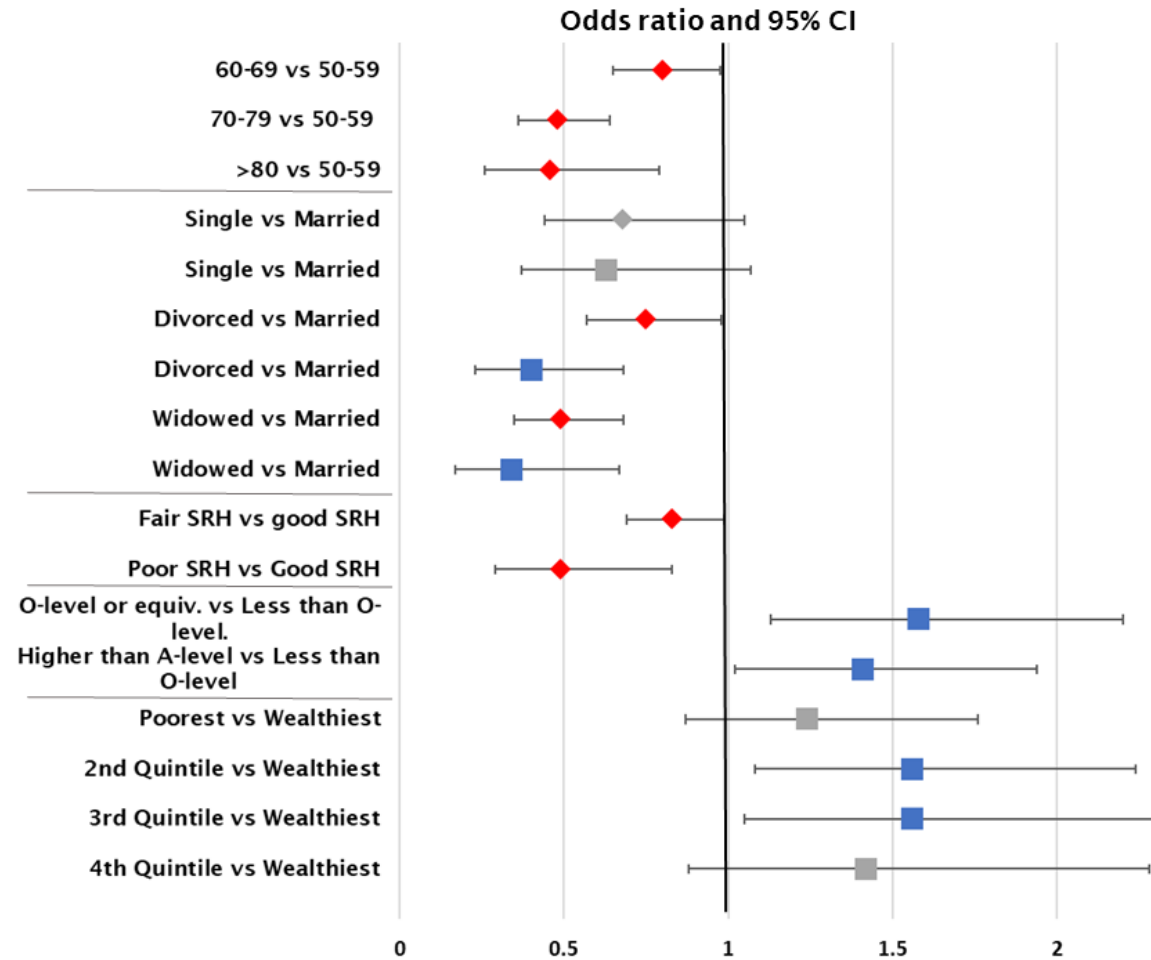


Figure 21 Forest plot of the longer-term predictors becoming a future carer by gender, the ELSA Waves 4, 5, 6 and 7

Red diamonds: female carers, Grey diamonds: female carers, variable not statistically significant. Blue squares: male carers, Grey squares: male carers, variable not statistically significant. If on the left-hand side of 1, the odds of becoming a carer is statistically significant lower, if on the right-hand side of 1 the odds are significantly higher.

Female model: $-2LLR=2917.32$, -12.8% change from base model, overall model: $X^2=102.37$, $p<0.001$. Male model: $-2LLR=1786.37$, -1.3% change from base model, overall model: $X^2=38.12$, $p<0.001$, see Appendix X for full models. Source: Author's own analysis of the ELSA Wave 7

5.1.5 Summary of the logistic regression of becoming a future carer

The binary logistic regression set out to answer Research Question 2.b. The results showed women had higher odds of becoming a future carer than men, which was expected as results from *Phase 1* had noted a similar pattern. Respondents in poor SRH had lower odds of providing care, than those in good SRH. Respondents who had higher education levels also had higher odds of becoming future carers, compared to those with less than an O-level education. This may be due to a better understanding of the health, social and benefit system, as well as associations with previous occupation, this is further discussion in section 6.3.2. Respondents from the lower end of the wealth distribution had higher odds of becoming future carers, than those in wealthier quintiles, which may be associated with gender, as more women in this sample were carers, but more women than men were in the poorer quintiles.

5.1.6 *Phase II* MODEL 8 and 9: the effects of a caring break on the carer's health

Research Question 2.c aims to explore if the timing of a caring episode (i.e. the duration after discontinuing care) had an impact on the carer's health changes from Wave 4 to 7. Therefore, carers who had provided care in Wave 5 or 6 only were identified and used as a sub-sample (Model 8). This was done to ensure that the caring duration for the two comparison groups was equal. Carers who had provided care in Wave 5 would have had a 4-year 'caring break' by Wave 7, and those providing care in Wave 6 would have had a 2-year 'caring break'. This is under the assumption that no care was provided between the ELSA interviews, however it is not possible to know if this assumption holds true. As a sensitivity test, the different timing of care provision was also tested (i.e. carers who provided care in Waves 5 and 6, compared to carers providing care in Wave 6 and 7), however provided no statistically significant results. Therefore, to allow for a longer break between the outcome measures and to ensure a higher cell-count, only caring in one wave (i.e. either in Wave 5 or Wave 6) was used.

Two multinomial logistic regressions were carried out, one including all carers in Waves 5 and 6, and one model including only those who provided care for a spouse. Evidenced from the literature and *Phase I* noted that providing care for a spouse is often associated with a higher intensity of care, which may have a greater adverse health impact on the carer (Carmichael and Ercolani, 2014) (see also sections 2.3.1.1 and 4.3.3.1). Spousal carers were therefore identified and analysed separately (Model 9). In both models non-carers acted as controls. It should be noted that in Model 9 the cell count for repeating spousal carers was too low to allow for robust analysis and this category was therefore omitted.

The dependent variable was change to SRH between Wave 4 and 7 (see section 3.3.3 change variables), and the independent variable was caring status (i.e. non-carers, repeated carers, cared in Wave 5 only, cared in Wave 6 only). Model 8(a) controlled for gender and age; Model 8(b) further controlled for marital status; and lastly Model 8(c) added work status to the regression, see Table 38. The effect of other health variables, such as LLSI and having difficulties with ADLs were also analysed, however no significant results were found.

Table 38 Modelling strategy for **Model 8**: Multinomial regression of self-reported health change by timing of care provision

Variables	Model a	Model b	Model c
Care Provision			
Non-carers	Reference	Reference	Reference
‘Repeating carers’	✓	✓	✓
Cared in Wave 5 only	✓	✓	✓
Cared in Wave 6 only	✓	✓	✓
Age	✓	✓	✓
Gender*	✓	✓	✓
Marital Status			
Married		Reference	Reference
Single		✓	✓
Divorced		✓	✓
Widowed		✓	✓
Economic Activity			
Retired			Reference
Employed full-time			✓
Employed part-time			✓
Economic inactive			✓

✓ Included in the model, * reference is female.

Source: Author’s own

Table 39 shows the results of the cross tabulation between SRH at baseline (Wave 4), SRH at first onset of care provision (i.e. Wave 5 or 6) and SRH at the final wave (Wave 7). A statistically significant difference was found between SRH and the timing of the caring episode at baseline ($X^2=15.24$, $p<0.05$). A higher proportion of the ‘repeating carers’ were healthier at Wave 4 compared to non-carers, which is also true for those providing care in Waves 5 or 6 only, albeit a slightly smaller proportion compared to the non-carers. Nevertheless, by Wave 7 there is no longer a significant difference between them. These results suggest that the carer’s health deteriorates at a faster rate compared to the health of non-carers, it is however extremely important to remember, that this analysis did not controlled for age. See also Appendix Y for a cross-tabulation of the age of the carers by the timing of the caring episode.

Table 39 Self-reported health and timing of the longer-term caring episode

	Good self-reported health	Fair self-reported health	Poor self-reported health	Total
Did not provide care in any wave				
SRH in Wave 4 (2009)	45.3%	49.0%	5.8%	100% (5,005)
SRH in Wave 7 (2015)	39.2%	53.2%	7.7%	100% (5,004)
'Repeating carers'				
SRH in Wave 4 (2009)	59.6%	36.5%	(-)	100% (50)
SRH in Wave 7 (2015)	50.0%	46.2%	(-)	
Provided care in Wave 5 ONLY				
SRH in Wave 4 (2009)	52.3%	45.3%	2.3%	100% (256)
SRH in Wave 5 (2011)	52.0%	43.8%	4.3%	
SRH in Wave 7 (2015)	45.3%	48.0%	6.6%	
Provided care in Wave 6 ONLY				
SRH in Wave 4 (2009)	51.5%	44.1%	4.5%	100% (202)
SRH in Wave 6 (2013)	42.1%	51.0%	6.9%	
SRH in Wave 7 (2015)	38.1%	54.0%	7.9%	

SRH in Wave 4 (2009) $X^2=15.24$, $p<0.05$, SRH in Wave 5 (2011) $X^2=12.74$, $p=0.175$, SRH in Wave 6 (2013) $X^2=2.20$, $p=0.988$, SRH in Wave 7 (2015) $X^2=6.87$, $p=0.333$.
(-): cell count under 5.

Source: Author's own analysis of the ELSA.

Table 40 depicts the predictors of SRH change between Wave 4 (2009) and Wave 7 (2015), all carers were included (i.e. 'repeating carers', cared in Wave 5 or in Wave 6 only). As seen there was no statistically significant difference in the odds of health change according to the timing of the care provision, compared to non-carers remaining in good SRH. Model 8a contained the care provision variable, age and gender only, while models 8b and 8c further added the independent marital status and economic activity. These last two independent variable were for most health changes statistically significant, with the exception of predicting improved health, where no effect of marital status or economic activity was observed, and the odds of deteriorating health noted economic activity to be not significant. This suggests that for people aged over 50, *ceteris paribus* marital status and employment in combination with care provision have no effect on health change, which implies that other factors may be involved in predicting the effect of care provision on health change.

Table 40 **Model 8:** The effect of a care-break on change in self-reported health outcome from 2009 to 2015

Change in Self-reported health from 2009 to 2015					
Variable	Remained in fair SRH (n=1,869)	Remained in poor SRH (n=167)	Deteriorated health (n=1,098)	Improved health (n=657)	(n)
Model a	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	
Care provision					
Non-carers	1.00	1.00	1.00	1.00	4,889
'Repeating carers'	0.64 (0.33 - 1.26)	0.45 (0.60 - 3.40)	0.71 (0.32 - 1.56)	0.59 (0.22 - 1.58)	51
Cared in Wave 5	0.79 (0.58 - 1.08)	0.64 (0.28 - 1.48)	0.94 (0.66 - 1.34)	0.73 (0.47 - 1.14)	256
Cared in Wave 6	0.94 (0.66 - 1.34)	0.76 (0.30 - 1.92)	1.28 (0.87 - 1.88)	0.62 (0.36 - 1.09)	200
Age	1.05 (1.04 - 1.06)***	1.03 (1.01 - 1.05)***	1.05 (1.04 - 1.06)***	1.07 (1.05 - 1.09)***	
Gender^a	0.85 (0.74 - 0.98)*	0.83 (0.60 - 1.15)	1.18 (1.03 - 1.37)*	1.12 (0.88 - 1.43)	2,389
Model b					
Care provision					
Non-carers	1.00	1.00	1.00	1.00	4,889
'Repeating carers'	0.67 (0.34 - 1.31)	0.52 (0.07 - 3.89)	0.73 (0.33 - 1.61)	0.60 (0.23 - 1.61)	51
Cared in Wave 5	0.79 (0.57 - 1.08)	0.66 (0.28 - 1.53)	0.93 (0.65 - 1.32)	0.73 (0.47 - 1.14)	255
Cared in Wave 6	0.97 (0.68 - 1.38)	0.82 (0.32 - 2.09)	1.31 (0.89 - 1.93)	0.63 (0.36 - 1.10)	200
Age	1.05 (1.04 - 1.05)***	1.03 (1.01 - 1.06)***	1.04 (1.03 - 1.05)***	1.01 (1.00 - 1.03)*	
Gender^a	0.91 (0.79 - 1.04)	0.91 (0.65 - 1.26)	1.25 (1.06 - 1.46)*	1.18 (0.98 - 1.42)	2,515
Marital Status					
Married	1.00	1.00	1.00	1.00	3,518
Single	1.33 (0.99 - 1.78)	2.34 (1.30 - 4.23)***	1.25 (0.88 - 1.75)	0.94 (0.62 - 1.42)	311
Divorced	1.49 (1.21 - 1.85)***	2.85 (1.87 - 4.34)***	1.44 (1.13 - 1.84)***	1.25 (0.95 - 1.66)	691
Widowed	1.46 (1.18 - 1.81)***	1.61 (0.99 - 2.63)	1.43 (1.12 - 1.82)***	1.13 (0.84 - 1.53)	875

Reference: remained in good health (n=1,605), ^areference female (n=2,880). Model a: -2LLR=2053.80, X²=186.41, p<0.001, Cox and Snell=0.034, Model b: -2LLR=3761.52, X²=232.90, p<0.001, Cox and Snell=0.045, Model c: -2LLR=5312.24, X²=407.91, p<0.001, Cox and Snell=0.073.

Source: author's own analysis of the ELSA Waves 4 and 7

Table 40 (continued) **Model 8:** The effect of a care-break on change in self-reported health outcome from 2009 to 2015

Variable	Change in Self-reported health from 2009 to 2015				(n)
	Remained in fair SRH (n=1,869)	Remained in poor SRH (n=167)	Deteriorated health (n=1,098)	Improved health (n=657)	
Model c					
Care provision					
Non-carers	1.00	1.00	1.00	1.00	4,870
'Repeating carers'	0.60 (0.30 - 1.18)	0.30 (0.04 - 2.37)	0.68 (0.31 - 1.50)	0.56 (0.21 - 1.51)	51
Cared in Wave 5	0.80 (0.58 - 1.09)	0.69 (0.29 - 1.64)	0.94 (0.66 - 1.34)	0.75 (0.48 - 1.16)	254
Cared in Wave 6	0.94 (0.66 - 1.35)	0.78 (0.30 - 2.01)	1.30 (0.88 - 1.91)	0.62 (0.36 - 1.09)	199
Age	1.04 (1.03 - 1.05)***	1.02 (1.00 - 1.05)	1.04 (1.03 - 1.05)***	1.01 (1.00 - 1.03)	
Gender^a	0.94 (0.82 - 1.09)	1.14 (0.81 - 1.60)	1.28 (1.09 - 1.51)***	1.22 (1.01 - 1.48)*	2,505
Marital Status					
Married	1.00	1.00	1.00	1.00	3,503
Single	1.29 (0.96 - 1.74)	2.09 (1.13 - 3.87)*	1.21 (0.86 - 1.70)	0.92 (0.61 - 1.39)	311
Divorced	1.48 (1.20 - 1.84)***	2.74 (1.78 - 4.23)***	1.43 (1.12 - 1.83)***	1.24 (0.93 - 1.65)	686
Widowed	1.47 (1.19 - 1.81)***	1.57 (0.96 - 2.56)	1.42 (1.11 - 1.81)***	1.13 (0.84 - 1.53)	874
Economic Activity					
Retired	1.00	1.00	1.00	1.00	3,659
Work full-time	0.71 (0.56 - 0.91)**	0.14 (0.04 - 0.45)***	0.99 (0.76 - 1.30)	0.87 (0.63 - 1.18)	631
Work part-time	0.69 (0.57 - 0.87)***	0.17 (0.06 - 0.47)***	0.91 (0.71 - 1.17)	0.94 (0.71 - 1.24)	698
Economic inactive	1.96 (1.44 - 2.68)***	9.33 (6.02 - 14.46)***	2.02 (1.42 - 2.87)	1.77 (1.17 - 2.66)**	386

Reference: remained in good health (n=1,605), ^areference female (n=2,880). Model a: -2LLR=2053.80, X²=186.41, p<0.001, Cox and Snell=0.034, Model b: -2LLR=3761.52, X²=232.90, p<0.001, Cox and Snell=0.045, Model c: -2LLR=5312.24, X²=407.91, p<0.001, Cox and Snell=0.073.
Source: author's own analysis of the ELSA Waves 4 and 7

The following multinomial regression also explored the predictors of SRH change between Waves 4 and 7, but this model only included spousal carers (Model 9). As seen from Table 41, very few categories were found to have a statistically significant difference in the odds of SRH change according to the timing of the care provision, compared to non-carers remaining in good SRH. It should be noted that this model excluded repeating spousal carers, as the cell count was too low (see section 5.1.6). Model 9a contained the care provision variable, age and gender only and Models 9b and 9c further added the independent socio-demographic variables, and these were for most health changes significant, with the exception of predicting improved health.

Model 9a found that the odds of having deteriorating health between Wave 4 and 7 compared to non-carers remaining in good SRH, were higher if having provided care in Wave 6 (OR 2.12, $p < 0.05$), however, once controlled for other socio-demographic factors, this effect no longer held true. Model 9b found that the odds of remaining in poor SRH between 2009 and 2015, compared to non-carers remaining in good SRH were higher, if providing care in Wave 5 (OR 2.88, $p < 0.05$), however this was not true for model 9a and model 9c. This is discussed further in section 6.3.4.

Table 41 **MODEL 9:** The effect of a care-break on change in self-reported health outcome from 2009 to 2015, Spousal carers

Change in Self-reported health from 2009 to 2015					
Variable	Remained in fair SRH (n=1,741)	Remained in poor SRH (n=162)	Deteriorated health (n=1,021)	Improved health (n=619)	(n)
Model a	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	
Care provision					
Non-carers	1.00	1.00	1.00	1.00	4,889
Cared in Wave 5	0.74 (0.37 - 1.47)	2.62 (0.95 - 7.22)	1.17 (0.57 - 2.36)	0.53 (0.18 - 1.59)	57
Cared in Wave 6	0.99 (0.47 - 2.05)	1.33 (0.30 - 5.95)	2.12 (1.05 - 4.27)*	1.05 (0.40 - 2.77)	59
Age	1.05 (1.04 - 1.06)***	1.03 (1.01 - 1.05)***	1.05 (1.04 - 1.06)***	1.02 (1.00 - 1.03)**	
Gender^a	0.85 (0.74 - 0.98)*	0.84 (0.60 - 1.17)	1.20 (1.02 - 1.41)*	1.16 (0.96 - 1.40)	2,389
Model b					
Care provision					
Non-carers	1.00	1.00	1.00	1.00	4,889
Cared in Wave 5	0.75 (0.37 - 1.50)	2.88 (1.04 - 7.99)*	1.18 (0.58 - 2.40)	0.54 (0.18 - 1.61)	57
Cared in Wave 6	1.04 (0.50 - 2.16)	1.59 (0.35 - 7.01)	2.21 (1.09 - 4.47)*	1.07 (0.40 - 2.82)	59
Age	1.04 (1.03 - 1.05)***	1.03 (1.01 - 1.06)***	1.04 (1.03 - 1.05)***	1.01 (1.00 - 1.03)*	
Gender^a	0.91 (0.79 - 1.05)*	0.91 (0.65 - 1.28)	1.27 (1.07 - 1.49)**	1.19 (0.98 - 1.44)	2,389
Marital Status					
Married	1.00	1.00	1.00	1.00	3,249
Single	1.33 (0.98 - 1.81)	2.39 (1.32 - 4.34)**	1.31 (0.93 - 1.86)	0.95 (0.63 - 1.47)	295
Divorced	1.48 (1.19 - 1.85)***	2.67 (1.73 - 4.13)***	1.41 (1.09 - 1.81)**	1.23 (0.92 - 1.65)	643
Widowed	1.51 (1.21 - 1.89)***	1.60 (0.97 - 2.62)	1.47 (1.14 - 1.89)***	1.13 (0.83 - 1.55)	818

Reference: Remained in good health (n=1,462), ^aReference female (n=2,216), Model a: -2LLR=1511.78, X²=176.61, p<0.001, Cox and Snell=0.035, Model b: -2LLR=3042.31, X²=220.25, p<0.001, Cox and Snell=0.049, Model c: -2LLR=4481.91, X²=388.94, p<0.001, Cox and Snell=0.075.

Source: author's own analysis of the ELSA Waves 4 and 7

Table 41 (continued) **MODEL 9:** The effect of a care-break on change in self-reported health outcome from 2009 to 2015, Spousal carers

Variable	Change in Self-reported health from 2009 to 2015				(n)
	Remained in fair SRH (n=1,741)	Remained in poor SRH (n=162)	Deteriorated health (n=1,021)	Improved health (n=619)	
Model c	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	
Care provision					
Non-carers	1.00	1.00	1.00	1.00	4,889
Cared in Wave 5	0.73 (0.36 – 1.47)	2.48 (0.85 – 7.22)	1.17 (0.58 – 2.38)	0.53 (0.18 – 1.59)	57
Cared in Wave 6	1.08 (0.52 – 2.26)	1.72 (0.37 – 7.98)	2.24 (1.11 – 4.55)*	1.09 (0.41 – 2.88)	59
Age	1.04 (1.03 – 1.05)***	1.02 (1.00 – 1.05)	1.04 (1.03 – 1.06)***	1.01 (0.99 – 1.03)	
Gender^a	0.94 (0.81 – 1.09)	1.16 (0.82 – 1.64)	1.30 (1.10 – 1.54)***	1.22 (1.01 – 1.49)*	2,389
Marital Status					
Married	1.00	1.00	1.00	1.00	3,249
Single	1.30 (0.96 – 1.77)	2.16 (1.16 – 4.01)**	1.28 (0.91 – 1.81)	0.94 (0.62 – 1.44)	295
Divorced	1.48 (1.18 – 1.84)***	2.52 (1.60 – 3.95)***	1.40 (1.08 – 1.80)**	1.22 (0.91 – 1.63)	643
Widowed	1.51 (1.21 – 1.88)***	1.52 (0.92 – 2.50)	1.46 (1.13 – 1.88)***	1.13 (0.83 – 1.55)	818
Economic Activity					
Retired	1.00	1.00	1.00	1.00	3,416
Work full-time	0.74 (0.58 – 0.96)*	0.15 (0.44 – 0.48)***	1.00 (0.75 – 1.33)	0.86 (0.62 – 1.18)	587
Work part-time	0.69 (0.54 – 0.86)***	0.18 (0.06 – 0.49)***	0.92 (0.70 – 1.19)	0.84 (0.63 – 1.13)	629
Economic inactive	1.97 (1.41 – 2.76)***	9.90 (6.29 – 15.57)***	2.21 (1.53 – 3.20)***	1.74 (1.13 – 2.69)**	354

Reference: Remained in good health (n=1,462), ^aReference female (n=2,216), Model a: -2LLR=1511.78, X²=176.61, p<0.001, Cox and Snell=0.035, Model b: -2LLR=3042.31, X²=220.25, p<0.001, Cox and Snell=0.049, Model c: -2LLR=4481.91, X²=388.94, p<0.001, Cox and Snell=0.075.

Source: author's own analysis of the ELSA Waves 4 and 7

5.1.7 *Phase II: Longer-term transitions in caring characteristics*

The transitions in intensity over the three waves were analysed, as the literature noted that there is an association between the carer's health and increased caring intensity (Carmichael and Ercolani, 2016) (see also section 2.3.2.1). Moreover, to answer Research Question 2.c, the transitions in the direction of care among the 'repeating carers' were explored. As also noted in the literature review, the type of care-recipient may influence the carer's health outcome (Bonsang, 2009; Carmichael and Ercolani, 2014). For example, spousal care tends to be provided at high intensity, and may therefore have a greater impact on the carer's health (see 4.3.3.1, Figure 13).

Table 42 depicts the changes in the intensity levels over the three waves between the different caring statuses (i.e. providing repeated care, for two consecutive waves or for non-consecutive waves).

Most of the 'repeating carers' provided care for more than 20 hours per week. A smaller proportion of this group had decreased their caring intensity level (12%) between Waves 5 and 7, whereas 15% increased the intensity during this time. Over 17% of the 'repeating carers' were classified as having irregular intensity levels of care provision between Waves 5 and 7, increasing the intensity in one wave and decreased the intensity in the next, or vice versa. Such a pattern may be associated either with the carer transitioning between different directions of care (see Table 43), or it may be due to the care-recipient's health conditions improving or deteriorating over time. However, due to the nature of the ELSA it is not possible to control for the care-recipient's health.

Carers who provided care for two-consecutive waves, had the highest proportion of stable caring intensity, and most provided low intensity care. As also seen for the 'repeating carers', more carers increased their caring intensity, than lowered it. The majority of carers (68%) caring for non-consecutive waves did so at low intensity, similar to the results also noted in *Phase I*.

Table 42 The intensity of care over the three waves (longer-term)

	'Repeating carers' (3 waves)	Provided care for 2 con. waves	Provided care non-con. waves
'Persistent light carers'	25.0%	45.7%	68.4%
'Persistent heavy carers'	30.8%	25.2%	30.5%
Decreased caring intensity	11.5%	13.9%	1.0% (-)
Increased caring intensity	15.4%	15.2%	0.3% ^a
Irregular intensity	17.3%	(-)	(-)
Total	100% (52)	100% (151)	100% (707)

^aThese carers would have increased care provision between caring at Wave 5 and Wave 7.

(-): cell count below 5.

Source: author's own analysis of ELSA Waves 4, 5, 6 & 7.

Table 43 shows the transitions between the directions of care. Among the 'repeating carers', 39% were classified as 'transitional carers', as they cared for multiple different persons between the years. Some 'transitional carers' had previously been caring for a combination of care-recipients (i.e. combination carers), but at a later point moved to providing care to only one type of care-recipient. For example, in Wave 5 the carer provided care for a spouse and a grandchild, however in Wave 7 the care then only provided care to a spouse. The remaining 'repeating carers' were 'persisting spousal carers' (26%), 'persisting parental carers' (11%) or 'persisting other carers' (7.3%). The cell count is too low for any further robust analysis, particularly for 'repeating carers'.

Table 43 The direction of care over the three Waves (longer-term)

	'Repeating carers' (3 waves)	Provided care for 2 con. waves	Provided care non-con. waves
'Persistent spousal carers'	25.7%	27.8%	25.0%
'Persistent parental carers'	11.0%	17.2%	20.8%
'Persistent cared for others'	7.3%	13.2%	19.8%
'Persistent grandchild carers'	5.8% (-)	9.9%	16.3%
'Persistent child carers'	3.8% (-)	0.7% (-)	2.5%
'Persistent combination carers'	5.8% (-)	3.3% (-)	8.9%
'Transitional carers'	38.5%	27.2%	6.6% ^a
Total	100% (52)	100% (151)	100% (707)

^aThese carers would have increased care provision between caring at Wave 5 and Wave 7. (-): cell count below 5.

Source: author's own analysis of ELSA waves 4, 5, 6 & 7

Chapter 5

Figure 22 is a visual display of the transitions between the care-recipients over three waves. The degree of thickness in the lines represents the number of individuals represented in each category. Therefore, the thicker solid lines represent the persistent carers, whereas the thinner lines (blue, red and brown) represents only a few carers. The figure displays the complexity of the transitions in the direction of care, and although the complex transitions are very individual to the carer, 38.5% (n=20) of the repeating carers moved between care-recipients. A breakdown on each individual 'repeating carer' transition can be found in Appendix Z.

A more detailed analysis of the transitions between caring characteristics is conducted in *Phase III* (see section 5.2.3) and a critical discussion of the implication can be found in section 6.3.7.

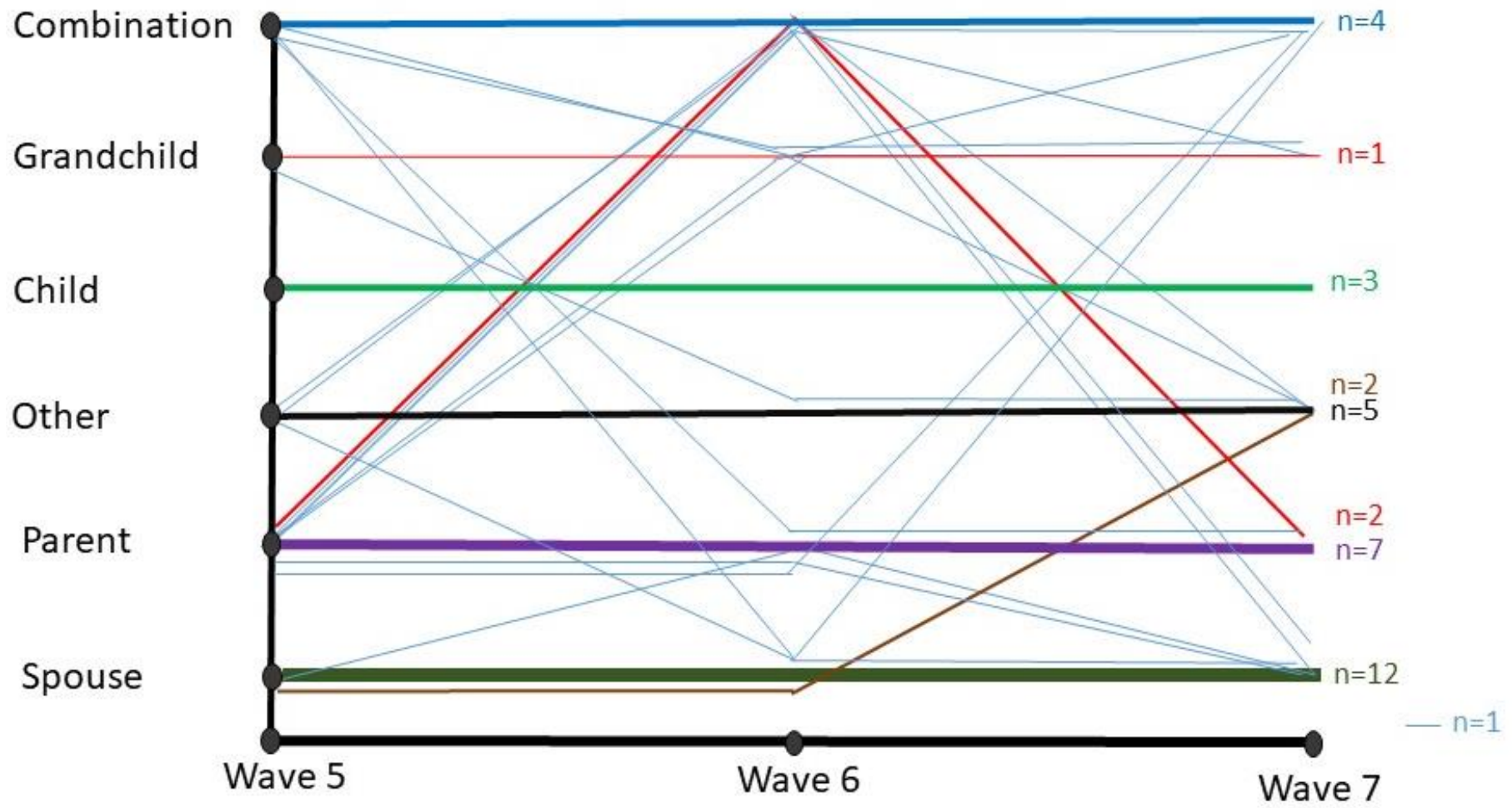


Figure 22 Longer-term transitions between directions of care, the ELSA Waves 5 to 7

The thin blue line represents single (n=1) movements between care directions, which in added together total 38.5%.
 The thin blue line represents single (n=1) movements between care directions, which in added together total 38.5%.

Source: Author's own analysis of the ELSA Wave 5 to 7

5.1.8 Case studies

A total of four case studies were created using the ELSA Waves 4 to 7. The case studies are used to generate an in-depth, multi-faceted understanding of a complex issue in its' real-life context (Crowe *et al.*, 2011). Moreover, conducting case study analysis allowed to explore greater nuances of the caring trajectories, such as who the carers are, their background, detailed family structures and the broader complexities of different health changes. It also contributed to a deeper understanding of how the intensity of care changes, who is being cared for and how the care-recipients change over time. It should, however, be recognised that case studies are only generalisable to theoretical propositions and not to the general populations, and the case studies are therefore seen as an expansion of theoretical considerations about care provision (Yin, 2003).

The case studies were conducted by randomly selecting a case from each of the following categories relating to changes (or not) to the direction of care: a persistent spousal carer, a persistent combination carer and a transitional carer, see also section 3.3.3. These directions of care were chosen because a) spousal care provision was found in *Phase 1* to be the predominant type of care provision (see also section 4.3.3.1) and b) examining the trajectories of persistent combination and 'transitional carers' provides an understanding of the complexity of the care provision relationships. After the cases were randomly selected, they were isolated in all waves and a total of 45 variables explored (see Box 2).

The variables chosen for the case studies were based on theories and evidence of issues related to informal care provision, presented in the literature review which may influence the choices made and pathways a carer takes into informal care provision, including demographic characteristics (section 2.3.1.2).

The family structure of the carer was explored, including the number of children, grandchildren, siblings and living parents, in accordance with the theory of inter-generational support, see also sections 2.2.3, 2.3.1.5 and 2.3.2.3). Likewise, the socio-economic characteristics of the carer were explored, which are associated with the opportunity cost of providing care, see also sections 2.3.1.4 and 2.3.2.2, Figure 3. In addition, how the carers' housing tenure can adapt to care provision was also examined (see also section 3.3.2.2).

Sections 2.3.1.3 and 2.3.2.1 examined how the health of the carers affect their ability and choice to provide care. The health variables were selected based on the

Chapter 5

most common conditions experienced by carers, such as difficulties with ADLs or IADLs, LLSI (see section 3.3.2.3), but also pain, hypertension and sleep patterns (Capistrant *et al.*, 2012; Lyons *et al.*, 2015; Caputo *et al.*, 2016). Information of how care respites were used (or not used) was also included, as well how the carers felt about providing care, but also more generally how the carers felt about life (Carers UK, 2012; IRISS, 2012; Lyons *et al.*, 2015). The carers' wellbeing has been associated with the ability to maintain leisure time and variables related to hobbies, holidays and reading the news paper were therefore also explored (IRISS, 2012). The variables explored for each respondent (case) in each wave (Waves 4 to 7) can be seen in Box 2, page 186.

Chapter 5

Box 2: Variables explored for the case studies

1. Gender
2. Age
3. Region of residence
4. Marital status
 - a. If married, partner's age
5. Is their mother alive?
 - a. If yes, aged of living mother; if no, at what age did the mother die?
6. Is their father alive?
 - a. If yes, aged of living father; if no, at what age did the father die?
7. Number of children (natural, adopted, foster or step-children)
8. Number of grandchildren
9. Number of living sibling
10. Self-reported health
11. Long-standing illness
12. Difficulties with activity of daily living
 - a. If yes, which activity
13. Difficulties with instrumental activity of daily living
 - a. If yes, which activity
14. Experience of pain
 - a. If yes, the severity and location of pain
15. Diagnosis of high blood pressure
 - a. If yes, is medication taken
16. Diagnosis of diabetes
 - a. If yes, is medication taken
17. Work status
18. If retired reason for retirement
19. NS-SEC for previous employment
20. Total non-pension wealth
21. Education level
22. Age left higher education
23. Housing tenure
24. Adaptions make to house
 - a. If yes, which?
25. Assess to car or van
 - a. If yes, does the respondent drive themselves?
 - b. If no, do they take public transportation?
26. Care provision
27. Number of people provided care for
28. Direction of care
29. Intensity of care provision
30. Is there someone else who can provide care should the carer need a break
31. Use of respite services
 - a. If yes, which once and how frequent?
32. Does the carer feel that they have gain from providing care?
33. Does the carer feel that they are appreciated?
34. Does the carer read a daily news paper
35. Has the carer been on a day-trip in the last few 12 months?
36. Has the carer been on a holiday either in the UK or abroad in the last few 12 months?
37. Self-perceived age
38. What age would the respondent like to be?
39. Whether felt depressed much of the time during the past week
40. Whether felt everything they did during the past week was an effort
41. Whether felt their slept was restless during the past week
42. Whether they felt happy much of the time during the past week
43. Whether felt lonely much of the time during the past week
44. Whether enjoyed life much of the time during the past week
45. Whether they could not get going much of the time during the past week

Source: author's own

5.1.8.1 Frank (ID: 107006)

Frank was 84 years old in 2009 and lived in London. Frank was married to Agnes, together they have 3 children and 6 grandchildren. Prior to retirement Frank was self-employed in a higher technical role. He took early retirement in order to enjoy life while still young and fit, but also to spend more time with Agnes and the family. Frank left school at 17 years old and has less than an O-level education. Frank and Agnes owned their house outright, which in 2009 had had no adaptation made to it. He had access to a car, which he drove himself.

In 2009 Frank did not provide care for anyone, but by 2011 Frank had started to provide care for Agnes in their home. In 2011 Frank provided 25 hours of care per week, however by 2013 this had increased to round-the-clock care. Frank relied on day-care at a centre for Agnes if he needed a break, and he used this service at least once a week, however by 2015 this was no longer applicable, although he was still providing round-the-clock care. Frank strongly agreed that he was satisfied with what he has gained from caring for Agnes and he feels appreciated.

His general SRH was good, he had no difficulties with ADLs or IADLs nor did he have any LLSI. Frank maintained his good health over the next 6 years. Although Frank was in good health and felt happy much of the time, in 2011 he did feel like everything he that done during the past week had been an effort and that his sleep was restless. Over the years this changed and by 2015 Frank no longer felt like things were an effort and he slept better, however he did have a week of feeling sad all the same. In 2009, although Frank was 84 years old, he felt like he was 75, but he would have liked to be 30. By 2013 Frank felt like he was 79 and by 2015 Frank felt like was 91, which was the age he was.

Frank read the Newspaper daily and had a hobby, but he had not been on a holiday or daytrip in the past years.

5.1.8.2 Edward (ID: 120438)

Edwards was aged 68 in 2009. He was married to Eleanor and together they lived in the East Midlands. They had 2 children and 6 grandchildren. Edward's parents had passed away, but Eleanor's parents were still alive.

Edward and Eleanor owned their house with a mortgage, however by 2013 the mortgage had been paid off. The house had had several adaptations, including widened doorways, ramps at the entrance and accessible parking. By 2011 further

Chapter 5

adaptations were made to the bathroom, including a walk-in shower, which was installed especially to assist people with health problems. Edward paid for this without any formal support. Edward had access to a car, which he drove himself. He had left school at 16 years old and had an O-level or equivalent education. He was now retired, but had worked in a higher managerial occupation, prior to retirement. Edward and Eleanor found themselves in the mid-range of the non-pension household wealth quintiles.

Edward was in good SRH, and although he had a LSI this was not limiting. He had been diagnosed with high-blood pressure for which he took medication. Edward was also troubled with mild pain most of the time. Nevertheless, he had no difficulties with either ADLs or IADLs. By 2013 this changed and Edward reported that he had difficulties with 1 ADL, namely difficulties getting in and out of bed, and his pain was now moderate. In March 2012 Edward was further diagnosed with osteoarthritis and in 2013 with diabetes for which he also took medication. For this reason by, 2015 Edward's LSI had become limiting. As well as having difficulties with the same ADL as in 2013, he also had difficulties with one IADL, which was doing work around and house and garden.

In 2009 Edward felt like he was 60, although he would have liked to be 21 again. By 2015 Edward's self-perceived aged was 65. He did not at any point over the 6 years feel depression and he felt happy much of the time, however he did have restless night sleep. When asked in 2011 and 2013 he did mention that he had felt lonely in the past week.

In 2011 Edward began providing care for Eleanor and for his parents-in-law, Sidney and Ruth, for 6 hours per week. Edward continued to provide care for Eleanor, Sidney and Ruth for the following 4 years. However, the intensity levels changes over the years, mostly likely due to Edward's deteriorating health. In 2013 Edward provides a combined 60 hours of care per week to Eleanor, Sidney and Ruth, but by 2015 this was reduced to 12 hours per week. The reductions in the intensity meant that Edward once again had time to read the daily newspaper and to go on a holiday in the UK, something he did not do in 2013. Throughout Edward's caring provision he had not relied on any respite services. Edward strongly agreed that he was satisfied with what he had gained so far from caring for Eleanor and his parents-in-law, and that he felt appreciated.

5.1.8.3 Margret (ID: 119009)

Margret was aged 60 in 2009. She was married to John and together they lived in the West Midlands. They had two children together and Margret had a further four step-children. In 2009 Margret had four grandchildren, which by 2011 had increased to 13 grandchildren. Margret's father had passed away, but Margret's 87-year-old mother was still alive. Margret also had 4 siblings. She left school at 16 years old and had an O-level education level.

In 2009 Margret worked 23 hours a week in a semi-routine occupation, however by 2011 she had retired. Margret and John owned their house with a mortgage. She has access to a car, but was only a passenger, which meant that once a week she used public transport.

In 2009 Margret's general SRH was good, however, by 2011 Margret's SRH was only fair. She had no difficulties with ADLs or IADLs, nor did she have any LLSI, which remained this way for following 6 years. In 2009 Margret felt like she was 50 years old, but would have liked to be 45. By 2015 Margret felt like she was 55 years old, even though her real age was 66.

In 2011 Margret began providing care for her parent-in-law, and although she did not live with them, she provided round-the-clock care. There was someone else Margret could rely on to provide care for her parent-in-law should she need a break. Moreover, Margret relied at least once a week on an in-home daytime respite service. In 2013 Margret stopped providing round-the-clock care, but in addition to providing care for her parents-in-law, she also started to provide care for her mother and a friend. Margret spent 30 hours per week providing care for these three people and by 2013 she no longer reported using respite services. By 2015, Margret's mother had passed away at the age of 90 of a cardiovascular-related illness. Margret now only provided care for her parent-in-law for 12 hours per week again without the use of respite services. When Margret first started providing care she strongly agreed that she was satisfied with what she had gained from providing caring and that she felt appreciated. However, by 2015 she disagreed with these two statements.

Margret never felt depressed or felt like things were an effort over the 6 years, on the contrary she always felt happy and she felt like she enjoyed life. Only in 2015 did she feel her sleep had become restless. She was able to read her daily

newspaper, have a hobby and go on holiday both in the UK and abroad both in 2013 and 2015.

5.1.8.4 Daphne (ID: 118184)

Daphne was aged 57 in 2009 and married to Daniel aged 58 years. They lived in a property which they owned outright in the North West of England. They had one child, who until 2015 lived with them in the household, and had no grandchildren. Both Daphne's parents had passed away and she had no living siblings. She left school at 18 years old, with an O-level education. In 2009 Daphne worked 36 hours per week in an intermediate administrative role, and by 2013 she had retired. She had access to a car, which she drove herself.

In 2009 Daphne's general SRH was very good and she remained in very good health over the years. She had no difficulties with ADLs or IADLs. She did have a LSI, which was not limiting, and by 2013 she had recovered. She was diagnosed with high-blood pressure of which she took medication.

In 2011 Daphne started providing round-the-clock care for Daniel. To facilitate the co-residential care they had some adaptations made to the house including: widening of doorways, accessible parking and a walk-in-shower. She had no one she could rely on if she needed a break, but she agreed that she felt like she had gained from providing care for others and that she felt appreciated. By 2013 Daniel had passed away and Daphne no longer provided care.

In 2009 Daphne felt like she was 25 years old, but by 2015 she felt 60. Over the years Dawn did not feel depressed or that everything was an effort, she felt happy much of the time and she felt that she enjoyed life. She did however feel like her sleep was restless in 2009 and 2011, but by 2013 this was no longer the case. Dawn did not read the newspaper daily. She did have a hobby and each year she went on holiday both in the UK and abroad.

5.1.9 *Phase II: Summary of longer-term transitions*

Phase II used longitudinal analysis to examine the trajectories of carers from Wave 4 (2009) to Wave 7 (2015). The analysis utilised both bivariate and multivariate methodologies to answer Research Question 2 '*What are the longer-term trajectories into informal care provision?*'

After the waves had been merged and respondents, who did not fulfil the inclusion criteria were excluded, the final sample size was 5,916. The results showed the demographic and socio-economic comparison of carers and non-carers between Wave 4 (2009) and Wave 7 (2015), and it showed a similar patterns to that seen in *Phase I*. Contrary *Phase I* (section 4.3.1) found more carers than non-carers worked part-time, in *Phase II* no statistical difference was noted between non-carers and future 'repeating carers' who were employed part-time at baseline. There was, however, a statistical difference in Wave 7, by which the proportion of non-carers had deduced by the proportion of 'repeating carers' working part-time had remained stable. These results could suggest that working part-time is a pathway into informal care provision for shorter-term carers, rather than a consequence of informal care.

Respondents who became future carers, independent of the duration they provided care, had better health at baseline (Wave 4) than non-carers, moreover the odds of becoming a future carer were higher for carers in better SRH, compared to those in poor health. This is likely a '*healthy carer effect*' and adds to the evidence that carers are self-selected into the role, as care provision can be a challenging role, which requires a certain level of good health.

The longer-term transitions of the care intensity and direction of care showed that, although for all caring statuses the majority provided care of a stable level of intensity over the waves, there was also a large proportion of carers who transited between intensity levels (i.e. increased or decreased the hours of care provided per week). When exploring the longer-term transitions of the direction of care, interestingly among the 'repeating carers', almost 40% changed between different care-recipients over the 3 waves, and a quarter provided persistent spousal care. However, the cell-count was often too low for a robust analysis.

The final analytical phase (*Phase III*) also uses a longitudinal approach, however provides a detailed focus on the transition of carers between Wave 6 (2013) and

Chapter 5

Wave 7 (2015), in order to explore how shorter-term transitions affect the health and employment of the carers and answer Research Question 3.

5.2 Phase III: Short-term transitions of informal care provision between 2013 (Wave 6) and 2015 (Wave7)

Phase III aims to answer Research Question 3, using a longitudinal analysis methodology to explore the shorter-term transitions of caring activities, using the ELSA Waves 6 (2012/2013) and 7 (2015/16) (Marmot *et al.*, 2017), (see also section 2.5, Figure 6). These two waves were at the time of the analysis the most recent subsequent waves. The advantage of exploring a shorter-time period is that it limits the effect of attrition, however the limitation is that any potential evidence of a casual effect is weaker (see section 3.6.2). This section provides detailed information of how the sample was compiled, as well as how the descriptive analysis and the logistic regression analysis was conducted.

The literature review revealed that transitions between caring statuses may be associated with different characteristics of the care provider, for example, the timings of when care provision is started, and the direction of care (Lee *et al.*, 2015; Carr *et al.*, 2016). Transitioning between caring statuses may have adverse consequences for the carers, affecting both their health, but also their financial situation, due to an accumulation of stress factors (Burton *et al.*, 2003; Lee *et al.*, 2015; Lyon *et al.*, 2015), see also section 2.3.2.1 and 2.3.2.2.

Research Question 3.a focuses on the ‘repeating carers’ only and explores the transitions between the intensity of care (hours of care per week) and the direction of care. Research Question 3.b, 3.c and 3.d uses multinomial and binary logistic regression analyses by caring statuses, in order to establish how health and employment factors have changed between 2013 and 2015 according to caring status and the determinants of discontinuing care compared to continued care provision.

5.2.1 The sample population of ELSA Wave 6 and Wave 7

Figure 23 depicts a flowchart of the final sample in Waves 6 and 7. After excluding selected respondents based on the same exclusion criteria as for Wave 7 (see also section 4.2), the final sample in Wave 6 comprised of 9,672 respondents. Those who were not present in both waves, were further excluded. This led to a total analytical sample consisting of 8,072 respondents.

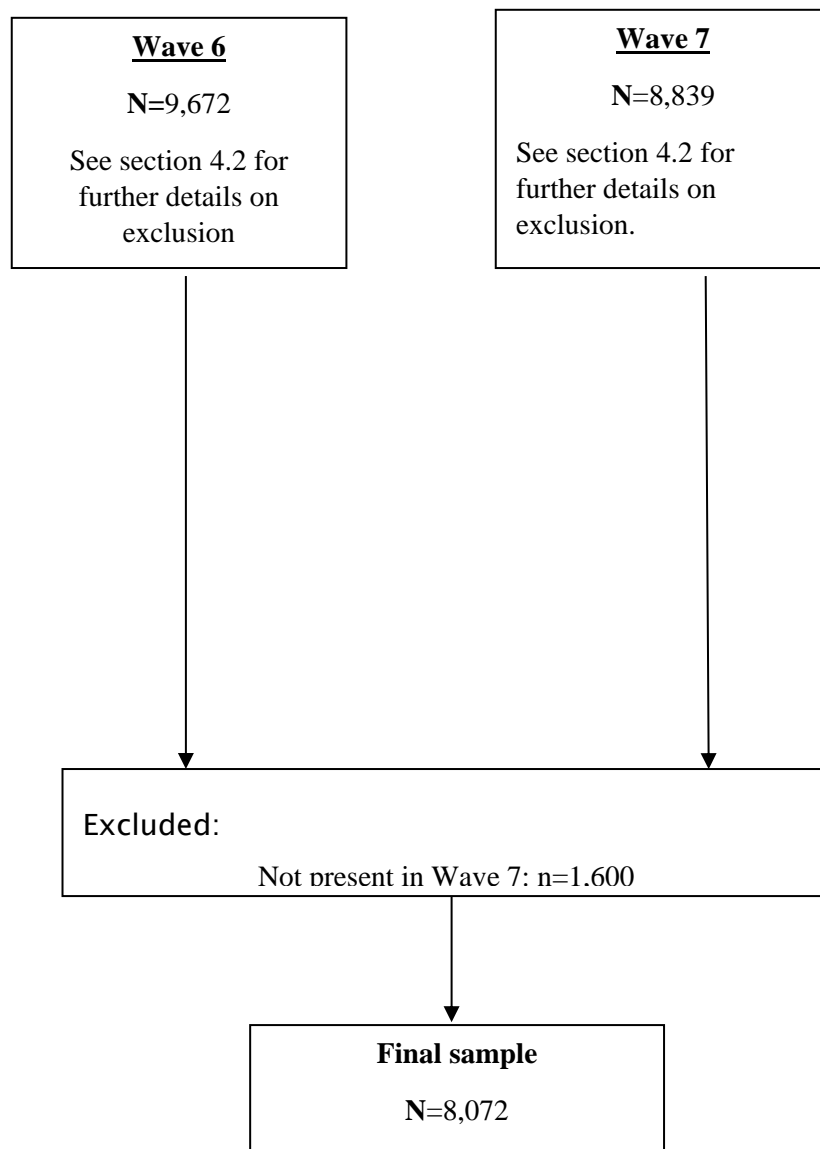


Figure 23 Flowchart of excluded respondents – the ELSA Waves 6 and 7

Source: Author’s own analysis of the ELSA Waves 6 and 7

5.2.2 *Phase III: Descriptive analysis of the demographic and socio-economic characteristics short-term transitions by caring status*

The respondents' demographic (gender, age and marital status), health (SRH, LLTI, difficulties with ADLs and IADLs) and economic characteristics (economic activity, education levels, housing tenure and wealth) at baseline (Wave 6) were summarised using descriptive statistics (frequencies and percentages) (Argyrous, 2014).

The characteristics of the non-carers were not presented, as the results were found to be almost identical to those of *Phase I* (see Chapter 4). The main descriptive data table presents the total sample number in column and row percentages, and the totals may differ due to item non-responses. A Pearson's Chi-Square (χ^2) test was used to assess the independence between the groups. Statistical significance was assumed at $p < 0.05$ (Argyrous, 2014).

As seen from Table 44 nearly 10% of respondents provided care in both Wave 6 (2013) and Wave 7 (2015). The turnover of carers was high, 10% provided care in Wave 6 only, and 8% provided care in Wave 7 only, similar to results noted by Robards *et al.* (2015). As highlighted in section 3.3.3.1, it is important to remember that it is unknown to the research whether 'repeating carers' had breaks from the caring role between waves, due to the nature of the survey questions asked, and this is discussed further in section 6.3.4.

Table 44 The short-term transitions between caring Wave 6 (2013) and Wave (2015)

Caring status	Description	% (N)
Non-carers	Did not provide care in 2013 or 2015	71.8%
'Repeating carers'	Provided care in both 2013 and 2015	9.8%
'Discontinued carers'	Provided care in 2013, but not in 2015	10.2%
'New carers'	Provided care in 2015, but not in 2013	8.2%
Total		100% (8,072)

Source: Author's own analysis of the ELSA Wave 6 and 7

Chapter 5

Figure 24 depicts the distribution of the caring statuses by sex. Among the female respondents, 37% were 'repeating carers', 35% 'discontinued carers' and 27% 'new carers'. Among the male respondents, 31% were 'repeating carers', 38% 'discontinued carers' and 31% were 'new carers'. The row percentages in Table 45 shows that 67% of 'repeating carers', 61% of 'discontinued carers' and 60% of 'new carers' were women. The majority of the 'repeating carers' provided care for the same direction of care at both time points. See also section 5.2.3 for further analysis of the changes in intensity and direction of care.

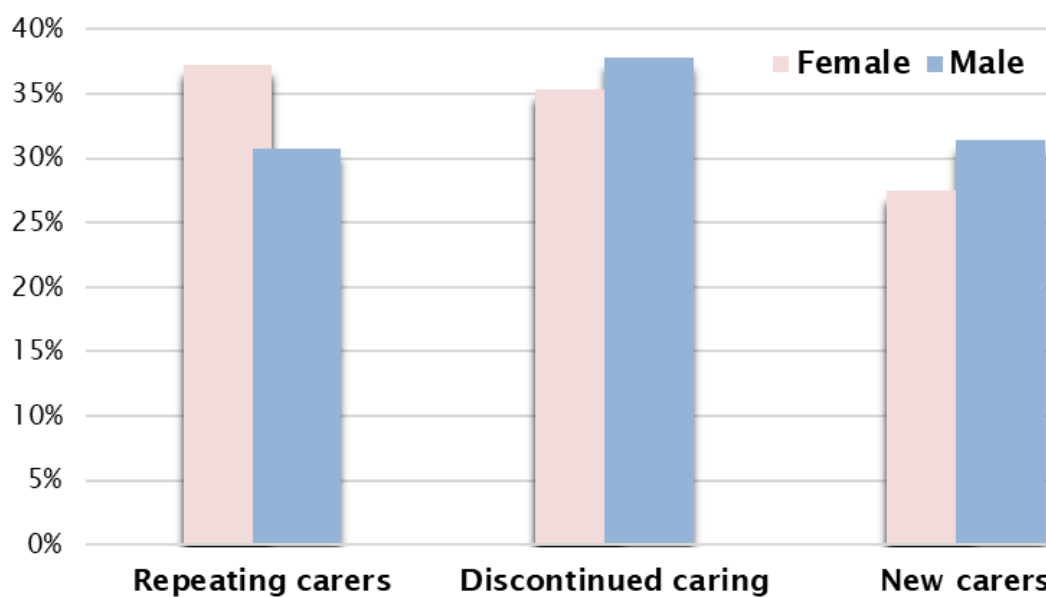


Figure 24 Caring status in 2015 by sex

$X^2=10.35$, $p<0.01$ - unweighted data. For row percentage, see also Table 45.

Source: author's own analysis of the ELSA Wave 6 and 7

Table 45 presents the socio-demographic and economic characteristics of the respondents by caring status, see section 5.2.2. Conversely, only a handful of variables were noted to have a statistically significant difference between the caring statuses, and these included gender, marital status, SRH and economic activity.

Table 45 Descriptive summary by short-term caring status

		'Repeating carers' N=791	Discontinued caring N=823	'New carers' N=657	Pearson X ² Square
Total of sample		N=791	N=823	N=657	
Gender					
	Male	32.7%	38.8%	40.3%	P<0.010
	Female	67.3%	61.2%	59.7%	
		100% (791)	100% (823)	100% (657)	
Mean Age (SD)^a		66.5 (7.9)	66.7 (8.3)	66.5 (8.4)	p=0.927
Age Group					
	50-59	21.5%	19.0%	23.9%	p=0.168
	60-69	45.8%	47.8%	41.6%	
	70-79	25.2%	24.2%	26.2%	
	Over 80	7.6%	9.1%	8.4%	
		100% (791)	100% (823)	100% (657)	
Marital Status					
	Single, never married	4.6%	3.9%	5.3%	p<0.001
	Married or partnered	78.3%	68.7%	76.6%	
	Divorced, including separated	9.1%	14.0%	9.9%	
	Widowed	8.1%	13.5%	8.2%	
		100% (791)	100% (823)	100% (657)	
Self-reported Health					
	Good	40.2%	42.3%	45.7%	P<0.050
	Fair	53.1%	50.5%	50.7%	
	Poor	6.7%	7.2%	3.7%	
		100% (791)	100% (823)	100% (657)	
Longstanding Illness					
	No	42.4%	45.9%	45.7%	p=0.396
	Yes, but not limiting	22.6%	21.3%	23.7%	
	Yes and limiting	35.0%	32.8%	30.6%	
		100% (791)	100% (822)	100% (657)	
Difficulties with ADLs					
	None	82.7%	85.1%	87.5%	p=0.532
	1 ADL	10.1%	8.0%	7.2%	
	2 or more ADLs	7.2%	6.9%	5.3%	
		100% (791)	100% (822)	100% (657)	
Difficulties with IADLs					
	None	82.7%	83.7%	82.8%	p=0.512
	1 IADL	10.1%	8.3%	10.5%	
	2 or more IADLs	7.2%	8.0%	6.7%	
		100% (791)	100% (823)	100% (657)	

The table continues on the following page. ADL: Activities of daily living, IADL: Instrumental activities of daily living. Unweighted data.

Source: author's own analysis of the ELSA Wave 6 and 7.

Table 45 (continued): Descriptive summary by short-term caring status

	'Repeating carers' % (n)	Discontinued caring % (n)	'New carers' % (n)	Pearson X ² Square
Economic Activity				
Retired	55.0%	57.3%	60.9%	p<0.001
Employed: Full-time(>=35hrs)	10.5%	14.1%	13.9%	
Employed: Part-time(<=35hrs)	17.9%	18.0%	17.7%	
Economic inactive	16.6%	10.5%	7.5%	
	100% (789)	100% (820)	100% (654)	
Mean Working Hours (SD)^a	27.9 (18.4)	29.2 (15.5)	30.0 (16.0)	p=0.271
Education Level				
less than O-level	37.8%	38.2%	36.8%	p=0.454
O-level or equivalent	32.6%	31.3%	29.3%	
higher than A-level	29.6%	30.6%	33.9%	
	100% (783)	100% (815)	100% (655)	
Housing Tenure				
Own outright	68.0%	69.8%	69.6%	p=0.089
Own with mortgage or loan	15.5%	15.2%	16.4%	
Private renting	2.8%	3.4%	3.7%	
Social renting	13.3%	10.0%	9.6%	
Live rent free	0.4% (-)	1.6%	0.8 (-)	
	100% (791)	100% (820)	100% (657)	
Non-pension Wealth Quintiles				
Poorest	16.8%	14.8%	14.5%	p=0.857
2 nd Quintile	19.4%	17.5%	17.0%	
3 rd Quintile	21.3%	22.9%	22.4%	
4 th Quintile	21.9%	23.0%	23.9%	
Wealthiest	20.6%	21.8%	22.2%	
	100% (695)	100% (721)	100% (553)	

^aIndependent-samples Kruskal-Wallis Test

Unweighted data.

Source: author's own analysis of ELSA Wave 6 and 7

Chapter 5

Figure 25 shows the association between caring status and marital status. Among single respondents (never married), there was a nearly even distribution between the caring statuses. Among those married (partnered), the proportion of ‘repeating carers’ was the highest (37%). By contrast, among those who were either divorced or widowed, the highest proportion were ‘discontinued carers’ (46% and 48%, respectively). A high proportion of carers in this study provides care to a spouse (section 4.3.3.1, Figure 14), which may also help to explain why more ‘discontinued carers’ were either divorced or widowed compared to ‘repeating carers’, as these carers may have stopped providing care by 2015, due to becoming widowed or getting divorced. The ELSA does unfortunately not allow for further exploration as to why carers stopped providing care. This is further discussed in section 6.3.7.

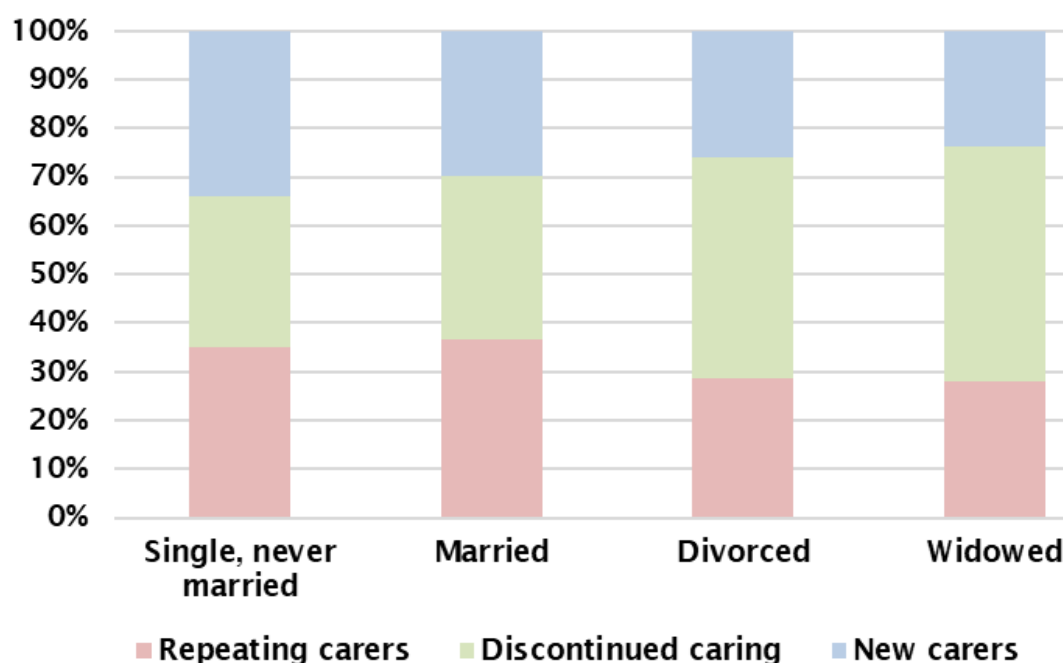


Figure 25 Short-term caring status in 2015 by marital status

$\chi^2=31.99$, $p<0.001$ - unweighted data. See also Table 45, for row percentage.

Source: author’s own analysis of the ELSA Wave 6 and 7

Among ‘repeating carers’ 40% were in good SRH, 53% in fair SRH, and 7% in poor SRH. Among ‘discontinued carers’ a similar pattern was observed. Among ‘new carers’ 46% were in good SRH, 51% fair SRH and only 4% in poor SRH. As seen from Figure 26, among those in poor SRH 43% discontinued providing care in 2015 and only 18% started providing care in 2015. This may suggest that being in good health came before the onset of care provision and that poor health causes carers to discontinue the role, this is similar to the ‘*healthy carer effect*’ found in *Phase II* (see section 5.1.6). These results should be interpreted with caution, as they have not been controlled for age and the question of causality therefore still stands: is

Chapter 5

the poor health caused by care provision or is biased by the association between health and age? (OECD, 2003), and this is further discussed in section 6.3.4. It should also be noted that no statistical difference was found between caring status and age (Table 45).

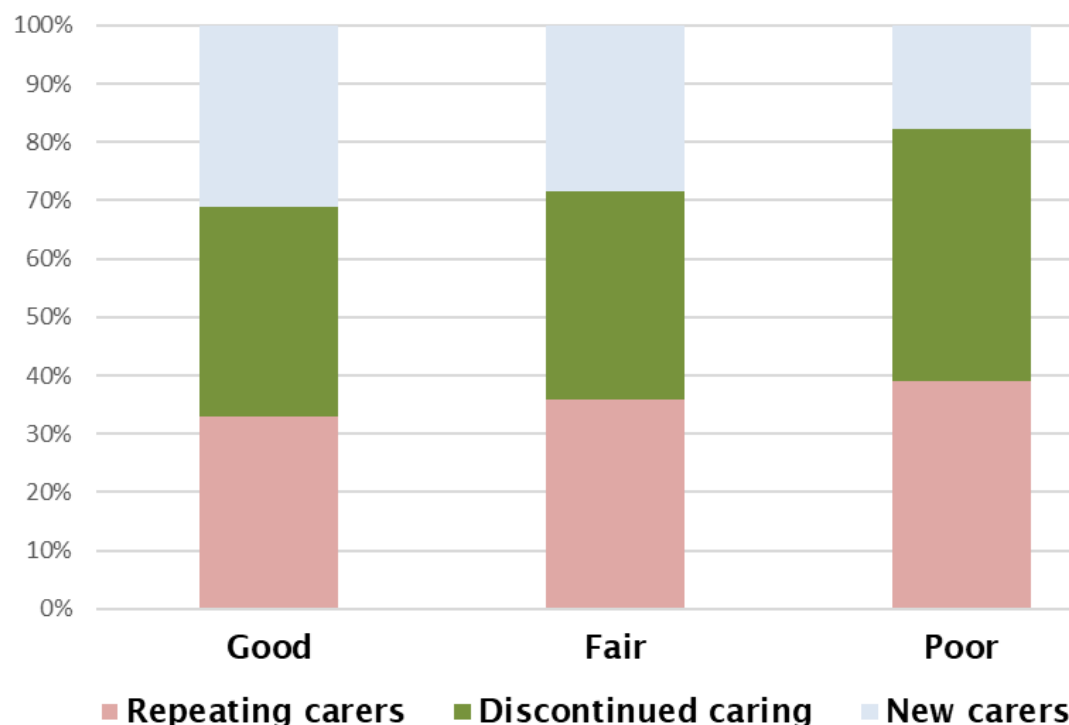


Figure 26 Short-term caring status in 2015 by self-reported health

$X^2=11.73$, $p<0.05$ - unweighted data. For row percentage, see also Table 45.

Source: author's own analysis of the ELSA (Wave 6 and 7).

As also seen from Table 45 a statistically significant difference was found between caring status and economic activity. Among 'repeating carers' 55% were retired, 11% worked in full-time employment, 18% part-time (which was the same for all three caring statuses) and 17% were economically inactive (see also section 3.3.2.2 for definition). Among 'discontinued carers' 57% were retired, 14% worked full-time and 11% were economically inactive. By contrast, among 'new carers' the highest proportion were retired (60%), 14% worked full-time and only 8% were economic inactive.

The next section further concentrates on the transition in the intensity and direction of care, mainly focussing on the 'repeating carers', but also exploring who the 'new carers' provide care for and the intensity of care provided by 'new carers'.

5.2.3 Phase III: Short-term transitions between intensity and directions of care

To address Research Question 3.a, transitions between the caring intensity and directions of care were explored. This is important not only to better understand the pathways into informal care, but also the journey within the caring episode. Transitions in the intensity of care, particularly increased intensity, have been associated with adverse health and financial circumstances (Lee *et al.*, 2015; Lyon *et al.*, 2015). Moreover, as seen from the care studies of Edward (section 5.1.8.2) and Margret (section 5.1.8.3), carers often have complex patterns of transitions.

The transitions between different levels of intensity of care can be seen in Table 46 and by sex in Table 47 and Table 48. The boxed area of the tables (bold line) symbolises 'repeating carers'; the grey shaded top row are 'new carers'. The bold figures represent no transition in the intensity, the percentages on the right of the bold figures represent an increase in the intensity and to the left a decrease in the caring intensity.

Table 46 Short-term transition in intensity (hours per week) of care between Wave 6 (2013) and Wave 7 (2015)

		Wave 7				
		1-19	20-49	50-167	168	
Wave 6	0	67.9%	15.6%	2.9%	13.5%	100% (652)
	1-19	73.9%	14.9%	2.5%	8.7%	100% (402)
	20-49	45.6%	31.9%	8.1%	14.4%	100% (160)
	50-167	22.2%	29.6%	25.9%	22.2%	100% (54)
	168	19.6%	12.7%	10.1%	57.6%	100% (158)

$\chi^2=278.13$ (df: 9), $p<0.001$ (based on the 'repeating carers' only) – unweighted data. (-) cell count below 5. The bold boxed area: 'repeating carers'; grey shading: 'new carers'. Bold figures: no transition in the intensity.

Source author's own analysis of the ELSA Wave 6 and 7.

Among the 'new carers' the largest proportion started to provide care between 1 to 19 hours per week (low intensity), and this pattern was similar for females and males, see Table 47 and Table 48. Contrastingly, 13.5% of the 'new carers' started providing 24-hour care, which was slightly less for females (12.3%) and more for males (15.3%).

The majority of the 'repeating carers' provided the same intensity of care in 2013 and 2015 or decreased the intensity (Table 46). For example, among those providing between 20 to 49 hours of care per week (moderate intensity) 32% provided the same intensity in both years, and 48% lowered the intensity level. However, 12% who provided care at moderate intensity in 2013, provided 24-hour

Chapter 5

care by 2015. Among carers who had provided low intensity care in 2013, 15% had increased the intensity to moderate intensity by 2015.

The sample was divided by sex to explore the differences between the transitions of caring patterns. The results of the female carers can be seen in Table 47 and shows that among those providing care of moderate intensity 32% remained at this level, whereas 48% had reduced the intensity, and over 20% increased the caring intensity.

Table 47 Short-term transition in intensity of care between Wave 6 and 7 - **Female**

		Wave 7				
		1-19	20-49	50-167	168	
Wave 6	0	67.2%	17.7%	2.8%	12.3%	100% (390)
	1-19	73.7%	15.3%	3.1%	8.0%	100% (262)
	20-49	48.0%	31.7%	8.1%	12.2%	100% (123)
	50-167	28.6%	28.6%	31.4%	11.4% (-)	100% (35)
	168	18.2%	14.1%	10.1%	57.6%	100% (99)

$X^2=196.15$ (df: 9), $p<0.001$ (based on the 'repeating carers' only) – unweighted data. (-) cell count below 5. Source author's own analysis of the ELSA Wave6 and 7

Table 48 shows the transitions for the male carers, here 32% also remained at moderate intensity, however a smaller proportion than females reduced their hours (38%) and 22% started to provide 24-hour care in 2015. Among female carers who had provided between 50 to 167 hours of care per week (heavy intensity), none had in 2015 moved to provide 24-hour care. By contrast, among male carers at this same intensity level, 42% provided 24-hour care in Wave 7. As discussed this gender difference is likely due to the age difference between the carers and the persons cared for, see also section 4.3.3.1, Figure 14.

Table 48 Short-term transition in intensity of care between Wave 6 and 7 - **Male**

		Wave 7				
		1-19	20-49	50-167	168	
Wave 6	0	69.1%	12.6%	3.1%	15.3%	100% (262)
	1-19	74.3%	14.3%	1.4% (-)	10.0%	100% (140)
	20-49	37.8%	32.4%	8.6% (-)	21.6%	100% (37)
	50-167	10.5% (-)	31.6%	15.8% (-)	42.1%	100% (19)
	168	22.0%	10.2%	10.2%	57.6%	100% (59)

$X^2=91.46$ (df: 9), $p<0.001$ (based on the 'repeating carers' only) – unweighted data. (-) cell count below 5. Source author's own analysis of the ELSA Wave 6 and 7

Research Question 3.b addressed transitions in the direction of care, as noted from the literature review the direction of care influences the pathways into informal care, see also section 2.2.3 and 2.3.2.3. Although transitions in the caring direction were also analysed in *Phase II* (section 5.1.7) the cell-count was too low to compare

Chapter 5

transitions by sex. Moreover, it was not possible in *Phase II* to examine the direction of care among the ‘new carers’ and ‘discontinued carers’.

Table 49 depicts the transitions in the direction of care and to whom the ‘new carers’ initially provided care to. Among the ‘new carers’ 26% started to provide care for a spouse, 20% for a parent, 25% for others (including other relatives, friend and neighbours), 16% provided care for a grandchild, 5% for a child and 9% started to provide care for a combination of care recipients. The transitions for ‘repeating carers’ who only provide care for one direction (i.e. spouse/parent/other) were minimal, see Table 49. Conversely, more transitions were noted among carers providing care for a combination of care-recipients in Wave 6, 34% still provided care for a combination of recipients, however 21% had changed to caring for a spouse only, 20% for a parent, 7% for others and 16% now cared for a grandchild.

Table 49 Short-term transition in direction of care between Wave 6 and 7

		Wave 7						
		Spouse	Parent	Others	Grandchild	Child	Combination	
Wave 6	No care provided in 2013	25.9%	19.8%	24.5%	16.4%	4.9%	8.5%	100% (657)
	Spouse	86.2%	1.5 (-)	3.8%	1.1% (-)	(-)	7.3%	100% (261)
	Parent	4.6%	74.3%	7.2%	4.6%	(-)	9.2%	100% (152)
	Others	8.2%	3.1% (-)	75.5%	9.2%	(-)	4.1% (-)	100% (98)
	Grandchild	7.0%	2.3% (-)	6.2%	77.5%	(-)	7.0%	100% (129)
	Child	6.7% (-)	4.4% (-)	6.7% (-)	(-)	68.9%	13.3%	100% (45)
	Combination	20.8%	19.8%	6.6%	16.0%	2.8% (-)	34.0%	100% (106)

$\chi^2=6074.58$ (df: 36), $p<0.001$ (based on the ‘repeating carers’ only) – unweighted data. The **bold** box: ‘repeating carers’; grey shading: ‘new carers’; and **bold** figures: no transition in the direction of care. (-): Cell counts less than 5 have been omitted, therefore totals may not add to 100%. Source: author’s own analysis of the ELSA (Waves 6 and 7).

Chapter 5

In order to address Research Question 2.a (see section 1.2) the analysis was divided by sex as a difference in the caring characteristics has been noted (see also section 4.3.2).

Table 50 shows more transitions between the directions of care among the female ‘repeating carers’ than the male ‘repeating carers’ (Table 51). For example, although 73% of female ‘repeating carers’ provided care to a parent at both time-points, 7.6% from parental care to others, 4.8% to a grandchild and 11% to providing care for a combination of individuals. Among female carers who had provided care for a combination of individuals in Wave 6, even more transitions of the direction of care were noted. For instance, 20% had changed to solely caring for a spouse, 17% for parents, 7% for others and 18% for grandchildren, this is further discussed in section 6.3.7.

Table 50 Short-term transition in direction of care between Wave 6 and 7 - Female

		Wave 7						Total
		Spouse	Parent	Others	Grandchild	Child	Combination	
Wave 6	No care provided in 2013	22.2%	20.7%	25.3%	17.3%	5.4%	9.2%	100% (392)
	Spouse	82.3%	2.8% (-)	5.0%	0.7% (-)	(-)	9.2%	100% (141)
	Parent	2.9% (-)	73.3%	7.6%	4.8%	(-)	11.4%	100% (105)
	Others	7.0%	5.6% (-)	74.6%	9.9%	(-)	2.8% (-)	100% (71)
	Grandchild	6.3%	3.1% (-)	8.3%	76.0%	(-)	6.3%	100% (96)
	Child	5.7% (-)	5.7% (-)	2.9% (-)	2.9% (-)	71.4%	11.4% (-)	100% (35)
	Combination	20.2%	16.7%	7.1%	17.9%	2.4% (-)	35.7%	100% (84)

$\chi^2=1135.05$ (df: 25), $p<0.001$ (based on the ‘repeating carers’ only) – unweighted data. The **bold** box: ‘repeating carers’; grey shading: ‘new carers’; and **bold** figures: no transition in the direction of care. (-): Cell counts less than 5 have been omitted, therefore totals may not add to 100%. Source: author’s own analysis of the ELSA (Waves 6 and 7).

Chapter 5

Table 51 shows that the transitions between the direction of care for males was minimal and 91% of male carers who cared for a spouse in 2013, also provided care for a spouse in 2015. As also seen for the female carers, among male carers who provided care for a combination of individuals, more transitions were seen, and 23% had transited into solely providing care for a spouse and 32% to a parent only.

Table 51 Short-term transition in direction of care between Wave 6 and 7 - **Male**

		Wave 7						
		Spouse	Parent	Others	Grandchild	Child	Combination	
Wave 6	No care provided in 2013	31.3%	18.5%	23.4%	15.1%	4.2%	7.5%	100% (265)
	Spouse	90.8%	0.8% (-)	3.3% (-)	(-)	(-)	5.0%	100% (120)
	Parent	8.5% (-)	76.6%	4.3% (-)	4.3% (-)	(-)	4.3% (-)	100% (47)
	Others	11.1% (-)	7.4% (-)	77.8%	(-)	(-)	3.7% (-)	100% (27)
	Grandchild	12.1% (-)	(-)	(-)	81.8%	(-)	6.1% (-)	100% (33)
	Child	20% (-)	20% (-)	(-)	(-)	60.0%	(-)	100% (10)
	Combination	22.7%	31.8%	13.6% (-)	4.5% (-)	(-)	27.3%	100% (22)

$\chi^2=615.91$ (df: 25), $p<0.001$ (based on the 'repeating carers' only) – unweighted data. The bold box: 'repeating carers'; grey shading: 'new carers'; and bold figures: no transition in the direction of care. Cell counts less than 5 have been omitted, therefore totals may not add to 100%.
Source: author's own analysis of the ELSA (Waves 6 and 7).

Transitions in the intensity and direction of care over a 2-year period revealed more movement than observed in *Phase II*, although the majority provided care at the same intensity level between Waves 6 and 7. Most transitions were undertaken by female carers and by carers providing care for a combination of care-recipients.

The next part of the *Phase III* analysis presents the predictors of a change in SRH status and economic activity by caring status. The section also presents a binary logistic regression model of the predictors of discontinuing care provision compared to continuing to provide care.

5.2.4 Introduction to the *Phase III* binary and multinomial logistic regression analysis design

In order to answer Research Question 3.b and 3.c and to explore the potential causal effect of the changes to carer's SRH and economic activity according to caring status between Wave 6 (2013) and Wave 7 (2015) were analysed. The literature had shown that changes in one's caring status may have an adverse effect on the carer's health (Vlachantoni *et al.*, 2016), see also section 2.3.2.1. It is important to ensure carers maintain good health, not only to avoid themselves needing care, but also to ensure a continuing supply of care provision. Moreover,

any changes to economic activity are especially important from a policy perspective, as this may help to understand how best to retain carers in employment.

When the dependent variable is nominal and has more than two levels, a multinomial logistic regression analysis can be applied (i.e. non-carers, 'repeating carers', 'discontinued carers' and 'new carers') (IBM, 2013a; Argyrous, 2014).

A total of four models are shown: 1) predictors of health change by caring status; 2) predictors of health change by changes to caring intensity; 3) changes to employment by caring status; and 4) predictors of discontinuing care provision. All the models controlled for age and results were displayed in separated table according to the caring status. The tables display the adjusted odds ratios (OR) and 95% confidence intervals (CIs).

5.2.4.1 *Phase III* MODEL 10 and 11: Short-term predictors of change in self-reported health by caring status and by change to caring intensity

Table 52 is a cross-tabulation of SRH in Waves 6 and 7 and the results show that the majority of carers remained in the same health status between the waves. Nearly 21% improved from fair to good SRH and 42% from poor to fair. Conversely, nearly 29% deteriorated from good to fair SRH, but only 7% from fair to poor health. There was only a marginal percentage of carers who changed from good to poor, or from poor to good.

Table 52 Self-reported health status in (Wave 6) 2013 by self-reported health in Wave 7 (2015), the ELSA

		2015 (Wave 7)			
		Good (n=3,278)	Fair (n=4,190)	Poor (n=599)	Total
2013 (Wave 6)	Good	70.7%	28.6%	0.7%	100% (3,436)
	Fair	20.7%	72.8%	6.5%	100% (4,093)
	Poor	0.7% (-)	42.1%	57.2%	100% (538)

Pearson Chi-Square 4099.623 (df:4), $p < 0.001$. Unweighted data. Source: Author's own analysis of the ELSA Waves 6 and 7.

Model 10 is a multinomial logistic regression analysing the determinants of the caring statuses (i.e. non-carers, 'repeating carers', 'discontinued carers' and 'new carers') and predictors of changes to SRH. The reference category for the independent variable was 'non-carers' and the reference category for the predictor variable was 'remaining in good SRH'. Each of the other three statuses were

Chapter 5

compared to these reference group, and the model has been controlled for age (Model 10b), see also section 3.4 for the analysis strategy.

The results in Table 53 found that respondents, who remained in fair SRH compared to remaining in good SRH, had higher odds of being a 'repeating carer', compared to a non-carer, once the model controlled for age (OR 1.21, $p < 0.05$). No other changes in SRH were of statistical significance in predicting the odds of being a 'repeating carer', compared to being a non-carer.

If one's SRH had improved compared to remaining in good SRH, the odds of 'discontinuing care' compared to being a non-carer were significantly lower (OR 0.71, $p < 0.01$).

Lastly, those who remained in fair health or who had a deteriorated SRH status showed lower odds of being a 'new carer' compared to those who remained in good health (OR 0.28, $p > 0.001$ and OR 0.73, $p > 0.01$, respectively). However, after controlling for age, the effect of deteriorated health was no longer statistically significant. This may be due to more 'new carers' providing care for a spouse (see Table 49), which in turn is associated with higher age of the carer, and higher age is associated with age-related deteriorated health (see sections 3.3.2.3 and 4.3.3.1).

Chapter 5

Table 53 **Model 10:** Multinomial regression by short-term change to self-reported health status

	Model A	Model B	
<i>'Repeating Carers'</i>	OR (95% CI)	OR (95% CI)	% (n)
Age	Omitted	0.97 (0.96 – 0.98)***	
Self-reported health transition			
Remained in good health	1.00***	1.00	28.7% (277)
Remained in fair health	1.08 (0.90 – 1.30)	1.21 (1.01 – 1.46)*	38.9% (288)
Remained in poor health	0.63 (0.40 – 1.01)	0.70 (0.44 – 1.12)	2.7% (30)
Deteriorated health	1.01 (0.80 – 1.27)	1.09 (0.86 – 1.38)	15.7% (139)
Improved health	1.06 (0.83 – 1.35)	1.13 (0.88 – 1.44)	14.0% (88)
Total			100% (822)
<i>'Discontinued Carers'</i>			
Age	Omitted	0.98 (0.97 – 0.98)***	
Self-reported health transition			
Remained in good health	1.00***	1.00	33.7% (277)
Remained in fair health	0.83 (0.69 – 0.99)*	0.91 (0.76 – 1.08)	35.0% (288)
Remained in poor health	0.74 (0.50 – 1.11)	0.80 (0.54 – 1.20)	3.6% (30)
Deteriorated health	0.92 (0.74 – 1.15)	0.98 (0.79 – 1.23)	16.9% (139)
Improved health	0.69 (0.53 – 0.89)***	0.71 (0.55 – 0.92)**	10.7% (88)
Total			100% (822)
<i>'New Carers'</i>			
Age	Omitted	0.97 (0.96 – 0.98)***	
Self-reported health transition			
Remained in good health	1.00***	1.00	34.1% (224)
Remained in fair health	0.87 (0.71 – 1.05)	0.98 (0.81 – 1.19)	37.1% (244)
Remained in poor health	0.28 (0.14 – 0.54)***	0.30 (0.15 – 0.60)***	1.4% (9)
Deteriorated health	0.73 (0.57 – 0.95)**	0.78 (0.60 – 1.02)	13.5% (89)
Improved health	0.88 (0.68 – 1.14)	0.94 (0.72 – 1.21)	13.9% (91)
Total			100% (657)

Reference group: Non-carers: n=5,680. OR: odds ratio; 95% CI: confidence interval. *p<0.05, **p<0.01, ***p<0.001

Model A: Valid N=8,072; -2LL=96.01, X²=38.24 (df: 12), p<0.001.

Model B: Valid N=7,935; -2LL=1951.12, X²=130.04 (df: 15), p<0.001.

Source: author's own analysis of the ELSA Waves 6 and 7

Chapter 5

The literature showed that increased intensity can have an adverse effect on the carer's health (Carmichael and Ercolani, 2016), see also section 2.3.2.1. Model 11 (Table 54) is a nominal regression analysing the change to caring intensity (i.e. 'persistent low-intensity' carer, 'persistent heavy-intensity' carer, decreased intensity or increased intensity) by changes to SRH between Wave 6 (2013) and Wave 7 (2015). Carers who provided 'persistently low-intensity' care were the reference (see sections 3.3.3.4 and 3.4 for the analysis strategy).

The results showed no statistically significant effect in the odds of any health change between the two waves between carers had increased or decreased their care intensity, compared to the 'persistently low-intensity' carers.

Compared to 'persistent low-intensity' carers, the 'persistent heavy-intensity' carers, who remained in fair (OR 2.12, $p > 0.001$) or poor SRH (OR 4.76, $p > 0.001$) or had deteriorating SRH (OR 2.03, $p > 0.05$) had higher odds of providing heavy intensity care than 'persistent heavy' carers who remained in good SRH. As discussed this may be due caring for to a spouse is associated with higher age of the care and higher caring intensity care. This effect remains significant after controlling for age. It should be noted that the confidence interval for remaining in poor health is wide, and this could indicate that the sample size was too small to make conclusions.

Chapter 5

Table 54 **Model 11:** Multinomial regression by short-term change caring intensity and self-reported health status

	Model A	Model B	
<i>Persistent High Intensity Carers</i>	OR (95% CI)	OR (95% CI)	% (n)
Age	Omitted	1.04 (1.02 – 1.06)***	
Self-reported health transition			
Remained in good health	1.00***	1.00***	28.6% (225)
Remained in fair health	2.12 (1.39 – 3.23)***	1.99 (1.30 – 3.05)***	38.9% (306)
Remained in poor health	4.76 (1.60 – 14.17)***	4.60 (1.53 – 13.83)**	2.7% (21)
Deteriorated health	2.03 (1.19 – 3.46)*	1.96 (1.15 – 3.36)*	15.8% (124)
Improved health	1.60 (0.94 – 2.74)	1.56 (0.91 – 2.67)	14.0% (110)
Total			100% (786)
Increased Intensity			
Age	Omitted	1.02 (0.99 – 1.05)	
Self-reported health transition			
Remained in good health	1.00***	1.00***	28.6% (225)
Remained in fair health	2.31 (1.33 – 4.00)*	2.23 (1.28 – 3.86)	38.9% (306)
Remained in poor health	1.78 (0.33 – 9.69)	1.73 (0.32 – 9.45)	2.7% (21)
Deteriorated health	1.80 (0.88 – 3.66)	1.75 (0.86 – 3.56)	15.8% (124)
Improved health	1.13 (0.53 – 2.44)	1.10 (0.51 – 2.38)	14.0% (110)
Total			100% (786)
Decreased intensity			
Age	Omitted	1.01 (0.98 – 1.04)	
Self-reported health transition			
Remained in good health	1.00***	1.00*	28.6% (225)
Remained in fair health	1.55 (0.93 – 2.59)	1.57 (0.94 – 2.63)	38.9% (306)
Remained in poor health	1.27 (0.24 – 6.83)	1.29 (0.24 – 6.95)	2.7% (21)
Deteriorated health	1.66 (0.88 – 3.15)	1.69 (0.89 – 3.21)	15.8% (124)
Improved health	0.95 (0.47 – 1.92)	0.89 (0.43 – 1.04)	14.0% (110)
Total			100% (786)

Reference group: Persistent low intensity carers=305. OR: odds ratio; 95% CI: confidence interval. *p<0.05, **p<0.01, ***p<0.001

Model A: Valid N=791; -2LL=68.27, X²=26.09 (df: 12), p<0.01. Model B: Valid N=786; -2LL=903.61, X²=38.09 (df: 15), p<0.001.

Source: author's own analysis of the ELSA Waves 6 and 7.

5.2.4.2 *Phase III MODEL 12: Short-term predictors of change in economic activity by caring status*

Research Question 3.d asked how carers transitioned between economic activities. To examine any potential causal effect of caring statuses on remaining in employment, reducing hours or retiring, the changes in economic activity between Wave 6 (2013) and Wave 7 (2015) were analysed, see also section 3.3.3.5 methodology.

Significant changes in economic activity were found between caring statuses and the results can be seen in Table 55. A multinomial logistic regression (Model 12) was used to analyse the determinants of changes in economic activity by different caring statuses (i.e. non-carers, 'repeating carers', 'discontinued carers' and 'new carers'). The reference category for the independent variable was 'non-carers' and 'remaining retired' for the dependent variable.

Model 12a in Table 55 shows the predictors of being a 'repeating carer', compared to non-carers (reference group) before controlling for age. The results noted that respondents who remained in full-time employment compared to those who remained retired, had lower odds of being a 'repeating carer' compared to being a non-carer (OR 0.74, $p < 0.05$), and when controlled for age the odds decreased (OR 0.45, $p < 0.001$). Conversely, remaining in part-time employment increased the odds of being a 'repeating carer' compared to remaining retired (OR 1.64, $p < 0.05$), however when controlling for age this was no longer significant. Remaining economic inactive compared to retired, also increased the odds of being a 'repeating carer' (OR 3.36, $p < 0.001$), and after controlling for age the odds were reduced (OR 2.25, $p < 0.001$). As seen from section 4.3.1, more female carers than male carers worked part-time, nonetheless, controlling for sex made no difference to the results of the multinomial analysis. The effect of age on part-time employment was similar across all caring statuses.

Compared to being a non-carer the odds of repeating the care provision were higher for respondents who had retired between Waves 6 and 7 (OR 1.48, $p < 0.001$), however after controlling for age this was no longer significant, and this effect of age was seen for all caring statuses. This would imply that the respondent's age is an important factor for retiring than care provision. Among respondents who had been either employed or retired in Wave 6 and by Wave 7 were economic inactive, compared to those who had remained retired at both time points, the odds of being a 'repeating carer' compared to non-carers were

Chapter 5

higher (OR 1.50, $p < 0.05$), however this also was no longer significant once controlling for age.

The odds of being a 'discontinued' carer compared to non-carers after controlling for age was lower for respondents working full-time compared to remaining retired (OR 0.58, $p < 0.001$), and for those who had reduced their working hours (OR 0.52, $p < 0.05$). The odds of discontinuing care were however increased for those who moved from being employed to being economic inactive (OR 1.56, $p < 0.05$) after controlling for age.

After controlling for age, remaining in full-time employment significantly decreased the odds of becoming a carer (i.e. 'new carer') compared to those who remain retired (OR 0.50, $p < 0.001$), in other words respondents were more likely to take on the caring role, if already retired compared to continuing full-time employment.

Chapter 5

Table 55 **Model 12: Multinomial regression by short-term change to economic activity**

	Model A		Model B	
<i>'Repeating Carers'</i>	OR (95% CI)		OR (95% CI) % (n)	
Age	Omitted		0.97 (0.95 – 0.98)***	
Employment transition				
Remained retired	1.00***		1.00***	45.2% (355)
Remained employed full-time	0.74 (0.57 – 0.97)*		0.45 (0.32 – 0.61)***	9.2% (72)
Remained employed part-time	1.64 (1.29 – 2.08)***		1.08 (0.83 – 1.42)	12.9% (101)
Remained economic inactive	3.36 (2.61 – 4.33)***		2.25 (1.69 – 2.99)***	12.9% (101)
Retired between 2013 & 2015	1.48 (1.14 – 1.92)***		1.15 (0.87 – 1.51)	10.1% (79)
Reduced working hours	1.52 (0.98 – 2.36)		0.99 (0.63 – 1.56)	3.2% (25)
Employed/retired to economic inactive in 2015	1.50 (1.01 – 2.25)*		1.29 (0.86 – 1.94)	3.8% (30)
Economic inactive/retired to employed in 2015	1.58 (0.93 – 2.68)		1.11 (0.65 – 1.90)	2.2% (17)
Increased working hours	0.67 (0.27 – 1.67)		0.41 (0.16 – 1.03)	0.6% (5)
Total				100% (785)
<i>'Discontinued Carers'</i>				
Age	Omitted		0.97 (0.95 – 0.98)***	
Employment transition				
Remained retired	1.00***		1.00***	47.0% (382)
Remained employed full-time	0.96 (0.76 – 1.21)		0.58 (0.44 – 0.77)***	12.3% (100)
Remained employed part-time	1.80 (1.43 – 2.50)***		1.19 (0.92 – 1.54)	14.7% (119)
Remained economic inactive	1.46 (1.05 – 2.02)*		0.98 (0.69 – 1.39)	5.8% (47)
Retired between 2013 & 2015	1.48 (1.15 – 1.91)***		1.16 (0.89 – 1.52)	10.5% (85)
Reduced working hours	0.79 (0.45 – 1.38)		0.52 (0.29 – 0.92)*	1.7% (14)
Employed/retired to economic inactive in 2015	1.82 (1.26 – 2.61)***		1.56 (1.08 – 2.25)*	4.8% (39)
Economic inactive/retired to employed in 2015	1.29 (0.74 – 2.25)		0.91 (0.52 – 1.61)	1.8% (15)
Increased working hours	1.37 (0.72 – 2.61)		0.83 (0.43 – 1.62)	1.4% (11)
Total				100% (812)
<i>'New Carers'</i>				
Age	Omitted		0.96 (0.95 – 0.97)***	
Employment transition				
Remained retired	1.00***		1.00***	48.6% (315)
Remained employed full-time	0.90 (0.69 – 1.16)		0.50 (0.36 – 0.68)***	11.9% (77)
Remained employed part-time	1.59 (1.24 – 2.05)***		0.99 (0.74 – 1.32)	13.4% (87)
Remained economic inactive	1.09 (0.73 – 1.62)		0.68 (0.44 – 1.04)	4.5% (29)
Retired between 2013 & 2015	1.69 (1.30 – 2.20)***		1.28 (0.97 – 1.69)	12.3% (80)
Reduced working hours	1.58 (1.00 – 2.49)		0.96 (0.60 – 1.55)	3.5% (23)
Employed/retired to economic inactive in 2015	1.02 (0.62 – 1.67)		0.85 (0.51 – 1.40)	2.8% (18)
Economic inactive/retired to employed in 2015	0.73 (0.34 – 1.59)		0.49 (0.22 – 1.07)	1.1% (7)
Increased working hours	1.81 (0.97 – 3.38)		1.01 (0.53 – 0.97)	1.9% (12)
Total				100% (648)

Reference group: Non-carers: n=5,745. OR: odds ratio; 95% CI: confidence interval. *p<0.05, **p<0.01, ***p<0.001. Model A: Valid N=7,990; -2LL=149.04, X²=168.15 (df:24), p<0.001. Model B: Valid N=7,859; -2LL=2175.06, X²=257.19 (df: 27), p<0.001. Source: author's own analysis of the ELSA Waves 6 and 7

5.2.4.3 Summary of short-term changes to health and economic activity by caring status

The multinomial regression by caring status found that the odds of being a ‘repeating carer’ compared to a non-carer were higher if remaining in fair SRH, compared to remaining in good health. The odds of discontinuing care, compared to being a non-carer, were higher for those in fair SRH and for those who’s SRH had deteriorated, compared to remaining in good health.

The changes to the carer’s SRH were also explored using a change of the caring intensity as the determining factor. However, this had little effect and only ‘persistent heavy-intensity’ carers compared to ‘persistent low-intensity’ carers had higher odds of remaining in fair or poor health compared to remaining in good health.

Before controlling for age, respondents who remained in full-time employment compared to remaining retired, had lower odds of being a ‘repeating carer’, whereas remaining in part-time employment increased the odds of being a ‘repeating carer’. However, once controlled for age this was no longer statistically significant. This suggests that the provision of informal care had little effect on retirement, remaining in part-time work, reducing one’s hours of work or returning to work.

The last part of the *Phase III* examines the predictors of discontinuing care compared to being a ‘repeating carer’.

5.2.5 *Phase III* MODEL 13: Predictors of discontinuing care

Research Question 3.d asks the question ‘*what are the determinants of providing care in both 2013 and 2015, compared to discontinuing care provision in 2015?*’ (see also section 1.2). The analysis conducted in *Phase II* solely focussed on the pathways into informal care, nonetheless, the literature and the results of this thesis have illustrated that the temporary nature of care provision means that starting and stopping caregiving, is more common than continued caring over an extended time. It is therefore also important to understand pathways out of informal care (Berecki-Gisolf *et al.*, 2008), see also section 2.3.2. From a policy perspective, this is imperative in order to better understand how to ‘discontinued carers’ are best support, and assists those who wish to re-enter the labour market (Ibid).

Table 56 shows the intensity of care provided in Wave 6 (2013) by the ‘discontinued carers’. 69% had provided care at low intensity, 15% at moderate intensity, 4% at heavy intensity, and 13% had provided 24-hour care; this was similar for females and males.

Chapter 5

Table 56 Caring intensity of ‘Discontinued carers’ (provided care in 2013, but not in 2015)

	1-19	20-49	50-167	168	Total
All	69.1%	14.5%	4.0%	12.5%	100% (809)
Female	69.1%	15.3%	3.8%	11.8%	100% (488)
Male	69.1%	13.2%	4.2%	13.5%	100% (311)

Between sex: $X^2=1.057$ (df: 3), $p=0.787$ – unweighted data.

Source author’s own analysis of the ELSA Wave 6 and 7.

Table 57 shows the direction of care of the ‘discontinued carers’, and found that 24% had previously provided care to a spouse (partner), 20% to a parent, 22% to others, 20% to a grandchild, 6% to a child and 8% had provided care to a combination of care-recipients. More males were ‘discontinued spousal carers’ (36%), compared to 18% of females. The relatively high proportion of ‘discontinued carers’ previously providing care to others and grandchildren is discussed in section 6.3.8.

Table 57 Direction of care of ‘Discontinued carers’ (provided care in 2013, but not in 2015)

	Spouse	Parent	Others	Grandchild	Child	Combi- nation	Total
All	24.4%	19.6%	22.0%	19.9%	5.8%	8.3%	100% (823)
Female	17.5%	20.0%	24.4%	23.0%	6.0%	9.1%	100% (504)
Male	35.4%	18.8%	18.2%	15.0%	5.6%	6.9%	100% (319)

Between sex: $X^2=38.83$ (df: 5), $p<0.001$ – unweighted data.

Source author’s own analysis of the ELSA Waves 6 and 7.

Model 13 is a binary logistic regression predicting the odds of discontinuing care provision in Wave 7 (the dependent variable) compared to continuing to provide care (the independent variable). To ensure the best fit of the model, preliminary analysis using ‘Backward’ elimination (likelihood ratio) was tested and compared to the ‘Forced entry’ method; (see Table 58) the latter performed the best and was therefore used (Field, 2005; IBM, 2013a), see section 3.4.

The independent variable age was entered as a continuous variable in order to minimise the number of parameters in the model. This model further contained independent variables related to caring activities at Wave 7, namely the direction of care, the intensity of care, if the care was co-residential and the number of people cared for, in order to determine the likelihood of care provision.

Chapter 5

As seen from Table 58, the preliminary tests found the blocks entered with variables LLTI, ADL difficulties, education, housing tenure and wealth were not statistically significant. As also found in *Phase 1*, having ADL difficulties is positively correlated with other health variables, therefore by only including SRH in this model the concerns of multicollinearity are limited (see section 4.4.1.1). The refined block of Model 13 used forced entry and excluded age, marital status and SRH as these variables were not statistically significant. Interaction effects between the direction of care and whether care was co-residential were tested, however no effect was noted and these were therefore omitted. See also the analysis strategy in section 3.4.

Table 58 Method comparison **Model 13**: ‘Discontinued carers’ and ‘repeating carers’, the ELSA

Variables (final model)	Forced entry	‘Backward’ elimination
Gender	√	√
Age (continuous)	Omitted	Omitted
Marital status	√	√
SRH	√	√
LLTI	Omitted	Omitted
Difficulties with ADLs	Omitted	Omitted
Difficulties with IADLs	√	√
Work status	√	√
Education	Omitted	Omitted
Housing tenure	Omitted	Omitted
Wealth	Omitted	Omitted
Direction of care	√	√
Intensity of care	√	√
Co-residential care	√	√
Number of people cared for	√	√
-2LLR	1780.73	1788.153

SRH: self-reported health, LLTI: limiting long-term illness, ADL: activities of daily living, IADL: instrumental activities of daily living.

Source: Author’s own analysis of the ELSA Wave 6

Table 59 is a summary of the main effects blocks, namely block 3 containing gender, age, marital status and economic activity; block 6, which added the caring characteristics; block 7 added the co-residential care variable, and the final model.

The final model contained 6 independent variables: gender, marital status, economic activity, intensity of care, number of people cared for and whether the provided care was co-residential. The model was statistically significant $X^2=122.95$, $p<0.001$. This indicated that the independent variables significantly predicted the dependent variable of having

Chapter 5

discontinued providing care. Detailed results of all blocks and statistical tests carried out can be found in Appendix X.

Male carers were more likely than female carers to have discontinued care provision compared to being a 'repeating carer' (OR 1.46, $p < 0.01$). The carers who were widowers in 2015 had higher odds of being a 'discontinued carer' (OR 2.10, $p < 0.01$), compared to those who were married. This may also be associated with the direction of care, and the high representation of spousal carers in the sample, see also section 4.3.3.

Carers who were economic inactive, compared to those who were retired had lower odds of discontinuing care provision (OR 0.57, $p < 0.01$). The results could imply that individuals who are economic inactive are less likely to discontinue care provision, as they may have more available time. Moreover, this may be confounded by gender roles (Scott and Clery, 2013), as more females in the sample were economic inactive (see section 3.3.2.2).

Although the model was tested for an interaction between gender and occupation and gender and age, however no effect of these was noted. This is further discussed in section 6.3.5.

Block 7 controlled for co-residential care, as this type of care is associated with high intensity of care (Arber and Ginn, 1990; Carmichael and Ercolani, 2014), see also section 2.3.1.1 and 4.3.3.1. Those providing extra-residential care were more likely to discontinue providing care (OR 1.70, $p < 0.01$). Carers who had provided care for more than 4 people in 2013 were less likely to discontinue providing care in 2015 compared to those who were 'repeating carers' (OR 0.42, $p < 0.01$). Carers who provide care to other(s) or to a grandchild compared to a spouse, had higher odds of discontinuing care (OR 1.83, $p < 0.001$ and OR 1.68, $p < 0.01$, respectively), however after controlling for number of care-recipients and if the care was co-residential, the result was no longer significant. Results are further discussed in section 6.3.8.

This reflects the findings noted in section 5.2.3, Table 57 and may be associated the intensity of care, and as carers providing higher intensity care also had statistically significantly lower odds of discontinuing providing care. For example, carers providing moderate care were 41% less likely to discontinue providing care in 2015 compared to those providing between low intensity care. However, after controlling for co-residential care provision, the intensity of care was less significant and the direction of care was no longer statistically significant. An interaction term between directions of care co-residential caring was added to the model, though it was not noted to be statistically significant nor did it have an effect on the direction of care. It should, however, be noted that the interaction term did make co-residential care non-significant.

Table 59 **Model 13: Determinants of discontinuing providing care compared to repeated caring**

	Block 3	Block 6	Block 7	Final Model
Gender				
Female	1.00***	1.00***	1.00***	1.00***
Male	1.41 (1.13 - 1.76)**	1.44 (1.15 - 1.82)**	1.46 (1.16 - 1.84)***	1.46 (1.17 - 1.83)***
Age	1.00 (0.99 - 1.01)	1.00 (0.98 - 1.01)#	0.68 (1.00 - 0.98)	Omitted
Marital Status				
Married	1.00***	1.00***	1.00***	1.00***
Single	1.03 (0.63 - 1.70)	1.09 (0.65 - 1.85)#	1.02 (0.60 - 1.73)	1.00 (0.60 - 1.67)
Divorced	1.95 (1.10 - 3.45)*	1.83 (1.01 - 3.29)#	1.70 (0.94 - 3.08)	1.70 (0.95 - 3.06)
Widowed	2.21 (1.22 - 4.02)**	2.20 (1.19 - 4.08)*	2.00 (1.07 - 3.73)*	2.10 (1.16 - 3.82)*
Economic Activity				
Retired	1.00**	1.00	1.00	1.00
Employed (Full-time >=35)	1.25 (0.87 - 1.80)	1.22 (0.84 - 1.77)	1.24 (0.85 - 1.80)	1.08 (0.79 - 1.48)
Employed (Part-time <35)	1.03 (0.76 - 1.40)	1.02 (0.75 - 1.39)	1.03 (0.75 - 1.40)	1.14 (0.86 - 1.52)
Economic inactive	0.63 (0.45 - 0.88)**	0.69 (0.49 - 0.97)*	0.70 (0.50 - 0.99)*	0.57 (0.42 - 0.79)*

Unweighted data, see Appendix X for all blocks entered into the model. *p<0.05, **p<0.01, ***p<0.001.

Continues on the following page.

Source: Author's own analysis of the ELSA Waves 6 and 7.

Table 60 (continued) **Model 13: Determinants of discontinuing providing care compared to repeated caring**

	Block 3	Block 6	Block 7	Final Model	
Spouse		1.00**	1.00		
Parent(s) & parents-in-laws		1.11 (0.79 - 1.56)	0.77 (0.49 - 1.20)		
Others		1.83 (1.29 - 2.62)***	1.23 (0.77 - 1.97)	Omitted	
Grandchild(ren)		1.68 (1.16 - 2.44)**	1.13 (0.70 - 1.83)		
Child(ren)		1.22 (0.76 - 1.98)	1.07 (0.66 - 1.76)		
Combination		1.01 (0.61 - 1.66)	0.84 (0.50 - 1.42)		
Intensity of Care					
1-19 hours per week		1.00***	1.00***		1.00***
20-49 hours per week		0.59 (0.44 - 0.79)***	0.60 (0.45 - 0.79)***	0.60 (0.45 - 0.79)***	
50-167 hours per week		0.53 (0.33 - 0.85)**	0.56 (0.35 - 0.91)*	0.55 (0.34 - 0.89)*	
168 hours per week		0.60 (0.44 - 0.82)***	0.68 (0.49 - 0.95)*	0.65 (0.47 - 0.91)*	
Number of People Cared for					
1		1.00***	1.00***	1.00***	
2		1.12 (0.80 - 1.56)	1.10 (0.79 - 1.54)	1.08 (0.81 - 1.43)	
3		0.67 (0.42 - 1.07)*	0.64 (0.40 - 1.03)	0.64 (0.42 - 0.96)*	
over 4		0.45 (0.24 - 0.84)	0.42 (0.23 - 0.79)**	0.42 (0.24 - 0.74)**	
Co-residential Care					
Yes			1.00***	1.00***	
No			1.64 (1.12 - 2.39)*	1.70 (1.33 - 2.19)***	
-2LLR	2140.13	2066.86	2060.29	2079.54	
% Change -2LLR from base block	1.97%	5.32%	5.62%	4.74%	
Significance change to block	$\chi^2=12.75, p=0.005$	$\chi^2=11.59, p=0.009$	$\chi^2=6.57, p=0.010$	$\chi^2=122.95, p<0.001$	
Hosmer & Lemeshow Test	$\chi^2=15.96, p=0.043$	$\chi^2=7.97, p=0.436$	$\chi^2=9.39, p=0.311$	$\chi^2=17.12, p=0.029$	
Chi-square overall model	$\chi^2=48.50, p<0.001$	$\chi^2=121.77, p<0.001$	$\chi^2=128.33, p<0.001$	$\chi^2=122.95, p<0.001$	

Unweighted data, see Appendix X for all blocks entered into the model. * $p<0.05$, ** $p<0.01$, *** $p<0.001$.

Source: Author's own analysis of ELSA Waves 6 and 7.

5.2.6 *Phase III: Summary of short-term transitions*

Phase III was the last phase of this analysis and aimed to answer Research Question 3. This phase used a longitudinal design to explore the shorter-term transitions of carers between Waves 6 (2013) and 7 (2015). The statistical data analysis included descriptive, binary and multinomial logistic regression analysis.

The results showed that there is a relatively high turnover of carers entering in and out of the caring role between Waves 6 and 7. The demographic and socio-economic characteristics of carers by caring status (i.e. 'repeating carers', 'discontinued carers' or 'new carers') were compared and the results showed a similar pattern to that also found in *Phase I* and *Phase II*, namely that the majority of respondents, regardless of caring status, were women, aged 60-69, married and retired. 'New carers' were in better SRH, compared to 'repeating carers' and 'discontinued carers'. Moreover, a lower proportion of 'new carers' had a LLSI or difficulties with ADLs/IADLs, compared to the other caring statuses.

Phase III also found no difference in the proportion of non-carers and future 'repeating carers' who were employed part-time in Wave 6. However, in *Phase I* (section 4.3.1) results found that more carers than non-carer worked part-time. The results suggests that working part-time could be a pathway into informal care provision, rather than a consequence care provision.

The majority of carers initially started to provide low-intensity care to a spouse or a parent. For 'repeated carers', the majority provided care at the same intensity between Waves 6 and 7, and those who changed tended to decrease the caring hours. Likewise, most of the 'repeating carers' provided care to the same care-recipient over the 2-years. More transitions between care-recipients was observed for carers who initially had provided care for a combination of care-recipients.

The multinomial regression found that respondents who remained in full-time employment compared to remaining retired, had lower odds of being a 'repeating carer' and a 'new carer'. Whereas remaining in part-time employment increased the odds of being a 'repeating carer', however, once controlled for age this was no longer statistically significant. Once controlled for age, changes in SRH status predicted that the odds of being a 'repeating carer' compared to a non-carer, were higher if the person remained in fair health, compared to remaining in good health

Research Question 3.d asked the question of what are the determinants of discontinuing care provision compared to continuing care provision. Men had higher odds of discontinuing caring, likewise did carers who were widowed or if the care was extra-

residential. Also, carers who provided more intense care (over 20 hours per week) had lower odds of discontinuing caring.

5.3 Summary of chapter 5, the longitudinal data analysis

Chapters 5 applied a longitudinal approach examining the longer and shorter-term transitions of carers. *Phase II* utilised the ELSA Wave 4 (2009) to Wave 7 (2015) to answer Research Question 2 '***What are the longer-term trajectories into informal care provision?***' *Phase II* also found that future carer had better health at baseline, and that the odds of becoming a future carers were higher for carers in better SRH, compared to those in poor health. This is likely a '*healthy carer effect*' and adds to the evidence that carers are self-selected into the role, as care provision can be a challenging role which requires a certain level of good health. The longer-term transitions of intensity and direction of care showed that the majority provided care of a stable level of intensity over the waves, however there was also a large proportion of carers who transited between intensity levels (i.e. increased or decreased the hours of care provided per week). When exploring the longer-term transitions of the direction of care, interestingly among the 'repeating carers', almost 40% changed between different care-recipients over the 3 waves, and a quarter provided persistent spousal care. However, the cell-count was often too low for a robust analysis.

The last phase was *Phase III* provided a detailed focus on the transition of carers between Wave 6 (2013) and Wave 7 (2015), in order to explore how shorter-term transitions affect the health and employment of the carers and address Research Question 3. The results showed that there is a relatively high turnover of carers entering in and out of the caring role between Wave 6 and 7. When carers initially started providing care, most did so at a lower level of intensity and most started providing care for a spouse or a parent. For 'repeating carers', the majority provided care at the same intensity between Waves 6 and 7, and those who changed tended to decrease their caring hours. Likewise, the 'repeating carers' mainly continued providing care for the same care-recipient. However, among combination carers a higher degree of transitioning between the directions of care was observed.

The results to changes in SRH status showed that once controlled for age, the odds of being a 'repeating carer' compared to a non-carer were higher when remaining in fair health, compared to good health. Moreover, compared to non-carers, discontinuing carers had lower odds of improving health, compared to remaining in good health. Men had higher odds of discontinuing caring, as did carers who were widowed or those who provided extra-residential care. Also, carers providing high-intensity care had lower odds of discontinuing caring.

Chapter 5

This concludes the results chapters for this thesis, the next chapter intends to critically discuss the findings, how they compare to the current literature and discuss the policy implication of the findings.

Chapter 6 Discussion and conclusion

6.1 Introduction

This thesis showed a complex interplay between the carer and the care-recipient, confirming how caring is a dynamic process, as carers through the life-course move in and out of the caregiving role. Although the timing and circumstances of the caring episode and how these affect the carer are individual (Barrett *et al.*, 2014), one thing all carers have in common, is that they have someone who is in need of care. Nevertheless, the question remains whether taking on the caring role is a free and deliberate choice (Schulz *et al.*, 2012; Al-Janabi *et al.*, 2017). The future demographic trends suggest that the demand for carers will increase with the ageing of the Baby-Boomers. It is becoming increasingly necessary for adult children, especially those who are children of Baby-Boomers, to prepare for the possibility that they may have to provide care for their parent, as well as preparing for their own potential future care needs. However, in the current time of austerity it may be problematic to set savings aside for the possibility of having to reduce working hours, or leave the labour market, in order to provide care for parents in the future (Schulz *et al.*, 2012; Wood and Vibert, 2017).

This thesis aimed is to investigate the pathways into informal care, and this chapter critically examines the key findings of this research against the background of the existing evidence. The structure of the discussion follows the conceptual framework presented in Figure 6. Firstly, section 6.2 provides a critical discussion of the cross-sectional evidence in addressing Research Question 1. Section 6.3 evaluates the transitions and trajectories of care provision and addresses Research Questions 2 and 3. The limitations and drawbacks of the thesis, and suggestions for future research are discussed in section 6.4, and the chapter concludes in sections 6.5 and 6.6 by stating the policy recommendation and the contributions of this thesis.

6.2 Discussion: The Cross-sectional evidence

6.2.1 Who are the informal carers in England?

Research Question 1.a asked how the socio-demographic, socio-economic and health characteristics differed between carers and non-carers, and between women and men. The focus of the following sections is on gender, age, marital

status, health status, economic activity, region and ethnicity of the informal carers.

The results in *Phase I* showed almost 18% (1,604) of the sample had actively provided informal care in the previous week, this prevalence is higher than presented in the literature review (Dahlberg *et al.*, 2007; Vlachantoni *et al.*, 2013; Robards *et al.*, 2015) (see section 2.3.1.1). This is due both to a possible increase of informal carers, as well as the inclusion of care provided to grandchildren in the analysis, and this is discussed further in section 6.2.2. The majority of carers were women and in younger age groups. Most of the carers provided care for a spouse and this was associated with a higher intensity of care provision.

6.2.1.1 What are the gender differences between the carers?

The findings showed a higher proportion of women providing care (63%), it also highlighted that men often provide care at a high intensity. Moreover, a larger proportion male carers (9%) were aged over 80, compared to only 5% of the female carers. This has also been noted by other studies (Vlachantoni, 2010; Glauber 2016; Del Bono *et al.*, 2009; Carmichael and Ercolani, 2014). Historically research into informal care has focussed mainly on women carers (Henz, 2004; Leinonen, 2011; Barnett, 2013). Research into older male carers has generally been lacking, however the recent shift in the gendered landscape of care in older age, has led to a need for more research on the effect of care provision on older male carers (Milligan and Morbey, 2016). An implication of the lacking research is that older male carers are at risk of being 'hidden carers' (Carers Trust, 2014). Men often fall through the formal system of support, as they may not describe or acknowledge themselves as carers, and older male carers may therefore miss out on much needed support, leaving them vulnerable to experience isolation and more susceptible to potential adverse health effects associated with care provision (Milligan and Morbey, 2016; Carers Trust, 2014). The difference in support needs of women and men carers is further discussed in section 6.5.2 and the general gender differences are discussed continuously though this chapter.

6.2.1.2 How old are the informal carers?

The average age of the informal carers was 64 years, which was younger than non-carers (see section 4.3.1, Table 20). Existing studies analysing the population aged over 50 years, also noted the provision of care to peak between 50 to 64 years of age (Lee *et al.*, 2015; Vlachantoni, 2010). The average age of women carers was 63 years and for men carers it was 65 years. In comparison, in the

study by Lee *et al.* (2015), albeit only including women carers, an average age of 59 years was noted; the finding from this thesis could imply an increase to the average age of female carers.

If so, a rise in the carer's age is likely associated with recent demographical changes, such as the slight rise in HLE over the last decade (ONS, 2017d). This rise is likely to have postponed the age at which care is needed by the care-recipient, which in turn delays the onset of care provision, and thereby raises the carer's average age. Moreover, the rise in HLE combined with the increase in LE (ibid) may result in the average age of the carer further increasing in the coming years before it plateaus. As the government rely on informal carers, this postponement of the onset of care, would further outstrip the supply of carers, and add additional pressure to the formal social care system (Pickard, 2015). Moreover, the rising age of the carers is a concern, as the risk of age-related conditions increases with age (Jeune and Christensen, 2005) and this may lead to carers themselves being in need of care (The Lancet, 2017). This highlights the necessity of additional support for informal carers. Section 6.5 discusses policy recommendations of how best to support carers.

6.2.1.3 Is one's marital status important?

In keeping with previous literature, the results showed that the majority of carers were married and lived in coupled households (Hiel *et al.*, 2015; Barnett, 2014; Lyons *et al.*, 2015). This is likely associated with the high proportion of spousal carers identified in this study, and may be due to a rise in married couples in the older population (Pickard, 2002). However, the landscape of marriage in older age is changing, and there has been an increase in the divorce rate among older people, however, there has also been an increase in older couples remarrying or cohabitating (Brown *et al.*, 2012; ONS, 2017c). Although these changes are likely to affect how spousal care is provided in the future, this could also lead to an increased need for intergenerational support. Nevertheless, research from the US has suggested that cohabiting partners provided on average a comparable amount of care to a married spouse (Noël-Miller, 2011). There is currently very limited evidence from the UK on care provision in non-traditional family structures, and more research is needed to fully understand how changes to the traditional family structure affect the pathways into care.

The results also showed that a high proportion of married carers provided care to care-recipients other than a spouse, particularly to a parent or a grandchild, see also section 4.3.3.1. This supports the theory that marriage (partnership) can act

as a facilitator of care provision, as these carers may have increased support from other family members, such as for example a spouse, and this provides the carer with more time to provide care to for example a parent or to others (Arber and Ginn, 1990; Carmichael and Ercolani, 2014), (see also section 2.3.1.2). The relationship status of the carer should be taken into account when a Carer's Assessment is carried out, as this could provide information of any support networks the carer may have. The idea of personalised support will be discussed in further detail in section 6.5.

6.2.1.4 Do people living in the North of England provide more care and does one's ethnic background make one more likely to provide care?

The results showed that a higher proportion of carers resided in the north of England (see Table 20). The '*Positive Care Law*' states that care is provided more where it is needed, and some literature suggests that this is in the North of England (Shaw and Dorling, 2004, p.901) (see Section 2.3.1.5). The findings support the '*Positive Care Law*', however, it is outside the scope of this study to conclude whether this is due to lower availability of formal care in the North of England, as suggested was the motivation of the positive care law (Ibid). More research would be needed into the association between informal care and geographical location (see also section 6.4).

Young *et al.* (2006) noted that in most ethnic groups women were more likely to provide care, however unexpectedly, this thesis noted that more non-white male provided care compared to non-white females (7% and 4%, respectively). This finding may be due to the perception of traditional gender roles (Zuccotti, 2018). Non-white men might identify themselves more as a carer than women, as culturally this may not be a 'traditional role', whereas non-white women may not see themselves as 'carers', as providing care is often a part of their traditional role as the family caretaker (Ibid). This study was limited by the cell counts of ethnic groups, and this is further discussed in section 6.4.

In order to further understand who the informal carers are and their pathways into care provision, the following section concentrates on the patterns of care, such as the intensity and direction of care.

6.2.2 How many hours of care do carers provide and who are the care-recipients?

Guided by Research Question 1.b and the results of the analysis, the patterns of caring intensity and direction of care are discussed in relation to existing literature.

The majority of carers provided care between 1 to 19 hours per week (low intensity), and this was similar for both women and men. Vlachantoni (2010) noted a similar pattern when analysing the ELSA Wave 3, however found that more female than male carers provided care at a low intensity. It is important to consider the caring intensity, as an association between higher intensity of care provision and adverse effect on the carer's health has been evidenced (ONS, 2013a; Carmichael and Ercolani, 2016). The longitudinal effect of the care intensity and changes to the caring intensity levels are discussed in section 6.3.

The findings showed that the intensity of care was associated with the direction of care, as well as whether the care was provided within or outside the carer's home (co-residential or extra-residential care), as also noted in the existing literature (ONS, 2013a; Carmichael and Ercolani, 2014) (see section 4.3.3.1, Figure 16 and Figure 17). Moreover, as seen from the findings, higher intensity care was particularly related to providing spousal care. That said, spousal care may be subject to a reporting bias, as literature suggests that women spousal carers may not report all the hours of care provided, as much of the support provided is seen as a part of their 'normal' role in the household, whereas men who have taken on the role, for example, as primary cook, might describe such activity as care provision (Kim *et al.*, 2016; Rutherford and Bu, 2017). This reporting bias also adds to the gender differences noted in the hours of care provided, and raises the question of whether many women care are in fact 'hidden carers' providing even more care than shown in research.

The intensity of care was further associated with co-residential care, and the results showed that all spousal care was co-residential. Co-residential care to parents was also of higher intensity, whereas the intensity for extra-residential care to parents was lower (Table 22). This would imply that the parents in need of care, only resided with the carer when their support need are at the highest, as also noted by Carmichael and Ercolani (2014). Research has indeed shown that the strongest influencing factor for taking on the caring role is the deterioration of care-recipient's health (Haberkern and Szydlik, 2010). In order to establish the association between the support need and health status of the care-recipient, more information would be required from the ELSA dataset, such as the type of care provided (i.e. physical, practical, emotional, see also section 2.3.1.1), as well as the number of ADLs/IADLs, which the carer provides help with, as further discussed in section 6.4.

Chapter 6

Uniquely, this thesis also distinguished between care provided to grandchildren, and it was found that 15% of carers provided care to a grandchild. A similar proportion of grandchild care was also noted by Lee and Tang (2013).

Interestingly, Lee and Tang found no significant difference in the characteristics of women and men providing care for grandchildren, whereas this thesis noted that a significantly higher proportion of older women (17%) than men (13%) provided care to a grandchild. Further research into men providing care to grandchildren is needed to disentangle the pathways into male grandparental care, see also section 6.4.

A tenth of carers provided care to a combination of care-recipients, and almost half were aged between 50 and 59 (see Table 22 and Figure 14). Providing care both for a child (or grandchild) and a parent (or parent-in-law) is often seen as being at risk of being '*sandwiched*' (Grundy and Henretta, 2006; Vlachantoni, 2010; Ben-Galim and Silim, 2013), yet only 1% of the carers in this thesis would be classified as '*sandwiched*' (see also section 1.1.1). There has recently been debates on whether there is a danger of people being "*sandwiched*" in the future (Keene *et al.*, 2017). Due to the rise in longevity the number of living generation within a family is increasing, known as the so-called "bean-pole" family structure (Bengtson, 2001; Harper, 2006) (see also section 1.1.1), but there is also an increase gap in age between these generations (Lundholm and Malmberg, 2009). These two demographic processes may in the future change how we define the '*sandwich generation*'. Traditionally the '*sandwich generation*' had been defined as having both ageing parents and children in need of support (Abramson, 2015; Grundy and Henretta, 2006), however with the rise in LE and postponement of childbearing, the model of an "open-faced" sandwich may be more appropriate as a higher proportion of care is provided to the older generation (i.e. adult children caring for both parents and grandparents) (Abramson, 2015). Therefore the potential to be '*sandwiched*' might be shifted upwards in the life course. Moreover, this upwards shift is also more likely to happen if the increase in LE in years is greater than the increase in the average parental age at the birth of the first child. Then again, maternal age at firstborn is a complex matter, which is strongly associated with both SES and education; women from lower SES and lower education are more likely to have their first child at a younger age (Berrington *et al.*, 2015; ONS, 2016b). Appendix BB shows an illustration of how more generations are in risk of being '*sandwiched*' in the future by this upwards shift. Nevertheless, as evidenced in this research and argued by Grundy and Henretta (2006) and Lundholm and Malmberg (2009), being '*sandwiched*'

between an older parent and grandchild needing care is rare, although the results from this thesis do suggest that providing care for a combination of care-recipients is not uncommon. Transitions between directions of care over time are discussed in further detail in section 6.3.1.

The previous research question described who the carers in England are and their characteristics by using descriptive analysis. The next section aims to establish what the predictors are of providing care in the ELSA Wave 7.

6.2.3 What are the predictors of providing care in 2015 and do such predictors vary according to gender?

The analysis addressing Research Question 1.c used logistic regression analysis to confirm the evidence noted by previous studies on informal care; such as women are more likely to provide care, as are those aged 50-59 (Lee *et al.*, 2015; O'Reilly *et al.*, 2015; Del Bono *et al.*, 2009; Pickard, 2015; Glauber, 2016).

The findings showed that marital status was a predictor of care provision for men, but not for women. This is compatible with the work by Del Bono *et al.* (2009), who argued that gender differences in care provision is an artefact of women being more likely to live with a partner, or someone within the household, who needs care. As male carers in this thesis commonly provided spousal care (34%), and this may be why marital status was only statistically significant for men. Nevertheless, a large proportion of women did provide spousal care (23%), so it is surprising that marital status was not significant for women. This finding does imply that women provide care regardless of their marital status, due to the fact they are also more likely to provide care to a wider range of care-recipients. The results also showed that being divorced lowered the likelihood of care provision and this may be due to divorcees having fewer potential caring responsibilities (i.e. no spouse or parents-in-laws), although they may be more likely to provide parental care (Young and Grundy, 2008).

Higher education levels were also a predictor of care provision (see Table 36). As discussed in section 2.3.1.4, higher educated individuals may have better access to support (Adler and Newman, 2002; Haberkern and Szydlik, 2010) and therefore be better positioned to sustain the caring role. This emphasises the need to have a support system in place for carers which is less complex, and for services to better signpost carers to where they access support. The policy implications of these findings are discussed in section 6.5.

The results of the regression analysis by sex found very few variables to be significant in predicting care provision. In fact, for women only 4 factors were

found to be significant (see Table 37), which suggests that other aspects are influencing whether they provide care, such as the availability of formal care, geographical proximity to the care-recipient or willingness to provide care (see also section 2.3.1.5). Unfortunately, the ELSA does not provide this information. Schulz *et al.* (2012) conducted a study on the perceived choice of becoming a carer and found that those providing care for a spouse or a parent had a strong perceived lack of choice compared to carers of other relatives. Figure 2 in section 2.2.3 introduced *The Solidarity Model*, which takes into consideration this conflict regarding choice and willingness, but also a commitment to filial and parental obligation, and the previously discussed structural dimensions of caring, such as proximity to the person cared for (Lowenstein, 2007). Taken together, this may suggest that reciprocity and altruism, as well as the structural dimensions may be more important factors when predicting care provision. More research is needed of individuals' willingness to provide care by gender, see also section 6.4.

The next section focusses on predictors of intense care provision, which the literature has shown to be associated with different characteristics of the carer (O'Reilly *et al.*, 2008; Drinkwater, 2015).

6.2.4 Among informal carers, what are the predictors of providing over 20 hours of care per week?

Research Question 1.d set out to establish the predictors of providing higher intensity care and the findings showed that gender was not significant. Other studies have likewise found that, after adjusting for marital status and household type, gender differences in care provision disappear (Del Bono *et al.*, 2009). The lack of gender differences in high-intensity care supports the argument that men 'catch-up' with women in care provision in later life (Glauber, 2016), see also section 2.3.1.2

The odds of providing high intensity care (≥ 20 hours/week) were more than twice as likely for carers aged over 80 than those aged 50-59, as also noted by other studies (Norman and Purdam, 2013; Aldridge and Hughes, 2016). It was estimated by the Carer's Trust (2015) that one in five carers are aged 85 years and over, and it is therefore concerning that this study noted such high odds of provided high intensity care among the oldest carers, as these carers may themselves be in need of support. The implications of this finding and recommendations for the support organised for older carers can be found in section 6.5.

As this part of the discussion was based on cross-sectional evidence it was not possible to establish the causal pathways, however this phase of the analysis opened the discussion of how caring characteristics may play a longer-term role. The following section discusses the longitudinal part of the pathways into and out of informal care provision.

6.3 Discussion: The longitudinal evidence

This part of the discussion focuses on the longitudinal analysis of *Phases II* and *III* and answers Research Questions 2 and 3. The advantage of longitudinal analysis is that it starts to disentangle the complex pathways of informal care, as well establish the potential causal influences of the pathways. As described in section 1.1, a transition is a discrete life change, or an onset of a change, whereas a trajectory is the individual's sequence or the progression of long-term patterns of stability and change (Elder, 1994). The findings in this research have indeed reflected how complex, dynamic and heterogeneous care provision is.

6.3.1 Short and long-term transitions and trajectories of informal care

Research Questions 2 and 3 explored the transitions into and out of the caring role, and the results from both *Phase II* and *III* draw attention to relatively high turnover of carers. The carer turnover is represented by the number of people who start or cease caregiving during a year, as a proportion of those continue to provide care at the end of that year (Hirst, 2002).

The findings showed that 10% of the carers discontinued the role between 2013 and 2015, 8% started providing care in 2015, and nearly 10% of respondents provided care at both time points, and these results are similar to other studies (Berecki-Gisolf *et al.*, 2008; Robards *et al.*, 2015). There are important financial and administrative implications associated with high rates of carer turnover. For example, it can be difficult for service providers to develop and plan support for carers. Likewise, policymakers may either underestimate or overestimate the turnover leading to slow and inflexible formal support (Hirst, 2002). Often service planning, commissioning and budgeting cycles are developed on cross-sectional estimates of the carers' population, however, such figures can cause resources to become stretched and support services inadequate, as they do not reflect change over time (Ibid). The findings from this study add to the evidence base, which confirms the need for reactive and flexible support services, as well as emphasising the need for policymakers to consider longitudinal evidence when

commissioning support and funding. Further policy implications are discussed in section 6.4.

The next section discusses the effects of this turnover in terms of the differences in the socio-demographic characteristics between carers starting, repeating or stopping the caring role.

6.3.2 The socio-demographic differences between caring statuses

Addressing Research Question 2.a the findings showed that regardless of the nature of the caring episode (i.e. caring repeatedly or intermittently), the majority of future carers were women, younger and married compared to respondents who did not provide care in any of the waves (see section 5.1.3). Other studies have noted similar characteristics of future carers (King and Pickard, 2013; Carmichael *et al.*, 2010), however as both of these studies only included respondents under the SPA, it was not possible to compare the effect of age. The characteristics of health and employment are discussed in sections 6.3.4 and 6.3.5.

The next part of the discussion further explores what predictors were associated with pathways into care provision.

6.3.3 Which socio-demographic characteristics in 2009 predict caring in 2015? And do the predictors vary by gender?

Research Question 2.b addressed the predictors of becoming a carer and whether these differed between genders. Although, the cumulative probability of becoming a carer increases with age (Hirst, 2002), the findings from *Phase II* showed that the likelihood of becoming a carer decreased in the older age groups. This is expected, as evidenced by *Phase I* the prevalence of carers decreases after the age of 70 (Table 22) and the first time-point carers could initiate the role was in 2011 (Wave 5), meaning that if the future carer was aged 70 or over in Wave 4, they would be aged 72 or over at the time of initiating the caring role. Additionally, the results showed that the majority of older carers (aged over 70) provided care to a spouse or partner. This finding resembles other studies, which have also noted that the likelihood of providing care for a spouse is positively correlated with age, and most caring dyads starting after the age of 55 were between spouses (Hirst, 2002).

As also expected, the likelihood of becoming a carer was lower for widowed, single or divorced persons compared to those who were married. Nonetheless, the results from *Phase I* showed that 18% of care was provided to 'others', which included other relatives, friends and neighbours (see Table 22). It could be

speculated that non-married persons may form caring dyads with others, such as for example non-married sisters and friends, who have no other adult children who could provide care for them (Nocon and Pearson, 2000). Future research would benefit from qualitative research on the dynamics of caring dyads between carers and care-recipients other than a spouse or parents, as this source of informal care is likely to increase in the future (see also section 6.4).

The overall lack of significant variables in the determinants of becoming a carer, again shows the complexity of the pathways into informal care provision and that potentially more important factors are influencing such pathways. For example, research has suggested that particularly spousal care is provided out of obligation and love, and as a part of the marital vows (Solomi and Casiday, 2016; Turner *et al.*, 2016). This would imply that spousal care is less about the carer's demographic and socio-economic characteristics and more about the circumstances of the partner's health. Moreover, spousal care is likely to be driven by direct reciprocity and altruism, rather than weighing up the opportunity cost of care provision (Feeney and Hohaus, 2001), as also discussed in section 2.2.3. This makes factors such as economic activity, wealth and education less relevant in understanding the pathways into care, and could account for why only a few socio-economic variables were significant in the statistical analysis. For policymakers, this makes it difficult to determine individuals at risk of becoming carers. However, it is important that support services are in place, which particularly focusses on older spousal carers, as they often carry a heavy caring load and may not self-identify as carers, thereby increasing the risk of being 'hiding carers' (Carmichael and Charles, 2010; Del Bono *et al.*, 2009; Rutherford and Bu, 2017). More qualitative research is required to understand the support needed for high intensity spousal carers, see further recommendation in section 6.5.

Nonetheless, when the analysis was divided by gender, a clear differentiation in the determinants of becoming a future carer was seen. For men it seemed that socio-economic characteristics, such as wealth and education had a significant influence on becoming a carer. Men in the middle-wealth quintiles were significantly more likely to become future carers compared to men in the wealthiest quintile, and similar results were noted in *Phase I* (see section 4.3.1). Mentzakis *et al.* (2009) also found that wealthier men were less likely to provide care compared to poorer men, which is likely associated with a higher past income and accumulated wealth for men, thus placing them in a better position to negotiate paying for formal care (Mentzakis *et al.*, 2009; Langner and

Chapter 6

Furstenberg, 2018). As the male carers in this study were older on average than the female carers, their accumulated wealth is likely to be higher. Moreover, as men's opportunity cost of care provision is typically higher than women (i.e. due to higher earnings), they may not have experienced an 'income penalty' as a result of caring, unlike women carers (Carmichael *et al.*, 2010; Hill *et al.*, 2011; Sovinsky and Stern, 2016; Gomez-Leon *et al.*, 2017). This suggests that financial support might be more important for women in terms of avoiding being financially worse off, but also that financial incentives are needed for men to take on the caregiving role.

Respondents with higher education levels also had increased odds of becoming future carers, which is consistent with some other studies (Lee *et al.*, 2015; Rafnsson *et al.*, 2015), but not all (Young and Grundy, 2008; Caputo *et al.*, 2016). One reason for the complex picture related to education, may be that higher educated carers have better access to support, however higher education is also associated with higher earnings and thereby an increased opportunity cost of providing care (Mulder and van der Meer, 2009; Habernkern and Szydluk, 2010) (see also sections 2.3.1.4). There may also be a cohort effect related to the education levels noted in this thesis, as respondents aged 50-59 in 2009 were born in 1950-1959, thereby belonging to a generation who generally had better educational opportunities than previous generations (Evandrou and Falkingham, 2006). The analysis did explore evidence of a gender difference in education levels, however none was found. Moreover, it has been suggested that there is an association between an occupational background in health and social care and being a carer (Young and Grundy, 2008), which would help explain the increased odds which higher educated individuals have of becoming a carer. The policy implications and recommendations of socio-economic factors are discussed in further detail in section 6.5.

As also discussed in sections 2.3.1.5, 2.3.2.3 and 6.2.1.1, the pathways into care provision for women are likely determined by factors such as proximity to the care-recipient and family structure, as also evidenced by the literature (Leinonen, 2011; Pillemer and Sutor, 2014). Moreover, the historical traditional gender role of women as carers may be one of the most important factors affecting the pathway into care for women (Langner and Fursten, 2018). Evidence from both *Phase I* and the literature, has shown that women are more likely to provide care to care-recipients other than, or in addition to, their spouse (Vlachantoni, 2010, Hoff, 2015). As this study did not disaggregate the data by care-recipient and due to the low cell counts, some of the nuances between the genders may have been

lost. Future research would benefit from further exploring the determinants of women carers by care-recipient, see also section 6.4.

As seen from the results the pathways into care are a complex interplay between demographic and socio-economic characteristics, as well as the norms and values of individuals, which this thesis was not able to control for. The following section discusses how the health status affects the likelihood of providing care and how care provision affects the carer's health.

6.3.4 Does the timing of the care provision have an impact on the carer's health?

Research Question 2.c addressed issues related to the carer's health in relation to the timing of the care provision. The *Phase II* analysis showed that regardless of caring duration, all future carers had significantly better SRH than non-carers at baseline. Research Question 3.b (*Phase III*) focussed on whether the carer's health changed differently between the different caring statuses and also here the results found that more 'new carers' were in good SRH compared to 'repeating carers' and 'discontinued carers'.

There was a significant deterioration in SRH between Wave 4 and 7 for non-carers and for carers caring for only one wave. Contrastingly, the change in SRH was not significant for 'repeating carers'. However, the results should be interpreted with caution as the analysis was not age-standardised. Consequently, it is likely that the results have been confounded by age, particularly as 'repeating carers' on average were younger than non-carers. Contrastingly, other studies noted that carers reported poorer SRH at baseline than non-carers, thereby questioning the existence of a selection effect (Ramsay *et al.*, 2013), however Ramsay and colleagues did include current carers at base line. The strength of thesis is that it did not include caregiving at baseline, reinforces the evidence of the '*healthy carer effect*' (Arrighi and Herz-Picciotto, 1994, p.189) (see also section 2.3.1.3). Ramsay *et al.* (2013) and McCann *et al.* (2004) both highlighted the need for controlling for the carer's health prior to the onset of caregiving, as otherwise the effects of care on the carer's health may be substantially overestimated. The analysis did indeed show that respondents in fair SRH were 18% less likely to become carers, and those in poor SRH were 56% less likely to do so, compared to those in good SRH. Many longitudinal studies examined the effect of care provision on health have found evidence of the '*healthy carer effect*' (O'Reilly *et al.*, 2008; Vlachantoni *et al.*, 2016; Lyons *et al.*, 2015, McCann *et al.*, 2004), with the exception of Ramsay *et al.* (2013) and Rafnsson *et al.* (2015). Rafnsson and colleagues however, only observed individuals who became spousal carers and

Chapter 6

they reasoned that any effect was due to spousal carers being older and providing high intensity care. Ramsay *et al.* (2013) using ONS LS data, noted that at baseline carers were more likely than non-carers, to have poor SRH and to report having a LLTI.

The analysis found no statistical significance in the health change between 'repeating carers' and non-carers (see section 5.1.6, Table 53). Other scholars have found that providing any amount of weekly care to a spouse was associated with a decline in SRH, compared to non-carers, however when controlled for subsequent socio-demographic control variables, this relationship between spousal care and a decline in health was no longer significant (Jenkins *et al.*, 2009).

The timing of the caring episode and the effect a break from care provision for either one or two waves were also analysed in this thesis, however also here the results were inconclusive. It is unclear whether the lack of an effect was genuine, or related to the health variable used (i.e. SRH) or due to a lack of statistical power; the latter will be further discussed in section 6.4. Previous research has shown that transitions in and out of the caring role can have an effect on the carer's health, however due to methodological inconsistencies, the evidence has been inconclusive (Burton *et al.*, 2003; Lyons *et al.*, 2015) (see also section 2.3.2.1).

The case studies may hold some answers as to the lack of statistical significance between care provision and health. The case studies revealed that the carer's individual specific health conditions, such as pain, sleep disruptions, high blood pressure or diabetes altered over the years (i.e. onset, deteriorated or improved), whereas there was little change in the more general self-reported health measure (i.e. SRH, LLSI, or difficulties with ADLs or/and IADLs) (see also section 5.1.8). As previously discussed, interpreting the relationship between health and informal care is complex, as this is ingrained in the determination and resilience of the carer to carry on with care provision, often despite their own deteriorating health (Martinez-Marcos and De la Cuesta-Benjumea, 2014). In fact, a report by Carers UK (2015) noted that carers often suffered from constant pain and arthritis, frequently neglecting their own health and pushing the carers close to breaking point.

Carers reaching breaking point, may be one reason for discontinuing care provision and Lyon *et al.* (2015) for example noted that older women, who stopped providing care, reported less perceived stress than women who had

never provided care. It is not possible to control for effects of an adaptation periods or bereavements in the quantitative data analysis of this study, and qualitative studies would be better suited to explore this in more depth. The case study of Daphne who provided care to her spouse is an example of this. She provided 24-hour care in 2011 but she discontinued care provision in 2013, after her spouse passed away. Her health remained very good and in fact, some aspects of her wellbeing improved after discontinuing care (recovered from LLSI and stopped feeling like her sleep was restless) (see section 5.1.8.4).

This study did not find a significant association between SRH and being a 'new carer' (see section 5.2.4.1, table 54). Nonetheless, an argument remains for the initial period of caring being more stressful, as the caring role often involves a steep learning curve and is taken on unexpectedly (Carers UK, 2012). As also discussed in section 6.2.1.1, many carers provide 'hidden care' or do not describe themselves as carers (Hughes *et al.*, 2013; Knowles *et al.*, 2015) and may therefore have provided care for an extended period before self-identifying as a carer. This may have allowed them to have had the so-called 'adaptation period', which Lyon *et al.* (2015) contested. A key element of the recent Carers Action Plan (Department of Health and Social Care [DHSC], 2018), and highlighted by multiple charity organisations is the importance of early identification of the carers, in order to ensure that carers can access the support, advice and information they need (Carers UK, 2012). The types of support and the benefits of these are further discussed in section 6.5.

SRH is an objective health measure which asks the individual to judge their SRH in relation to their peers (i.e. potentially the care-recipient), and this limitation associated with SRH could lead carers to overestimate their own health (Benitez-Silva and Ni, 2008), see also discussion in section 3.3.3.4. Moreover, the subjectivity of the SRH measure may also lead to carers overrating their own health as a coping mechanism. Indeed, some studies have shown that carers often disregarding their own health or downplaying how they feel (Martinez-Marcos and De la Cuesta-Benjumea, 2014; Solomi and Casiday, 2016). Brown and Brown (2014) debated whether it was conceivable that both arguments held true (i.e. both the '*healthy carer effect*' and the reverse). Brown and Brown gave the example of individuals who become carers in older age and who were in fact healthier than age-matched non-carers, whereas those who become carers at a younger age may report poorer health. As seen from the findings in this thesis, the largest proportion of carers provided spousal care and a counter-argument to Brown and Brown's hypothesis is that evidence has consistently noted that

partners in married couples often have a similar or concordant healthy status (Meyler *et al.*, 2007; Monden, 2007), which would dismiss the theory that older carers are in general more healthy.

As also discussed by Bauer and Sousa-Poza (2015) the pillar for policymakers when promoting and/or supporting informal carers should be maintaining/improving the carer's health. Moreover, it is also important that carers who want to remain in employment are supported (Aldridge and Hughes, 2016), as this in turn helps carers to maintain the necessary resources needed to protect their own health, see also section 6.5.2. The next section explores the effect of care provision on the carer's economic activity, drawing on results from both *Phase II* and *III*.

6.3.5 The association between economic activity and pathways into informal care provision

Research Question 3.c addressed the effect of informal care on economic activity, among different caring statuses. The findings in *Phase I* showed that the largest proportion of carers were retired, and more non-carers worked full-time compared to carers. This trend was reversed for part-time employment, and more carers worked part-time compared to non-carers (see section 4.3.1). It could be argued that gender may have confounded the results, as women are both more likely to provide care and to work part-time, independently of each other (ONS, 2018c). The gender confounding factor may have been further exacerbated by more carers found to be economically inactive compared the non-carers, and this category included those seeking work, sick and disabled or looking after the family and home, which had a higher proportion of female respondents (see also section 3.3.2.2), as also observed by Evandrou *et al.* (2015). Lee *et al.* (2015) referred to the vicious cycle that women are more likely to have a lower income, as a consequence of caring for older parents, but also that women's lower income status made them likely to assume care for older parents. Moreover, scholars have highlighted a weaker labour market attachment for women, which to some extent may help to explain why there are more younger female carers than male carers (Young and Grundy, 2008; Schneider *et al.*, 2013; Gomez-Leon *et al.*, 2017). Although there has been a policy drive to increase women's entry into the labour market, there has not been an equal incentive for men to enter the caregiving role (Knowles *et al.*, 2015; Eurocarers, 2017). The unequal distribution of caring responsibilities between the genders over the lifecycle may help explain some of the gender differences noted in this thesis. With the increased demand for informal care, the question remains if women will continue to be the main

providers of care, possibly by occupying multiple roles (i.e. caring and employment).

Results from *Phase II* further showed a higher proportion of 'intermittent carers' worked part-time at baseline, compared to both non-carers and 'repeating carers'. This suggests that working part-time is a pathway into informal care provision for the 'intermittent carers', rather than a consequence of informal care. It has been suggested that individuals who are economically inactive or working part-time are self-selected into the caring role, as they have more time available to carry out care responsibilities alongside their employment compared to those working full-time, possibly due to a lower opportunity-cost of providing care (Heitmueller, 2007; Hutton and Hirst, 2010; Bauer and Sousa-Poza, 2015; Carr *et al.*, 2016), see also section 2.3.2.2, Figure 4. However, some studies have disputed this and found that women take up caring responsibilities independent of labour force opportunities, even after taking into account their health and SES (Berecki-Gisolf *et al.*, 2008). Policy recommendations of how carers can combine employment and work can be found in section 6.5.2.1.

Conversely, *Phase II* showed no difference in the proportion of non-carers and 'repeating carers' who worked part-time at baseline. However, by 2015 the difference between the two groups had increased by 5 percentage points, and 17% of the 'repeating carers' worked part-time compared to only 12% of the non-carers. The results imply that shorter-term carers did not display much change to their working hours (i.e. results from *Phase III*), but carers caring over a longer period did (i.e. results from *Phase II*). This is consistent with existing evidence, noting that many carers do not initially alter their work status, however over prolonged periods of care provision many carers reduce their hours or exit the labour market completely (Berecki-Gisolf *et al.*, 2008; King and Pickard, 2013; Leopold *et al.*, 2014; Carr *et al.*, 2016). It has further been noted that male carers were less likely to reduce their working hours (Lee and Tang, 2013; Gomez-Leon *et al.*, 2017). Gomez-Leon and colleagues suggested that this indicated how men carers, due to financial reasons, needed to continue working consistent hours. Berecki-Gisolf *et al.* (2008) noted that women taking up the care role was associated with a reduction in working hours, which held true even after controlling for health and SES. This current analysis was not able to further disaggregate the data of reductions in working hours by gender, due to low cell counts.

The findings further showed that retired respondents were more likely to become carers than those employed. It could be assumed that retirement results in individuals' availability to provide care. Moreover, retirement is associated with a lower financial opportunity cost of care provision and indeed it has been noted that caregiving may facilitate retirement (Berecki-Gisolf *et al.*, 2008; King *et al.*, 2013; Carr *et al.*, 2016). Nonetheless, it was found that retiring between 2013 and 2015 was not a significant predictor of care provision. Moreover, results from *Phase III* suggested that once controlled for age, the provision of care had little effect on retirement, remaining in part-time work, reducing employment hours or returning to work. As previously discussed, this is likely due to many carers not changing their work status at the initial stage of care provision, and that age plays a more significant role in retirement decisions (Henz, 2004; Berecki-Gisolf *et al.*, 2008; Leopold *et al.*, 2014). Although the results in relation to the association between retirement and care provision were not unexpected, it was somewhat surprising that the inclusion of care to grandchildren did not affect the results. The timing of becoming a grandparent often coincides with approaching retirement age, and studies have noted an association between retirement and grandparenting (Van Bavel and De Winter, 2013). For policymakers this causes a conflict between keeping people in employment for longer and the need for a family member to provide childcare (Di Gessa *et al.*, 2016; Kanji, 2017). See further discussion on policy recommendations in section 6.5.2.1.

As discussed above, employment influences the availability of the carers, and conversely increases in the caring intensity may limit labour force participation. The discussion therefore continues by exploring the pathways of transitions between different levels of intensity and the direction of care, which have been associated with adverse health and financial circumstances (Lee *et al.*, 2015; Lyon *et al.*, 2015).

6.3.6 How do carers transition between different levels of intensity of care?

To further understand the complexities of the pathways into care provision and to address Research Questions 2.d and 3.a, the patterns of changes to the intensity and direction of care were explored. The literature noted that changes to the intensity of care may have a negative effect on the carer's health, employment and financial situation (Lee *et al.*, 2015; Lyons *et al.*, 2015; Carmichael and Ercolani, 2016). The case study of Edward provided an example of a carer whose intensity changed over time. Edward provided care for his parents-in-law and his wife. In 2011, he provides just 6 hours of care per week, by 2013 this had

increased to 60 hours per week, however by 2015 the intensity reduced to 12 hours per week. It was speculated, that the decrease in 2015 was due to Edward's deteriorating health, as he suffered from pain and was diagnosed with diabetes and osteoarthritis. Many of the carers identified in this research, provided care at high intensity levels over an extended period, which raises important policy implications discussed in section 6.5.

The findings from *Phase II* showed that the majority of the 'repeating carers' consistently provided care at high intensity. A small proportion (12%) decreased their caring intensity, whereas 15% increased the intensity. This pattern of increased intensity has also been noted in existing literature (Leopold *et al.*, 2014). Lyons and colleagues (2015) noted that carers who experienced short durations of increased care intensity were more stressed than those who either did not provide care or who consistently provided care at a lower intensity. Indeed the results from *Phase I* showed that carers in fair or poor SRH were more likely to provide high intensity care. It is important for policymakers to understand the temporal nature of care provision and the implications of this (see also section 6.5).

The intensity of care was further explored in *Phase III* and it was found that the majority of 'repeating carers' provided the same level of caring intensity in 2013 and 2015. For the 'transitional carers' there was a trend towards decreasing the intensity. This not only contradicts findings from *Phase II*, but also from existing literature, which noted that the longer-term 'repeating carers' mainly increased their care intensity over time (Vlachantoni *et al.*, 2016; Gomez-Leon *et al.*, 2017). This discrepancy may have been caused by data limitations, as the caring intensity measure in *Phase III* was aggregated to ensure sufficient cell count (high intensity care ranged from 20 to 168 hours per week). Carers could have altered their caring intensity within the upper threshold. This was for example noted in *Phase II*, particularly among the moderate caring intensity range (50-167 hours per week), see also section 5.2.3, Table 46. Moreover, the range from 20 hours to 168 hours of care is vast, and one could argue that a carer transiting between these hours might experience greater adverse effects of the care provision, than a carer transiting from 18 hours to 20 hours per week. Moreover, due to the high proportion of repeating spousal carers in *Phase II*, the care duration may be longer and more intensive, and as the spousal care-recipients tend to be older at the onset of care and age-related health deterioration leads to increased intensity over time (Victor, 2006). Additionally, the deterioration of health might be gradual and therefore only notable over the longer time period, hence only

Chapter 6

notable in *Phase II*. The change in intensity has an important policy implication, as it illustrates the temporary nature of caring (Berecki-Gisolf *et al.*, 2008). Knowing the carers' patterns of intensity could help ensure policies are in place to best support carers at crucial times, such as an increase in intensity, see more in section 6.5.

The intensity of care was disaggregated by gender in *Phase III*, and the analysis showed that a higher proportion of men initiated care provision at the highest intensity levels, which is likely associated with more men providing spousal care, which is in turn associated with higher intensity of care (Vlachantoni, 2010; Glauber, 2016) (see also section 5.2.3, Table 48). Between 2013 and 2015, 42% of men carers had increased their caring intensity from heavy caring (50-167 hours per week) to providing 24-hour care, whereas only 11% of women made this same transition. The consistently provision of high intensity over a prolonged period, is of some concern, as this can lead to a cumulative disadvantage often experienced by carers in terms of adverse health and financial disadvantage (Alwin, 2012; Dannefer, 2003). As also evidenced in section 2.2.1, providing high intensity care is likely to lead to poorer health for the carer and a decrease in their labour force participation. The results also showed that male carers both initiate and transition into very high intensity care. If considered alongside the fact that male carers tend to be older, as seen from *Phase I* (see Table 22), policies need to be in place to identify these male carers. Moreover, the high rate of transition provides evidence for better and continuous follow-up of the Carers Assessments, to meet the carer's needs. Policymakers must be concerned with this prolonged provision of care, as it implies a potential for higher health care expenditure and decrease in the workforce, as well as a decrease in the caregiver's capability to provide informal care (Bauer and Sousa-Poza, 2015). The policy recommendations are further discussed in section 6.5.

The next section discusses the transitions in the directions of care, as most caregiving relationships are based on close personal ties within and between generations, which converge over the life course. These relationships therefore largely determine the incidence, timing, and duration of caring episodes (Hirst, 2002).

6.3.7 How do carers transition between different directions of care?

Research Questions 2.d and 3.a further considered the transitions between the directions of care. The transitions seen in *Phase II* between the directions of care were relatively prevalent among the 'repeating carers', and 39% changed between

care-recipients over the course of the 6 year period. This is an important finding and adds to the gap in the literature on the pathways of informal care. Most research exploring care transitions has focussed on the change in intensity and duration of a caring episode, but has failed to identify who the care was provided to and the transitions taking place (Evandrou *et al.*, 2015; Lyons *et al.*, 2015; Vlachantoni *et al.*, 2016; Gomez-Leon *et al.*, 2017).

As seen from *Phase I*, carers who provided care to a child and to a combination of care-recipients (mainly parent and another care-recipient), were largely aged under 70 (see also Appendix R). This is likely due to the association between the age and health of the care-recipients. For example, the life expectancy of a child with a severe disability may be shorter and the carer therefore younger (Barnes, 2004). Likewise, the cared-for parent may either recover, move to a residential home or pass away (Scrutton and Creighton, 2015). Watts and Cavaye (2016) noted that carers providing care for a terminally ill relative were the least likely to give up their jobs completely.

Phase III showed that female carers tended to change more between care-recipients than male carers (see also section 5.2.3, Table 50). A good example of a 'transitional carer' with a complex network of care-recipients was Margret who provided care to her parent-in-law, her mother and a friend. In 2015 Margret's mother had passed away, after which point Margret only provided care for her parent-in-law (see section 5.1.8.3). The higher rate of transition among women may be associated with women's increased likelihood of occupying multiple roles (Carmichael and Ercolani, 2016). As already mentioned, more female carers provided care to other care-recipients in addition to a spouse. Combined with the fact, that these categories of caring direction tended to have lower caring intensity, and provided by younger carers, as seen from *Phase I*, creates an ideal environment for women combining multiple roles within the family and the labour market (Vlachantoni *et al.*, 2013; Stone *et al.*, 2015). This may further place women in a disadvantaged position, as it may cause them stress which could affect their health, and additionally they may not be able to work, thereby lowering their pension contributions (Holman *et al.*, 2018). The policy implications of this are further discussed in section 6.5.2.1. The higher rate of especially female carers transiting between care-recipients, may also be related to the inclusion of grandchildren in the analysis, as noted from Appendix C, the combination of care-recipients often included a grandchild and another care-recipient. Therefore, the combination of the two-year (i.e. 2013 to 2015) transition period used by *Phase III* and the inclusion of grandchildren may have

added to the relatively high transitional rate of carers, as the grandchild may have entered school age by 2015 and thereby ending the need for grandchild-care.

A longitudinal study conducted by Hutton and Hirts (2010) noted a decline in the proportion of individuals who took on the caring role, compared to those who discontinued the caring role. However, the authors noted that the proportion of carers over successive years had increased, which they suggested was an increase in the length of a caregiving episode. While the results from *Phase II* complement Hutton and Hirts' theory, this thesis further also argues that while there may be an increase in carers' episodes, this is due to carers staying within the caregiving role, but transitioning between several care-recipients, rather than providing care for the same recipient over a prolonged period. The concept of a "serial" carer introduced in section 2.3.2, reflects the phenomenon of caring for one individual before changing to provide care to a different individual (Larkin, 2008). The potential "serial" carers identified in this research only accounted for 39% of the carers' sample, compared to the 70% identified in Larkin's study, however the two studies did not have a similar methodology which makes comparability difficult.

Larkin (2008) also discussed that changes to the caring directions involving a very close relative, such as caring for a parent and thereafter a spouse, appeared to leave carers with little control over their continuation of the role of carer. As seen from Appendix Z, many of the 'repeating carers' initially provided care for a parent, but for someone else in Wave 7. By contrast, those who initially provided spousal care had fewer transitions. The results should be interpreted with caution, as only 52 respondents were identified as 'repeating carers'. Nevertheless, one interpretation of why carers remain within the role could be that the care support system is rather complex and can be difficult to navigate, therefore once a carer has become familiar with the system it is easier for them to take on another caring role. A study conducted by Peel and Harding (2013) found that especially dementia carers often found the system like a 'terrible maze' (Ibid, p.650). However, the authors did not speculate whether carers were likely to continue providing care after they got familiar with the system. There is evidence to suggest that many carers do find that the support services are inadequate, unaffordable or hard to access, moreover the information about the services is often also difficult to navigate (HM Government and Carers UK, 2013; Haines and Wetton, 2016; Brimblecombe *et al.*, 2018). Therefore, once a carer has knowledge of the formal care system, they may be better placed to return to the caring role (continued discussion follows in section 6.5.3). More qualitative research into

“serial” carers would be needed to fully understand their pathways into care and use of support services, see also section 6.4.

Although, the research title is ‘*Pathways into informal care provision*’, the pathway out of care provision cannot be ignored. The next section discusses the predictors of discontinuing care, compared to those repeating the care provision.

6.3.8 Among those who cared in 2013, what are the predictors of discontinuing care in 2015, compared to repeating care provision in 2015?

Research Question 3.d aimed to assess the predictors of discontinuing care provision. As evidenced from *Phase III* the turnover of carers is high and this implies a similar proportion of carers entering and exiting the role. The results found that 70% of ‘discontinued carers’ had provided care at low intensity and carers providing high intensity care also had statistically significantly lower odds of discontinuing providing care. For example, carers providing moderate care were 41% less likely to discontinue providing care in 2015 compared to those providing low intensity care, and similar results were also noted by Robards *et al.* (2015). Nevertheless, there is evidence to suggest that caring intensity increases more towards the end of a caring episode, than in the initial period, and this was especially true among those caring for a spouse or a parent (Hutton and Hirst, 2010).

Among the former male carers over a third had provided care to a spouse, compared to only 18% of former female carers (section 5.2.3, Table 56). The finding supports existing studies, which also noted that a majority of former carers had provided care to a spouse (Cronin *et al.*, 2015). Additionally, as expected, widowed carers were twice more likely than married carers to discontinue care provision. Carers who provide care to other(s) or to grandchild(ren), compared to a spouse similar had higher odds of discontinuing care. The results complement the notion that those providing care to grandchildren and to care-recipients other than a spouse, tended to do so for a shorter duration, hence more carers discontinue this type of the care provision (see section 6.3.7). Additionally, this may be explained by the difference in the motivation between intra-generational care and care to other relatives and non-kin. The motivation to provide care to a spouse is mainly driven by emotional attachment, based on the theories of altruism and obligation, whereas care provision to example a neighbour or a friend is more likely driven by delayed reciprocity (Lapierre and Keating, 2013) (see also section 2.2.3).

Chapter 6

Larkin and Milne (2017), identified 6 possible routes to becoming a former carer, related to the care-recipient, as such the care-recipient 1) dies, 2) is admitted to a hospital, 3) a hospice or 4) into long-term care, 5) recovers from their health problem, 6) goes into remission. However, discontinuation of care may also be related to the carer's own deterioration of health (Cronin *et al.*, 2015; Watts and Cavaye, 2016). As this study focusses on older carers, routes one and four, as well as the effect on the carer's own health are the most likely to be relevant, although no evidence of the latter was observed. It was unfortunately not possible to identify the reasons to why a carer stopped providing care, however future surveys could include questions to former carers on why they had discontinued the care provision.

This thesis adds to an increasing pool of research into the experiences of former carers (Larkin, 2008; Larkin and Milne, 2014; Cronin *et al.*, 2015; Watts and Cavaye, 2016). The next step is however to ensure that policymakers and service providers recognise the importance of constructing a life post-caring. This includes encouraging and supporting carers to enter, for example, either a voluntary or paid role (Cronin *et al.*, 2015), see also section 6.5.3 for further policy recommendations.

This concludes the discussion of the longitudinal phase of the thesis, the following sections outline the limitations of the thesis, policy recommendations and the contributions to research, as well as future research directions

6.4 Limitations of this thesis and future directions of research

This thesis offered a critical perspective of the pathways into informal care provision, but like all research a number of limitations were encountered which require closer consideration. This section aims to address these limitations and set recommendations for potential future directions of research. Attempts were made to highlight shortcomings as they occurred throughout the thesis, however five limitations were identified for further critically discussion: 1) missing information, 2) under-representation of minorities, 3) attrition, 4) the application of the filter question and 5) small sample size, and each limitation is next addressed in turn.

Firstly, despite the strength of the ELSA dataset the analysis was limited by the availability of the variables and the sample population. As the data was not collected with a specific research question in mind, it is not uncommon that information is missing. To overcome this, a joint 'data-driven' and 'research

question-driven' approach was used (Cheng and Phillips, 2014) (see also sections 3.2 and 3.6). Nevertheless, the research would have benefitted from more information related to the care-recipients, such as age and severity of their health condition. Although, a variable which broadly stated the care-recipient's age-ranges was present in the ELSA dataset, this variable had a high rate of item missing and imputation mistakes, see Appendix CC. Moreover, information on the specific caregiving tasks carried out by the carer would have been benefitted the analysis (see also section 2.3.1.1). The thesis used the number of hours of care provided per week as a justified proxy of the severity of the care-recipients' needs, however not knowing the particular support task may have diluted the true effect of the caring intensity (Rafnsson *et al.*, 2017). Added value would be obtained from expanding the ELSA dataset to include further questions related to the caring tasks. Lastly, although the ELSA dataset did include variables on respite support use, this variable also had a high number item missing, see also Appendix CC. The ELSA must address this issue of item missing, as exploring the usage of respite care is important for policy recommendations.

Secondly, the ELSA suffers from an underrepresentation of ethnic minorities and other so-called 'hard-to-reach' groups (Steptoe *et al.*, 2013) (see also section 3.6). This thesis relied on aggregated data, such as combining all ethnic groups, or collapsed variable categories, to ensure a high enough cell count for robust statistical analysis. However, reducing the level of detail generates a problem for the interpretation of the analysis (Wasserman and Ossiander, 2018). For instance, in *Phase I* all minority groups were combined in the category of 'non-white', which conceals important cultural and ethnic differences (Willis *et al.*, 2013). Moreover, due to low cell counts, the ethnicity variable was omitted in *Phase II* and *III*. As a consequence the findings may not be fully representative of the English population aged over 50. The low representation of ethnic groups is a reoccurring issue in the ELSA dataset and attempts need to be made to address this in future waves (Steptoe *et al.*, 2013). Another example of a loss of detail, was that all non-kin and other relatives were merged into one single category (see also section 3.3.2.4). This may have obscured potentially significant differences between the types and amount of care provided to this particular group. As seen from Table 22, 'other' carers was a relatively large proportion the carers (18%). More research, especially qualitative research, into these 'other' caring dyad is recommended.

Thirdly, attrition is the primary limitation of any longitudinal analysis. Attrition is problematic as it reduces the sample size, which can threaten the statistical

power of the analysis (Ahern and Le Brocque, 2005). Moreover, the validity of the findings can be questioned if the non-response is not missing at random (Ibid) (see also section 3.6.2). This thesis did suffer from attrition, and after excluding respondents not present in all four waves, and those ineligible for inclusion (such as respondents who had provided care in Wave 4), the retention rate was 47% in *Phase II* and 83% in *Phase III* (see sections 5.1.1 and 5.2.1). Nevertheless, as the overall patterns and trends observed in *Phase I* were similar in the longitudinal analysis (*Phases II* and *III*), it was judged that the attrition bias was limited, an approach recommended by Ahern and Le Brocque (2005). The refreshment samples introduced in Waves 6 and 7 (see section 3.2.1) further added to the attrition rate, as new members were excluded from the longitudinal analysis. Moreover, the refreshment sample may have contributed to the higher age range noted in *Phase II*, as respondents in both refreshment samples were aged between 50 to 54 (and these were excluded). On the other hand, the exclusion may have ensured better statistical robustness, as it counter-balanced the otherwise lower representation of respondents in the older age ranges generally seen the ELSA waves (Steptoe *et al.*, 2013).

Fourthly, the application of the filter question in *Phase II* to Waves 6 and 7 had a large effect on the prevalence of carers by excluding over 1,800 carers (see also section 5.1.1). An analysis of the characteristics of the excluded carers, noted that the excluded carers were younger and provided lower intensity care (Appendix M). The application of the filter reduced the statistical power of *Phase II*, due to the low sample size, and may have contributed to the general lack of statistical effect seen in *Phase II*. Nonetheless, if the filter had not been applied it would have created a conceptual inconsistency in the sample, and any comparison made would be questionable. As the waves in the ELSA dataset expand, future researchers will be able to conduct analysis on informal care transitions with a similar number of waves included in this thesis without having to apply a filter, allowing for a higher future cell-count.

Fifthly, *Phase II* was restricted by the small sample size and only 52 carers were observed in all three waves. This is by no means representative of the population of informal carers. Moreover, this thesis speculated the patterns of the transition observed by the 52 carers was evidence of a 'serial carer' effect. However, due to the low sample size this speculation is merely hypothesis generating, rather than concrete evidence. Future in-depth qualitative research should be conducted on why some individuals have multiple caring transitions over a longer-time period.

Attempts were made to minimise the impact of the limitations, nonetheless, due to restrictions of time, multi-collinearity of independent variables, unobserved heterogeneity and issues of variable availability in the ELSA dataset, and the analysis conducted was selective, thus leaving several opportunities for extensions to the work. At the time of writing in 2018, the ELSA Wave 8 had only just been launched and data collection of ELSA Wave 9 underway (ELSA, 2018). It was therefore beyond the scope of this study to include these more current waves of the ELSA. An extension of the research including these latest ELSA waves would give further details of how the rise in the SPA for women affected the pathways into informal care, as well as including a bigger proportions of the baby-boomer generation who are more likely to be squeezed between employment and care provision (ONS, 2018b).

6.5 Policy implications and recommendations

In a policy context, the ELSA Waves 4 (2009) to 7 (2015) used in this analysis, coincided with the UK recession in 2008, followed by a particularly deep cut to social care services during the ongoing period of fiscal austerity policies introduced by the Coalition Government in 2010 (Brimblecombe *et al.*, 2017). This consequentially increased the reliance on informal care to account for the unmet care needs (Vlachantoni *et al.*, 2011; The Lancet, 2017; Brimblecombe *et al.*, 2018; Burchardt *et al.*, 2018). Long-term care services need to be designed in a complementary manner between informal and formal care provision (Verbakel, 2017; Burchardt *et al.*, 2018). A report from NHS England (2017) recommended a typology of carers to help understand the health outcomes and the risk implications of different types of caring, which in turn would help to develop better support services. This thesis provides a central understanding of how care provision can affect certain subgroups of carers (i.e. spousal carers, high intensity carers, combination carers etc.). However, an important element which the NHS England report failed to recognise, and as highlighted by this thesis, is that carers are a highly heterogeneous group and many carers make short and long-term transitions, which would overlap and complicate any carer typology. That said, the need to access personalised health and social care services was acknowledged in the Government's Carers Action Plan (DHSC, 2018, p.14). This thesis supports the need for services and systems which are flexible and reactive to the dynamic and changing needs of the carers, rather than a typology and a "one-fits-all" approach to services.

This section of the chapter outlines the policy implications and recommendations which have emerged from this thesis. The section aims to reflect the full range of diverse caring role, and stages of the caring journey as a continuum over the lifecycle. The policy recommendations have taken inspiration from the 2010 public health White Paper '*Healthy Lives, Healthy People*' (DH, 2010), setting out three main recommendations in relation to individuals' pathway into caring and their caring activity: 1) '*Starting Well*', 2) '*Maintaining Well*', and 3) '*Discontinuing well*'. The recommendations aim to complement the recent 'Carers Action Plan 2018-2020 – Supporting carers today' (DHSC, 2018).

6.5.1 '*Starting Well*' - supporting the initial start of the journey

The English Carers' Strategy 2008-2018 '*Recognised, valued and supported: next steps for carers strategy*' (DH, 2010), highlighted the need to identify carers at an early stage and involve the carer developing and planning an individual care packages.

As discussed in section 6.2.1.1 older people are at risk of being 'hidden' carers. Moreover, results showed that the average aged of 'new carers' was 67 years, and this was higher for male carers (68 years). Stakeholders (i.e. health and social care staff) need to identify carers that may be considered to be 'high-risk' (e.g. spousal carers due to providing higher intensity care) and as emphasised in the Carers Action Plan, stakeholders need to be aware of the key points of the caring journey, where information, advice and support are crucial, such as hospital entry or discharge, diagnosis of a health condition, application for Attendance Allowance or other benefits, contact with local support groups or charities and contact with private care and support services (DHSC, 2018). Once care is initiated the carer needs to be aware where to access support, however, a major barrier to the receipt of social care for the carers is the lack of information on eligibility and available services (Brimblecombe *et al.*, 2017). A relatively high turnover of carers, as well as carers transitioning between intensity levels and care-recipients was evidenced in this thesis. Therefore opportunities to offer carers the support that they need to perform their caring roles, for example via the Carer's Assessment may be missed (see section 1.1.2. for details of the Carer's Assessment). Although almost 70% of 'new carers' entered the role at a low intensity, almost 15% entered the role providing 24-hour care (section 5.2.3). High-intensity carers (spousal carers and end-of-life carers) should be prioritised and fast-tracked, as these carers are at higher risk of health deterioration and

exiting the labour market, compared to carers initiating the role at low intensity (O'Reilly *et al.*, 2008; Carmichael and Ercolani, 2016).

The type of support most valued by carers is emotional space and peer support/training groups, rather than pure respites and 'replacement' care (i.e. reduced hours of care), particularly in the earlier stages of the caring episode (Jenkins *et al.*, 2009; Knowles *et al.*, 2015). It is recommended that training and education provided to carers is tailored to the stages of the caring episode. For example, this thesis showed how male carers often take on high intensity caring in later life and male carer's training and support needs are likely to be vastly different from that of younger female carer. Indeed evidence suggest that many male carers wanted training related to providing medical and personal care, cooking and cleaning (Hughes *et al.*, 2017).

To ensure better multi-agency working, the use of local Community Navigators is recommended, as these are often in the best position to signpost carers and stakeholders to local available support groups, services and organisations (University College London, 2019).

6.5.2 'Maintaining Well' - ensure good health and support working carers to remain in employment

As discussed in section 6.3.4, carers were initially in overall better health than non-carers. However, studies have consistently highlighted the detrimental effect of care provision on the carer's health (ONS, 2013a; Roth *et al.*, 2015; Carmichael and Ercolani, 2016), see also sections 2.3.1.3 and 2.3.2.1. It is therefore of utmost importance that policies aim to maintain the carer's good health. Evidence has shown that carers often neglect their own health, including maintenance and treatment and often fail to attend routine health appointments (Sullivan and Miller, 2015; Carers UK, 2018). If carers are not supported to maintain their health, consequently the carer's themselves will be in need of care, creating a double burden of need for the health and care system (i.e. both the care-recipient and the carer). In order to enable carers to better care for themselves, more reliable and flexible health appointments should be offered outside normal working hours, or alternatively home visits by health-care worker for the carer are recommended (NHS England, 2014). The Government's investment in community healthcare, with a 24/7 rapid response teams is a welcomed initiative, which could benefit both carers and care-recipients alike (GOV.UK, 2018).

The dual aspect of need, for both the carer and the care-recipient, should be balanced by the policy-makers, as the needs for particular services diverge

between the two (Pickard, 2004; Lloyd, 2010). For example, 'replacement' care has been shown to help working carers (Pickard, 2018), however the care-recipient may not feel comfortable receiving formal care, leaving the carer to decline the support (Pickard, 2004; Brimblecombe *et al.*, 2017) (see also section 1.1.2). Services need to consider both the needs of the informal carer and the needs of the care-recipients, when developing support plans (Lloyd, 2010; Wagner and Brandt, 2018).

6.5.2.1 Working-age carers

As seen from section 5.2.4.2, Table 55, carers were less likely to remain in full-time employment compared to non-carers, however there was no significant difference between carers and non-carers remaining in part-time employment. This adds to the notion that the flexible nature of part-time work allows more carers to combine work and care provision over a longer period and flexible working arrangements are promoted in 2018 Carers Action Plan (DHSC, 2018), see also sections 1.1.2 and 2.3.2.2).

This study further adds to the evidence of the temporary nature of caring, and as relative high turnover of carers. Working carers need a mixture of support, ranging from understanding and flexibility at work, to reliable and affordable care services (Carers UK, 2018). Disruptions in one's employment due to caring responsibilities can lead to a loss of job skills, and carers who take leave or leave their job may require retraining to re-enter the workforce (Bainbridge and Broady, 2017). Policies should aim to enable carers who previously participated in the labour force, to get back to paid employment, via for example re-employment programmes either into the former profession or as re-training (Berecki-Gisolf *et al.*, 2008).

The eligibility criteria for receiving the Carers Allowance only allow carers to earn £120 per week from paid work (GOV.UK, 2019). Furthermore, in order to be eligible for Carers Allowance the carer has to provide a minimum of 35 hours of care per week (Ibid). The combination of these two criteria would make this benefit relevant to part-time employees only, as also suggested by the relatively high proportion of working carers in part-time employment seen in this thesis, particular among the female carers. The eligibility criteria for the Carers Allowance could be viewed as a gendered policy, which keeps more women within the caregiving role. Policymakers should reconsider the earnings threshold for carers, as this limits the type of work carers can do. In addition, the current Carers Allowance may place women in multiple roles (i.e. carers and part-time

workers), which has been shown to have detrimental health effects (Kalwij *et al.*, 2014; Stone *et al.*, 2015). There is therefore a need for a policy drive to increase the public provision of care, and indeed evidence from the OECD has shown that the more a country invests in caring for older people, the more women aged 55-64 have access to paid work (EUROCARERS, 2017).

6.5.2.2 Older carers

It was clear from the results that carers aged over the SPA carried out a large proportion of the caring possibilities, often at high intensity. Moreover, the proportion of older carers is likely to be underestimated, as many older people do not always recognise themselves as carers (COPNI, 2014; Carers Trust, 2015; Knowles *et al.*, 2015). Many older carers do not ask for help and often decide to provide care without any additional support (Carers Trust, 2015). There is a need for campaigns in community settings, such as GP surgeries and community pharmacies focussing on the ‘hidden carers’, in order to help carers to self-identify, as many may also be unaware of the support available to them (COPNI, 2014). Additionally, social and health care workers need more training in how to identify ‘high-risk’ carers, such as women providing care at high intensity and older male spousal carers.

As noted by this thesis, older carers often provide care over pro-longed periods, particularly spousal carers. Therefore, creating personalised long-term support plans would be beneficial. The plan should include help with benefits, house adaptation assessments and plans for emergency support (i.e. should be carer suddenly become ill), as well as counselling and mentoring (peer) support for the carer (Carers Trust, 2015).

6.5.3 ‘Discontinuing Well’- the needs of the former carers

Post-care provision trajectories are an integral part of a caring journey that all former carers experience. Providing services after the caring episode provides a holistic approach to care support, and can help carers to feel perceived as a human being, rather than an instrument in the care plan for the care-recipient (Larkin, 2008; Orzeck and Silverman, 2008).

The characteristics of the former carers were discussed in section 6.3.8 and showed that nearly 13% of ‘discontinued carers’ had provided 24-hours care and the likelihood of having stopped providing care was higher for widowers. Support needs to be in place for ‘discontinued carers’, as this period is often associated with feelings of a loss of identity and being left-behind by the support services,

which were in place during the care provision (Cronin *et al.*, 2015). Moreover, many of the adverse effects on the former carer's health may continue post-caring, such as sleeping troubles and musculoskeletal problems (Larkin and Milne, 2017; Watts and Cavaye, 2016).

Any benefits (i.e. Carer's Allowance) the carer may have received are quickly withdrawn, this can leave the former carer in a financially difficult situation, particularly if the carer had left work to provide care (Carers Trust, 2015). A safety net of post-caring benefits, such as a one-off payment as part of an 'end of care review' would support the former carer restore their financial situation. The 'end of care review' should also include support to return to the job market and support services for former carer which may include: counselling services, 'life after caring' peer support and training groups, information and signposting, befriending schemes and mentoring services (Ibid).

6.6 Contributions to research and conclusion

This thesis has greatly added to the pool of evidence needed for policymakers, as public policy decisions are driven by information, often in the form of statistical data like in this present study. This thesis makes several major contributions to existing research on informal care provision.

The analysis contributed to the study of the pathways into informal care provision, by being the first to this date to include four waves of the ELSA dataset including Wave 7. Employing a longitudinal approach has the advantage of more effectively exploring the potential causal pathways into care provision. By creating a 'pure' baseline (i.e. no carers at baseline) this study was in a position to examine the true effect of longer-term care provision, and thereby, this thesis showed evidence in support of the debated '*healthy carer effect*'.

Additionally, the study disaggregated the care-recipients to explore transitions between the directions of care over a longer time-period. Although only a low number of carers provided care at all data collection points, the results show a complex pattern of transitions. This thesis adds to the hypothesis of a '*serial carer*' effect and encourages further research into the characteristics of these particular carers, as well as the cause and consequences of this effect.

Third, the study included care provided to grandchildren, which previously have been omitted. Moreover, the study showed how methodologically it is almost impossible to distinguish how the intensity is divided between multiple care-recipients.

The findings of this thesis have important policy implications, as they demonstrate that informal carers start their caring pathway in good health, however carer's health declined over time. The thesis also highlighted the need for more personalised support for carers, which should consider the carers' age, the intensity of care and who is the care-recipient, as these have an influence on the type of support needed. Lastly, policy-makers needs to take a more holistic approach and consider the whole caring journey from helping the whole population to plan for older age, starting the caring journey, maintaining health and employment while providing care, as well as support once the caring episode ends.

Appendix A Quality of studies – methodological and limitations

The sample size of the studies reviewed varied from smaller-scale studies with fewer than 1,000 respondents (Seltzer and Li, 2000; Burton *et al.*, 2003; Lyons *et al.*, 2015) to national survey with over 10,000 respondents (Dahlberg *et al.*, 2007; O'Reiley *et al.*, 2008; Young and Grundy, 2008; Del Bono *et al.*, 2009; Haberkern *et al.*, 2015; Robards *et al.*, 2015). Large national representative samples sizes are the preferred standard, as smaller-scale studies may have less statistical power to show the real effect of informal care. However, this is not always possible to achieve high sample sizes, especially when researching a topic such as informal care, which although common, only applies to a minority of the population.

The response rates in the studies varied from 45% (Stuifbergen *et al.*, 2008) to 75% (Glaser and Grundy, 2002). The response rate is an important indicator of how representative the survey is, thus higher response rates are preferable (Lynn, 2012). When data are collected over two or more time-points is it not unlikely for some respondents to drop-out of the study prematurely, this may be by choice or due to sickness or death, and this may have caused the original sample to be unrepresentative of the population or affect the outcomes by under or over-estimating effects (Ahern and Brocque, 2005; Miller and Hollist, 2007). Attrition was a common bias in the longitudinal studies reviewed in this study, and attrition rate varied from 13.5% (Jenkins *et al.*, 2009) to 29% (Caputo *et al.*, 2016), and in many cases the attrition was due to the researchers' inability to locate respondents or the death of the respondent (Jenkins *et al.*, 2009; Hiel *et al.*, 2015; Caputo *et al.*, 2016). Hiel *et al.* (2015) found that participants who had been lost-to-follow-up were generally older, lower educated and more often retired; these socio-demographic characteristics have also been associated with a lower response rate (Ahern and Brocque, 2005).

In addition to the non-response bias, the nature of all the studies only allowed for comparison of carers with non-carers, however the reason why some individuals did not provide care remained unclear. Carmichael and Charles (2010) highlighted how this created a bias, as a) the non-carers may not have any family member or others who needed care; or b) there is someone for whom they could provide care to, but they chose not to; or c) they are not able to provide care, either due to health or

Appendix A

financial reasons. The motivations between these are distinctly different and information on why individuals choose not to or are unable to provide care would present a broader understanding of the pathways into informal care for others.

Many of the studies reviewed were overrepresented by women, with some studies having 71% female respondents (Henz, 2004, Leinonen, 2011, Barnett, 2013). As informal care has historically focussed more on women's role, and many studies excluded men all-together, no studies solely included male respondents, which may be due to low sample sizes of male carers (Seltzer and Li, 2000; Lee *et al.*, 2015; Lyon *et al.*, 2015; Caputo *et al.*, 2016). Caputo *et al.* (2016) highlighted that to their knowledge, no longitudinal analysis of men's health and providing informal care had been conducted, and with the increase in men providing care this was needed. Furthermore, Barnett (2013) acknowledges the need to compare role pathways of daughter and son carers to further determine the gender differences in parental care provision. The gender bias may mask the true effect care has on women and men.

The definitions of informal care used by national surveys varied, which resulted variations in how the question of informal care provision was asked. Furthermore, the interpretation of the caring intensity and the task carried out, may not be comparable across the studies. Moreover, the before mentioned gender bias, may also influence how caring intensity and task were reported by women and men. For example, due to traditional expectations of household tasks, men might have over-reported the tasks carried out, compared to women, or vice versa women may be more inclined to define themselves as carers (Carmichael and Charles, 2010; Del Bono *et al.*, 2009). A study by Rutherford and Bu (2017) noted that the most common measures of informal care underestimated both the intensity and the activities carried out. The authors further noticed, that individuals who spend less than 9 hours per week providing care, were more likely to underestimate the scale and scope of caring, than those providing moderate to heavy care provision (Ibid). Rutherford and Bu (2017) recommended that careful consideration of the content of informal care survey questions, as terms like 'help', 'support' 'cared for' focused on different aspects of the activities and needs of both the care provider and care-receiver (Ibid).

The literature review included two primary study designs: cross-sectional and longitudinal analysis, each with their own set of limitations. Cross-sectional studies only assessing one point in time, which means these studies may underestimate the

total number of carers. Moreover, some studies asked the respondents retrospectively to report whether they had provided any informal care during the last month or week. As this set a time period, the bias of 'forward-telescoping' may have occurred, meaning that the respondents reported a caring episode to be more recent than it may actually have been, thereby potentially over-reporting the prevalence of informal carers. (Prohaska *et al.*, 1998). Although the reasons for forward-telescoping bias are multiple, social desirability and wanting recognition for providing care would play a major part in the evidence provided in this review. The evidence from longitudinal studies showed that many carers transition in and out of the caring role, however due to the nature of cross-sectional studies this would not be captured, thereby losing the full picture of the dynamics of caregiving.

The majority of the longitudinal studies presented in this review explored a relatively short time period, spanning from a two-year period (Jenkins *et al.*, 2009; Rafnsson *et al.*, 2015; Kim *et al.*, 2016) to a twenty-year time period (Carmichael and Ercolani, 2016). Studies covering longer time periods focused almost exclusively on employment transition of the carers. However, the longest time period for studies focussing on health outcomes of the carers was nine years (Rafnsson *et al.*, 2015). Some longitudinal studies only reported a few time points over a certain time period, such as Pillemer and Suitor (2014) and Szinovacz and Davey (2012) both of whom conducted longitudinal analyses over a 7 and 9 year period, respectively, but with only 2 time-points. The short time span and the limited number of waves used for the data analysis provided a limited perspective of any changes in or effects of the care provision, as this period may not capture all transitions in and out of the caring role. At the same time, it is not possible to distinguish true change from a potential measurement/response bias in the survey (Singer and Willett, 2003). As illustrated by McCann *et al.* (2004) longitudinal studies with a baseline sample with current carers may also substantially underestimate the impact which caring has, especially on the health among older people providing informal care.

Appendix B ERGO Ethics approval email

From: [ERGO](#)
To: [Palmer M.E.E.](#)
Subject: Your Ethics Submission (Ethics ID:21164) has been reviewed and approved
Date: 10 June 2016 15:43:32

Submission Number: 21164

Submission Name: Pathways into informal care provision

This email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments

1. ELSA is a single research dataset that does not contain personal information. The UKDS terms and conditions of use govern its appropriate usage.

[Click here to view your submission](#)

Coordinator: Maja Palmer

ERGO : Ethics and Research Governance Online
<http://www.ergo.soton.ac.uk>

DO NOT REPLY TO THIS EMAIL

Appendix C Direction of care

Table 60 Appendix C: Count of possible combination of direction of care

CIRCUMSTANCE OF THE DIRECTION OF CARE	FREQUENCY
1 No caring	8019
2 Spouse/partner	487
3 Grandchild	276
4 Parent	256
5 Friend	202
6 Child	100
7 Other	75
8 Parent-in-law	57
9 Grandchild & Parent	23
10 Unknown	18
11 Spouse/partner & Grandchild	15
12 Spouse & Child	15
13 Spouse & Friend	13
14 Spouse & Parent	11
15 Parent & Parent-in-law	10
16 Grandchild & Others	10
17 Grandchild & Child	9
18 Parent & Friend	8
19 Grandchild & Friend	8
20 Grandchild & Parent-in-law	8
21 Parent & Other	5
22 Child & Parent	5
23 Spouse & Other	4
24 Child & Other	3
25 Child & Parent & Parent-in-law	3
26 Spouse & Child & Grandchild	2
27 Other & Friend	2
28 Parent-in-law & Other	2
29 Spouse & Parent-in-law	2
30 Spouse & Parent & Parent-in-law	2
31 Parent & Friend	1
32 Grandchild & Parent & Friend	1
33 Grandchild & Parent & Other	1
34 Grandchild & Parent & Other & Friend	1
35 Grandchild & Parent & Parent-in-law	1
36 Child & Parent-in-law	1
37 Grandchild & Child & Parent	1
38 Grandchild & Child & Parent & Other	1
39 Spouse & Parent & Friend	1
40 Spouse & Parent & Other	1
41 Spouse & Grandchild & Parent	1
42 Spouse & Child & Friend	1
43 Spouse & Child & Parent & Other	1
44 Spouse & Child & Grandchild & Parent-in-law	1

Source: Author's own analysis of the ELSA Wave 7

Appendix D Comparison of the bivariate and multivariate including and excluding grandchildren

Table 61 Appendix D: Descriptive summary of analytical sample, by caring status comparing the inclusion of grandchildren.

	Informal carers Including grandchild carers	Informal carers Excluding grandchild carers
Total of sample - %	17.6% (1,604)	14.9% (1,334)
Gender -%		
Male	37.3%	38.5%
Female	62.7%	61.5%
	100% (1,604)***	100% (1,334)***
Mean age – in years. (SD)^{a,b}	64.0 (± 9.5)***	64.0 (± 9.8)***
Age Group (in years) -%		
50-59	39.5%	41.4%
60-69	34.1%	31.1%
70-79	19.7%	19.7%
Over 80	6.7%	7.7%
	100% (1,604)***	100% (1,334)***
Marital Status -%		
Single, never married	6.7%	7.6%
Married or partnered	75.9%	75.8%
Divorced or separated	11.1%	10.9%
Widowed	6.3%	5.7%
	100% (1,604)***	100% (1,334)***
Household Type -%		
Single	10.9%	10.2%
Lone plus children	6.5%	7.3%
Couple	56.3%	54.9%
Couple plus children	20.1%	21.2%
Extended family	5.0%	6.5%
	100% (1,584)***	100% (1,334)***
Ethnicity - %		
White	94.9%	94.3%
Non-white	5.1%	5.7%
	100% (1,604) [#]	100% (1,334) [#]
Self-reported health -%		
Good	41.4%	41.7%
Fair	52.9%	51.8%
Poor	5.7%	6.4%
	100% (1,604)**	100% (1,334) [#]
Longstanding illness -%		
No	47.7%	47.3%
Yes, but not limiting	20.7%	19.7%
Yes and limiting	31.6%	33.0%
	100% (1,604) [#]	100% (1,334) [#]
ADLs -%		
None	88.5%	88.2%
1 ADL	6.4%	6.4%
2 or more ADLs	5.1%	5.4%
	100% (1,604)***	100% (1,334)***
IADLs -%		
None	83.5%	82.1%
1 IADL	10.1%	10.7%
2 or more IADLs	6.4%	7.2%
	100% (1,604)***	100% (1,334)***

^a weighted mean (67.7 years unweighted); ^b Independent-samples Mann Whitney U test; *** p<0.001, ** p<0.01, * P<0.05, # no statistically significance. Source: Author's analysis of the ELSA Wave 7

Table 61 (continued): Descriptive summary of analytical sample, by caring status comparing the inclusion of grandchildren.

	Informal carers Including grandchild carers	Informal carers Excluding grandchild carers
Economic activity -%		
Retired	45.6%	44.3%
Employed: Full-time(>=35hrs)	18.2%	18.0%
Employed: Part-time(<=35hrs)	21.0%	21.2%
Economic inactive	15.2%	16.5%
	100% (1,598)***	100% (1,330)***
Mean working hours –hrs (SD) (2,327)^{a,b}	31.2 (±15.4)***	30.9 (±15.0)***
Education Level - %		
NVQ4/NVQ5/Degree or equiv	15.5%	14.7%
Higher education below degree	13.6%	13.0%
NVQ3/GCE/A-level or equiv	9.7%	9.4%
NVQ2/GCE/O-level or equiv	23.2%	24.2%
NVQ1/GSE or grade equiv	2.9%	3.0%
Foreign/other	12.4%	12.4%
No qualification	22.7%	23.3%
	100% (1,562)**	100% (1,299)*
Housing tenure - %		
Own, outright	59.7%	58.9%
Own with mortgage or loan	21.6%	21.9%
Private renting	4.6%	3.9%
Social renting	13.7%	14.9%
Live rent free	0.4%	0.5%
	100% (1,603) [#]	100% (1,333) [#]
Access to car or van - %		
Yes	89.1%	88.0%
No	10.9%	12.0%
	100% (1,604)***	100% (1,334)***
Non-pension wealth Quintiles -%		
Poorest	19.8%	20.3%
2 nd Quintile	19.9%	19.7%
3 rd Quintile	19.3%	19.2%
4 th Quintile	22.1%	21.9%
Wealthiest	18.9%	18.9%
	100% (1,337) [#]	100% (1,104) [#]
Region - %		
North East	5.9%	5.1%
North West	12.7%	11.4%
Yorkshire and the Humber	10.3%	10.8%
East Midlands	10.4%	8.7%
West Midlands	9.9%	10.8%
East of England	13.9%	14.7%
London	11.7%	12.1%
South East	16.0%	15.7%
South West	9.3%	10.6%
	100% (1,604)*	100% (1,334)*

^a Weighted mean (SD); ^b independent-samples Mann Whitney U test; ^c independent Samples T-test *** p<0.001, ** p<0.01, * P<0.05, # no statistically significance

Source: Author's analysis of the ELSA Wave 7.

Appendix D

Table 62 Appendix D Descriptive summary of analytical sample, by caring status and sex, excluding grandchildren.

	Male n= 3,906 (100%)		Female n=4,933 (100%)	
	Informal carers Including grandchildren n= 13.8% (587)	Informal carers Excluding grandchildren n= 12.1% (504)	Informal carers Including grandchildren n= 21.0% (1,017)	Informal carers Excluding grandchildren n= 17.4% (830)
Mean age – in years (SD)^{a,b}	65.3 (±10.1) [#]	65.3 (±10.4) [#]	63.1 (±9.0) ^{***}	63.2 (±9.4) ^{***}
Age Group - %				
50-59	35.5%	37.2%	41.9%	44.1%
60-69	31.5%	29.4%	35.6%	32.2%
70-79	23.9%	23.3%	17.3%	17.5%
Over 80	9.1%	10.1%	5.2%	6.2%
	100% (587) [#]	100% (504) [#]	100% (1,017) ^{***}	100% (830) ^{***}
Marital Status - %				
Single, never married	8.3%	9.2%	5.8%	6.6%
Married or partnered	81.0%	80.1%	72.9%	73.1%
Divorced	7.7%	8.1%	13.1%	12.7%
Widowed	3.0%	2.6%	8.2%	7.6%
	100% (587) ^{***}	100% (504) ^{***}	100% (1,017) ^{***}	100% (830) ^{***}
Household Type - %				
Single	8.9%	8.5%	12.1%	11.2%
Lone plus children	5.3%	6.1%	7.1%	8.1%
Couple	60.6%	59.2%	53.7%	52.1%
Couple plus children	19.9%	20.8%	20.3%	21.4%
Extended family	5.3%	5.4%	6.8%	7.3%
	100% (587) ^{***}	100% (504) ^{***}	100% (1,017) ^{***}	100% (830) ^{***}
Ethnicity - %				
White	93.3%	92.7%	95.9%	95.3%
Non-white	6.7%	7.3%	4.1%	4.7%
	100% (587) [#]	100% (504) [#]	100% (1,017) [#]	100% (830) [#]
Self-reported health - %				
Good	37.8%	38.2%	38.7%	44.0%
Fair	55.3%	54.3%	51.8%	50.3%
Poor	6.9%	7.5%	9.5%	5.8%
	100% (587) ^{**}	100% (504) [*]	100% (3,930) ^{***}	100% (830) ^{***}
Long-term illness -%				
No	46.9%	47.0%	46.1%	47.4%
Yes, but not limiting	23.2%	21.7%	17.6%	18.5%
Yes and limiting	29.9%	31.3%	36.3%	34.1%
	100% (587) [#]	100% (504) [#]	100% (3,915) [#]	100% (830) [#]
ADLs -%				
None	88.6%	88.3%	80.8%	88.2%
1 ADL	6.2%	6.4%	8.2%	6.4%
2 or more ADLs	5.2%	5.3%	11.0%	5.5%
	100% (587) [#]	100% (504) [#]	100% (3,916) ^{***}	100% (830) ^{***}
IADLs -%				
None	85.7%	84.5%	76.5%	80.5%
1 IADL	10.1%	10.9%	10.1%	10.6%
2 or more IADLs	4.2%	4.6%	13.4%	8.9%
	100% (587) ^{**}	100% (504) ^{**}	100% (3,916) ^{***}	100% (830) ^{**}

Please note that the statistically significance measures the within gender between carers and non-carers. ^a Weighted mean (SD); ^b independent-samples Mann Whitney U test; ^c Mean working hours were derived from respondents, who had reported being employed or self-employed. *** p<0.001, ** p<0.01, * P<0.05, Chi-Square test, # no statistically significance. Source: Author’s analysis of the ELSA wave 7

Table 62 (continued): Descriptive summary of analytical sample, by caring status and sex, excluding grandchildren.

	Male		Female	
	Informal carers Including grandchildren	Informal carers Excluding grandchildren	Informal carers Including grandchildren	Informal carers Excluding grandchildren
Economic activity - %				
Retired	49.5%	48.5%	43.3%	41.7%
Employed: full time (≥35hrs)	26.1%	25.7%	13.5%	13.1%
Employed: Part time (≤35hrs)	13.5%	13.6%	25.4%	26.0%
Economic inactive	10.9%	12.2%	17.8%	19.2%
	100% (587)***	100% (504)***	100% (1,011)***	100% (826)***
Mean working hours – hrs (SD)^{a, b, c}	36.4 (±14.1)*	35.9 (±12.4)*	28.3 (±15.4) [#]	28.0 (±15.7)***
Education Level - %				
NVQ4/NVQ5/Degree or equiv	17.4%	16.6%	14.3%	13.6%
Higher education below degree	16.8%	15.5%	11.7%	11.4%
NVQ3/GCE/A-level or equiv	9.0%	8.8%	10.3%	9.8%
NVQ2/GCE/O-level or equiv	22.0%	22.9%	23.8%	25.0%
NVQ1/GSE or grade equiv	4.1%	4.4%	2.2%	2.1%
Foreign/other	11.9%	11.4%	12.7%	13.0%
No qualification	18.8%	20.4%	24.9%	25.0%
	100% (569) [#]	100% (490) [#]	100% (993) [*]	100% (809) [#]
Housing tenure - %				
Owned, outright	58.9%	57.9%	60.2%	59.5%
Owned with mortgage or loan	23.3%	23.3%	20.7%	21.0%
Private renting	2.6%	1.7%	5.7%	5.2%
Social renting	15.1%	16.9%	12.8%	13.7%
Live rent free	[-]	[-]	0.5%	0.7%
	100% (587) [*]	100% (587)***	100% (1,016) [*]	100% (1,016) [#]
Access to car or van - %				
Yes	90.8%	89.7%	88.0%	86.9%
No	9.2%	10.3%	12.0%	13.1%
	100% (587) [*]	100% (504) [#]	100% (1,017)***	100% (830)***
Non-pension wealth Quintiles - %				
Poorest	21.6%	22.0%	18.7%	19.2%
2 nd Quintile	18.1%	18.4%	21.0%	20.6%
3 rd Quintile	18.5%	18.7%	19.7%	19.5%
4 th Quintile	24.3%	24.0%	20.8%	20.5%
Wealthiest	17.5%	17.0%	19.8%	20.2%
	100% (482) [*]	100% (413) [*]	100% (855) [#]	100% (691) [#]
Region - %				
South of England	38.7%	40.1%	40.3%	41.5%
London	13.1%	13.7%	10.8%	11.1%
North of England	48.2%	46.2%	48.9%	47.4%
	100% (587) [#]	100% (504) [#]	100% (3,916) [#]	100% (830) [#]

Weighed percentages, unweighted frequencies. Please note that the statistically significance measures the within gender between carers and non-carers.

^a weighted mean, ^b Independent-samples Mann Whitney U test; *** p<0.001, ** p<0.01, * P<0.05, Chi-Square test, [#] no statistically significance.

Source: Author's analysis of the ELSA Wave 7.

Appendix D

Table 63 Appendix D: Descriptive analytical summary of caring characteristic comparing inclusion of grandchild carers, by sex

	Overall care providers including grandchild carers	Overall care providers excluding grandchild carers	Male including grandchild carers	Male excluding grandchild carers	Female including grandchild carers	Female excluding grandchild carers
	100% (1,334)	100% (1,334)	37.7% (587)	38.5% (504)	62.7% (1,017)	61.5% (830)
Hours spent providing care -%						
1-19	59.7%	57.7%	59.3%	56.7%	59.8%	58.3%
20-49	17.1%	15.9%	14.9%	14.3%	18.4%	16.9%
50-167	5.2%	5.5%	4.4%	4.9%	5.7%	5.8%
168	18.0%	21.0%	21.4%	24.2%	16.0%	18.9%
	100% (1,584)	100% (1,316)	100% (581) [#]	100% (498) [#]	100% (1,003) [#]	100% (818) [#]
Number of people providing care for - %						
1	73.9%	78.4%	76.2%	80.3%	72.5%	77.3%
2	15.8%	13.1%	14.8%	12.4%	16.4%	13.6%
3	6.5%	4.9%	6.7%	5.2%	6.3%	4.6%
Over 4	3.8%	3.6%	2.3%	2.2%	4.7%	4.5%
	100% (1,604)	100% (1,334)	100% (587) [#]	100 (504) [#]	100% (1,017) [#]	100% (830) [#]
Co-residence with person cared for - %						
Yes	41.4%	48.0%	48.1%	54.3%	37.4%	44.0%
No	58.6%	52.0%	51.9%	45.7%	62.6%	56.0%
	100% (1,603)	100% (1,334)	100% (586) ^{***}	100% (504) ^{***}	100% (1,017) ^{***}	100% (830) ^{***}
Relationship to person looked after - %						
Spouse or partner (only)	27.0%	32.0%	33.5%	38.3%	23.2%	28.0%
Parent(s)/Parent-in-law(s) (only)	22.8%	27.0%	20.1%	23.0%	24.5%	29.5%
Child(ren) (only)	5.9%	7.00%	6.3%	7.2%	5.7%	6.9%
Others (only)	15.4%	21.3%	12.7%	19.7%	17.1%	22.3%
Grandchildren (only)	18.0%	Omitted	17.2%	Omitted	18.5%	Omitted
Other combinations	10.8%	12.7%	10.3%	11.8%	11.1%	13.3%
	100% (1,604)	100% (1,334)	100%** (587)	100%** (504)	100%** (1,017)	100%** (830)

Weighed percentages, unweighted frequencies. *** p<0.001, ** p<0.01, Chi-Square test,* P<0.05[#] no statistically significance; based on a Chi-Square test.

Source: Author's analysis of the ELSA Wave 7

Table 64 Appendix D: Binary logistic regression of the total population of the ELSA Wave 7, excluding grandchildren.

	Block 2	Block 5	Block 10	Final Model
Gender				
Female (Ref.)	1.00***	1.00***	1.00***	1.00***
Male	0.62 (0.54 - 0.71)***	0.62 (0.54 - 0.72)***	0.75 (0.64 - 0.86)***	0.72 (0.63 - 0.83)***
Age				
50-59 (Ref.)	1.00	1.00	1.00**	1.00***
60-69	0.87 (0.74 - 1.03)	0.87 (0.74 - 1.03)	0.72 (0.59 - 0.88)***	0.73 (0.61 - 0.89)***
70-79	0.91 (0.75 - 1.10)	0.90 (0.74 - 1.09)	0.7 (0.55 - 0.90)***	0.71 (0.56 - 0.91)***
>80	0.74 (0.57 - 0.97)	0.75 (0.57 - 0.99)	0.63 (0.46 - 0.87)***	0.63 (0.46 - 0.87)***
Marital Status				
Married (Ref.)	1.00***	1.00***	1.00***	1.00***
Single	0.85 (0.60 - 1.20)	0.88 (0.62 - 1.24)	0.84 (0.59 - 1.20)	0.9 (0.64 - 1.27)
Divorced	0.49 (0.35 - 0.67)***	0.49 (0.36 - 0.68)***	0.50 (0.36 - 0.70)***	0.56 (0.41 - 0.76)***
Widowed	0.40 (0.27 - 0.60)***	0.41 (0.27 - 0.61)***	0.45 (0.30 - 0.68)***	0.47 (0.32 - 0.69)***
Household Type				
Couple (Ref.)	1.00***	1.00***	1.00***	1.00***
Couple plus children	0.95 (0.79 - 1.14)	0.94 (0.78 - 1.14)	0.94 (0.77 - 1.14)	0.95 (0.79 - 1.15)
Single	0.62 (0.44 - 0.87)***	0.59 (0.42 - 0.84)***	0.55 (0.38 - 0.79)***	0.53 (0.38 - 0.75)***
Single plus children	2.15 (1.46 - 3.17)***	2.09 (1.42 - 3.09)***	1.89 (1.26 - 2.82)***	1.8 (1.22 - 2.64)***
Extended Family	1.59 (1.17 - 2.16)***	1.59 (1.16 - 2.16)***	1.55 (1.13 - 2.14)**	1.46 (1.07 - 1.98)*
Self-reported Health				
Good (Ref.)		1.00	1.00	Omitted
Fair		1.12 (0.97 - 1.29)	1.04 (0.89 - 1.20)	
Poor		0.94 (0.69 - 1.29)	0.73 (0.52 - 1.01)	
ADLs				
None (Ref.)		1.00***	1.00***	1.00***
1 ADL		0.80 (0.61 - 1.06)	0.74 (0.56 - 0.99)*	0.76 (0.58 - 1.00)
Over 2 ADLs		0.51 (0.36 - 0.72)***	0.46 (0.33 - 0.66)***	0.45 (0.32 - 0.63)***
IADLs				
None (Ref.)		1.00***	1.00**	1.00**

Appendix D

1 IADL		1.58 (1.24 - 2.01)***	1.47 (1.15 - 1.87)***	1.46 (1.15 - 1.84)***
Over 2 IADLs		1.22 (0.89 - 1.67)	1.04 (0.76 - 1.43)	1.01 (0.74 - 1.37)
Economic Activity				
Retired (Ref.)			1.00***	1.00***
Employed (Full-time >=35)			0.47 (0.37 - 0.61)***	0.47 (0.37 - 0.60)***
Employed (Part-time <35)			0.99 (0.80 - 1.23)	1.00 (0.81 - 1.24)
Economic inactive			1.61 (1.27 - 2.05)***	1.59 (1.26 - 2.00)***
Education				
Less than o-level or equivalent (Ref.)			1.00*	1.00
o-level or equivalent			1.23 (1.05 - 1.45)**	1.18 (1.00 - 1.38)*
Higher than a-level			1.13 (0.94 - 1.35)	1.06 (0.90 - 1.26)
Wealth Quintiles				
Poorest (Ref.)			1.00***	Omitted
2nd Quintile			1.00 (0.71 - 1.43)	
3rd Quintile			0.92 (0.63 - 1.35)	
4th Quintile			0.87 (0.59 - 1.27)	
Wealthiest			0.76 (0.52 - 1.12)	
Housing tenure				
Own outright (Ref.)			1.00	Omitted
Own with mortgage			0.89 (0.72 - 1.09)	
Renting, social			0.83 (0.52 - 1.31)	
Renting, private			1.28 (0.87 - 1.87)	
Live rent free			0.61 (0.24 - 1.54)	
Assess to car				
Yes (Ref.)			1.00	Omitted
No			0.80 (0.63 - 1.01)	
-2LLR	5891.783	5796.099	5674.655	5855.46
% Change -2LLR				
Significance of block	$\chi^2=169.26, p<0.001$	$\chi^2=13.37, p<0.001$	$\chi^2=3.652, p=0.056$	$\chi^2=368.132, p<0.001$
Hosmer & Lemeshow Test	$\chi^2=15.81, p=0.045$	$\chi^2=12.47, p=0.132$	$\chi^2=14.52, p=0.785$	$\chi^2=9.75, p=0.283$
Cox & Snell R squared	0.023	0.036	0.052	0.049
Chi-square overall model	$\chi^2=169.26, p<0.001$	$\chi^2=264.95, p<0.001$	$\chi^2=386.39, p<0.001$	$\chi^2=368.132, p<0.001$

*Significant at the 0.05 level, ** Significant at the 0.01 level, *** Significant at the 0.001 level. Source: Author's own analysis of the ELSA Wave 7

Table 65 Appendix D: Binary logistic regression of the MALE population of the ELSA Wave 7, excluding grandchildren.

	Block 2	Block 5	Block 10	Final Model
Age				
50-59 (Ref.)	1.00	1.00	1.00	Omitted
60-69	0.94 (0.72 - 1.23)	0.92 (0.70 - 1.21)	0.72 (0.52 - 1.00)	
70-79	1.20 (0.89 - 1.62)	1.15 (0.85 - 1.56)	0.83 (0.55 - 1.25)	
>80	1.20 (0.81 - 1.77)	1.14 (0.76 - 1.70)	0.91 (0.55 - 1.49)	
Marital Status				
Married (Ref.)	1.00***	1.00***	1.00***	1.00***
Single	0.73 (0.43 - 1.25)	0.72 (0.42 - 1.24)	0.6 (0.34 - 1.05)	0.65 (0.37 - 1.13)
Divorced	0.42 (0.24 - 0.73)***	0.40 (0.23 - 0.70)***	0.34 (0.19 - 0.61)***	0.37 (0.21 - 0.65)***
Widowed	0.25 (0.11 - 0.53)***	0.24 (0.11 - 0.53)***	0.25 (0.11 - 0.55)***	0.26 (0.12 - 0.58)***
Household Type				
Couple (Ref.)	1.00***	1.00***	1.00***	1.00***
Couple plus children	0.84 (0.63 - 1.13)	0.81 (0.61 - 1.09)	0.81 (0.60 - 1.10)	0.86 (0.64 - 1.16)
Single	0.70 (0.40 - 1.23)	0.68 (0.39 - 1.20)	0.62 (0.34 - 1.14)	0.58 (0.32 - 1.05)
Single plus children	5.05 (2.59 - 9.87)***	4.8 (2.44 - 9.44)***	4.3 (2.08 - 8.89)***	4.82 (2.38 - 9.74)***
Extended Family	1.59 (0.96 - 2.62)	1.63 (0.98 - 2.69)	1.64 (0.96 - 2.79)	1.61 (0.97 - 2.67)
Self-reported Health				
Good (Ref.)		1.00**	1.00	Omitted
Fair		1.43 (1.14 - 1.79)***	1.24 (0.98 - 1.57)	
Poor		1.67 (1.05 - 2.66)*	1.17 (0.72 - 1.91)	
ADLs				
None (Ref.)		1.00	1.00*	1.00*
1 ADL		0.70 (0.45 - 1.08)	0.59 (0.38 - 0.93)*	0.64 (0.41 - 0.99)*
Over 2 ADLs		0.58 (0.34 - 1.00)	0.53 (0.31 - 0.91)	0.54 (0.31 - 0.92)*
IADLs				
None (Ref.)		1.00**	1.00**	1.00**
1 IADL		1.74 (1.19 - 2.55)***	1.58 (1.07 - 2.34)*	1.77 (1.21 - 2.58)***
Over 2 IADLs		0.82 (0.47 - 1.44)	0.64 (0.36 - 1.13)	0.69 (0.39 - 1.22)
Economic Activity				

Appendix D

Retired (Ref.)			1.00***	1.00***
Employed (Full-time >=35)			0.46 (0.31 - 0.67)***	0.5 (0.37 - 0.68)***
Employed (Part-time <35)			1.21 (0.84 - 1.74)	1.14 (0.82 - 1.58)
Economic inactive			1.52 (0.95 - 2.41)	1.64 (1.09 - 2.47)**
Education				
Less than o-level or equivalent (Ref.)			1.00**	1.00**
o-level or equivalent			1.35 (1.04 - 1.77)*	1.33 (1.03 - 1.73)*
Higher than a-level			1.00 (0.76 - 1.31)	0.91 (0.7 - 1.18)
Wealth Quintiles				
Poorest			1.00	Omitted
2nd Quintile			0.65 (0.37 - 1.14)	
3rd Quintile			0.57 (0.32 - 1.02)	
4th Quintile			0.6 (0.33 - 1.09)	
Wealthiest			0.45 (0.25 - 0.82)***	
Housing tenure				
Own outright (Ref.)			1.00**	1.00***
Own with mortgage			1.09 (0.79 - 1.52)	1.23 (0.9 - 1.68)
Renting, social			0.29 (0.12 - 0.70)**	0.47 (0.22 - 1.01)
Renting, private			1.22 (0.67 - 2.22)	1.88 (1.33 - 2.64)***
Live rent free			0.15 (0.01 - 1.84)	0.21 (0.02 - 2.55)
Assess to car				
Yes (Ref.)			1.00	Omitted
No			0.70 (0.47 - 1.04)	
-2LLR	2448.57	2423.66	2339.26	2398.99
% Change -2LLR	1.75%***	0.41%**	0.14%	4.74%*** #
Hosmer & Lemeshow Test	$\chi^2=6.05$, p=0.534	$\chi^2=7.63$, p=0.470	$\chi^2=14.41$, p=0.072	$\chi^2=16.88$, p=0.031
Chi-square overall model	$\chi^2=77.06$, p<0.001	$\chi^2=101.98$, p<0.001	$\chi^2=186.38$, p<0.001	$\chi^2=163.72$ p<0.001

Weighed data. *Significant at the 0.05 level; ** Significant at the 0.01 level; *** Significant at the 0.001 level. Source: Author's own analysis of the ELSA Wave 7

Table 66 Appendix D: Binary logistic regression of the FEMALE population of the ELSA Wave 7, excluding grandchildren.

	Block 2	Block 6	Block 11	Final model
Age				
50-59	1.00***	1.00***	1.00***	1.00**
60-69	0.84 (0.68 - 1.05)	0.83 (0.67 - 1.03)	0.71 (0.55 - 0.92)**	0.79 (0.62 - 1.00)
70-79	0.74 (0.57 - 0.95)*	0.72 (0.55 - 0.94)*	0.6 (0.43 - 0.83)***	0.66 (0.48 - 0.89)**
>80	0.5 (0.35 - 0.73)***	0.51 (0.34 - 0.75)***	0.45 (0.29 - 0.70)***	0.49 (0.33 - 0.75)***
Ethnicity				
White	1.00	1.00	1.00	Omitted
Non-white	0.83 (0.55 - 1.26)	0.92 (0.6 - 1.39)	0.81 (0.53 - 1.25)	
Marital Status				
Married	1.00***	1.00***	1.00**	1.00**
Single	1.01 (0.64 - 1.60)	1.09 (0.69 - 1.74)	1.13 (0.70 - 1.82)	0.93 (0.61 - 1.43)
Divorced	0.54 (0.36 - 0.80)***	0.56 (0.37 - 0.85)***	0.62 (0.41 - 0.95)*	0.63 (0.44 - 0.91)*
Widowed	0.52 (0.32 - 0.84)**	0.55 (0.34 - 0.89)**	0.61 (0.37 - 0.98)*	0.52 (0.33 - 0.82)**
Household Type				
Couple	1.00***	1.00***	1.00***	1.00***
Couple plus children	1.08 (0.84 - 1.38)	1.1 (0.85 - 1.41)	1.1 (0.85 - 1.43)	1.11 (0.88 - 1.41)
Single	0.58 (0.37 - 0.91)**	0.54 (0.35 - 0.85)**	0.51 (0.32 - 0.81)***	0.59 (0.39 - 0.89)**
Single plus children	1.52 (0.94 - 2.47)	1.5 (0.92 - 2.44)	1.39 (0.84 - 2.3)	1.49 (0.95 - 2.31)
Extended Family	1.58 (1.06 - 2.35)*	1.54 (1.03 - 2.3)*	1.57 (1.04 - 2.37)*	1.45 (0.99 - 2.14)
Self-reported Health				
Good		1.00**	1.00***	1.00*
Fair		0.85 (0.69 - 1.04)	0.82 (0.67 - 1.01)	0.89 (0.73 - 1.07)
Poor		0.49 (0.31 - 0.77)***	0.42 (0.26 - 0.66)***	0.54 (0.35 - 0.82)***
Long-Term Limiting Illness				
None		1.00**	1.00*	1.00*
Yes, not limiting		1.15 (0.90 - 1.46)	1.16 (0.91 - 1.49)	1.16 (0.91 - 1.46)
Yes & limiting		1.49 (1.17 - 1.90)***	1.38 (1.08 - 1.78)**	1.41 (1.12 - 1.77)***
ADLs				
None		1.00***	1.00***	1.00***
1 ADL		0.79 (0.54 - 1.14)	0.76 (0.52 - 1.11)	0.77 (0.54 - 1.10)

Appendix D

Over 2 ADLs		0.43 (0.27 - 0.67)***	0.39 (0.25 - 0.63)***	0.49 (0.33 - 0.73)***
IADLs				
None		1.00	1.00	Omitted
1 IADL		1.35 (0.98 - 1.86)	1.32 (0.95 - 1.82)	
Over 2 IADLs		1.43 (0.96 - 2.11)	1.29 (0.86 - 1.92)	
Economic Activity				
Retired			1.00***	1.00***
Employed (Full-time >=35)			0.52 (0.36 - 0.74)***	0.61 (0.44 - 0.84)***
Employed (Part-time <35)			0.90 (0.69 - 1.19)	0.92 (0.71 - 1.20)
Economic inactive			1.66 (1.24 - 2.21)***	1.59 (1.20 - 2.09)***
Education				
Less than o-level or equiv.			1.00	Omitted
o-level or equivalent			1.11 (0.90 - 1.37)	
Higher than a-level			1.20 (0.94 - 1.53)	
Wealth Quintiles				
Poorest			1.00	Omitted
2nd Quintile			1.48 (0.92 - 2.38)	
3rd Quintile			1.42 (0.85 - 2.38)	
4th Quintile			1.28 (0.76 - 2.15)	
Wealthiest			1.24 (0.73 - 2.10)	
Housing tenure				
Own outright			1.00	Omitted
Own with mortgage			0.83 (0.64 - 1.08)	
Renting, social			1.63 (0.91 - 2.94)	
Renting, private			1.50 (0.90 - 2.51)	
Live rent free			1.04 (0.37 - 2.97)	
Assess to car				
Yes			1.00	Omitted
No			0.86 (0.64 - 1.15)	
-2LLR	3349.062	3314.777	3260.696	3566.598
% Change -2LLR	0.91%***	0.15%	0.03%	-5.53%
Hosmer & Lemeshow Test	$\chi^2=13.31$, p=0.065	$\chi^2=13.02$, p=0.111	$\chi^2=13.30$, p=0.103	$\chi^2=13.35$, p=0.100
Chi-square overall model	$\chi^2=154.23$, p<0.001	$\chi^2=188.52$, p<0.001	$\chi^2=242.60$, p<0.001	$\chi^2=212.62$, p<0.001

Weighed data. *Significant at the 0.05 level, ** Significant at the 0.01 level, *** Significant at the 0.001 level. Source: Author's own analysis of the ELSA Wave 7

Table 67 Appendix D: Binary logistic regression of over 20 hours of care per week, the INFORMAL CARERS of the ELSA Wave 7, excluding grandchildren.

	Block 4	Block 6	Block 11	Final model
Gender				
Female	1.00	1.00	1.00	Omitted
Male	0.85 (0.66 - 1.11)	0.79 (0.60 - 1.04)	0.96 (0.72 - 1.29)	
Age				
50-59	1.00***	1.00***	1.00***	1.00**
60-69	1.15 (0.84 - 1.58)	1.13 (0.81 - 1.56)	0.94 (0.62 - 1.40)	0.93 (0.64 - 1.36)
70-79	2.41 (1.67 - 3.49)***	2.21 (1.51 - 3.23)***	1.75 (1.05 - 2.91)*	1.63 (1.01 - 2.62)*
>80	3.26 (1.92 - 5.54)***	2.95 (1.71 - 5.10)***	2.17 (1.12 - 4.23)*	1.87 (1.00 - 3.47)
Ethnicity				
White	1.00	1.00	1.00	Omitted
Non-white	1.61 (0.92 - 2.80)	1.31 (0.75 - 2.30)	1.46 (0.79 - 2.71)	
Marital Status				
Married	1.00*	1.00	1.00	Omitted
Single	1.32 (0.69 - 2.52)	1.18 (0.61 - 2.29)	0.84 (0.41 - 1.74)	
Divorced	1.45 (0.76 - 2.73)	1.26 (0.65 - 2.43)	1.59 (0.80 - 3.15)	
Widowed	0.47 (0.21 - 1.09)	0.48 (0.20 - 1.15)	0.56 (0.23 - 1.38)	
Household Type				
Couple	1.00***	1.00***	1.00***	1.00***
Couple plus children	1.45 (1.02 - 2.06)*	1.45 (1.01 - 2.08)*	1.58 (1.07 - 2.34)*	1.46 (1.02 - 2.09)*
Single	0.3 (0.15 - 0.62)***	0.29 (0.14 - 0.61)***	0.2 (0.09 - 0.44)***	0.19 (0.11 - 0.33)***
Single plus children	1.13 (0.55 - 2.34)	1.01 (0.48 - 2.13)	0.57 (0.25 - 1.31)	0.73 (0.42 - 1.27)
Extended Family	1.93 (1.11 - 3.38)*	1.85 (1.04 - 3.29)*	1.93 (1.05 - 3.55)*	1.98 (1.16 - 3.39)**
Self-reported Health				
Good		1.00***	1.00***	1.00***
Fair		1.82 (1.34 - 2.46)***	1.81 (1.30 - 2.51)***	1.67 (1.27 - 2.19)***
Poor		4.72 (2.47 - 9.01)***	3.23 (1.63 - 6.40)***	2.4 (1.34 - 4.32)***
Long-Term Limiting Illness				
None		1.00	1.00*	Omitted

Appendix D

Yes, not limiting		1.23 (0.86 - 1.74)	1.34 (0.93 - 1.95)	
Yes & limiting		1.04 (0.74 - 1.48)	0.76 (0.52 - 1.11)	
Economic Activity				
Retired			1.00***	1.00***
Employed (Full-time >=35)			0.57 (0.33 - 0.97)*	0.58 (0.35 - 0.95)*
Employed (Part-time <35)			0.69 (0.44 - 1.09)	0.71 (0.46 - 1.09)
Economic inactive			2.19 (1.36 - 3.53)***	2.05 (1.31 - 3.23)***
Education				
Less than o-level or equiv.			1.00	Omitted
o-level or equivalent			1.27 (0.91 - 1.76)	
Higher than a-level			0.97 (0.67 - 1.39)	
Wealth Quintiles				
Poorest			1.00*	Omitted
2nd Quintile			0.99 (0.47 - 2.07)	
3rd Quintile			0.62 (0.28 - 1.36)	
4th Quintile			0.50 (0.23 - 1.11)	
Wealthiest			0.70 (0.31 - 1.57)	
Housing tenure				
Own outright			1.00***	1.00***
Own with mortgage			0.45 (0.3 - 0.68)***	0.55 (0.38 - 0.81)***
Renting, social			1.76 (0.66 - 4.71)	1.89 (0.93 - 3.84)
Renting, private			0.95 (0.44 - 2.08)	1.37 (0.91 - 2.06)
Live rent free			1.58 (0.21 - 12.2)	2.24 (0.32 - 15.75)
Assess to car				
Yes			1.00***	1.00***
No			1.86 (1.15 - 2.99)**	1.91 (1.23 - 2.99)***
-2LLR	1374.763	1334.88	1241.149	1359.27
% Change -2LLR	2.30%***	0.10%	0.53%**	5.12%
Hosmer & Lemeshow Test	$\chi^2=7.48$, p=0.486	$\chi^2=10.73$, p=0.218	$\chi^2=4.86$, p=0.772	$\chi^2=6.79$, p=0.560
Chi-square overall model	$\chi^2=78.56$ p<0.001	$\chi^2=118.44$, p<0.001	$\chi^2=212.17$, p<0.001	$\chi^2=196.64$ p<0.001

Weighed data. *Significant at the 0.05 level, ** Significant at the 0.01 level, *** Significant at the 0.001 level. Source: Author's own analysis of the ELSA Wave 7

Appendix E Sensitivity analysis – alternative cut-off points for intensity of care provision

Table 68 Appendix E: Descriptive characteristics of carers at alternative cut-off points of intensity of care provision

	Cut off 10hrs		Cut off 20hrs		Cut off 35hrs	
	Under (n=692)	Over (n=892)	Under (n=978)	Over (n=626)	Under (n=1,143)	Over (n=441)
Gender						
Female	62.6	63.9	63.2%	63.7%	63.8%	62.1%
Male	37.4	36.1	36.8%	36.3%	36.2%	37.9%
Total	100%#	100%#	100%#	100%#	100%#	100%#
Age						
50-59	30.2%	23.9%	20.9%	22.5%	28.1%	22.9%
60-69	42.3%	42.0%	37.7%	39.1%	45.0%	34.9%
70-79	21.5%	25.8%	27.6%	29.2%	21.1%	31.3%
Over 80	5.9%	8.3%	13.8%	9.1%	5.9%	10.9%
Total	100%***	100%***	100%***	100%***	100%***	100%***
Health						
Good	50.4%	35.9%	47.4%	33.7%	46.3%	31.7%
Fair	46.0%	57.1%	48.8%	58.0%	50.0%	58.0%
Poor	3.6%	7.1%	3.8%	8.3%	3.8%	10.2%
Total	100%***	100%***	100%***	100%***	100%***	100%***

, *** Significant at the 0.001 level, # Not significant.

Source: Author's own analysis of the ELSA Wave 7

Table 69 Appendix E: Predictors of care provision at alternative cut-off points of intensity

	Over 10 hours per week	Over 20 hours per week	Over 35 hours per week
Variables			
Gender			
Female	1.00	1.00	1.00
Male	0.88 (0.68 - 1.14)	0.91 (0.70 - 1.18)	1.04 (0.78 - 1.39)
Age			
50-59	1.00	1.00**	1.00***
60-69	1.15 (0.79 - 1.66)	1.17 (0.80-1.72)	1.02 (0.66-1.57)
70-79	1.39 (0.90 - 2.17)	1.80* (1.15-2.83)	2.03** (1.23-3.35)
Over 80	1.87 (1.03 - 3.39)	2.24* (1.24-4.04)	3.01*** (1.59-5.71)
Ethnicity			
White	1.00	1.00	1.00
Non-white	1.17 (0.59 - 2.32)	1.15 (0.58 - 2.26)	1.61 (0.80 - 3.24)
Marital status			
Married	1.00	1.00	1.00
Single	1.41 (0.70 - 2.85)	1.31 (0.65 - 2.63)	1.19 (0.54 - 2.60)
Divorced	1.05 (0.59 - 1.89)	1.13 (0.62 - 2.04)	0.72 (0.36 - 1.44)
Widowed	0.69 (0.36 - 1.34)	0.81 (0.41 - 1.63)	0.77 (0.34 - 1.73)
Household type			
Coupled	1.00	1.00***	1.00***
Coupled plus children	1.29 (0.88 - 1.90)	1.54 (1.05 - 2.27)*	1.29 (0.88 - 1.97)
Single	0.51 (0.28 - 0.93)	0.34 (0.18 - 0.64)**	0.29 (0.10 - 0.50)
Single plus children	0.77 (0.35 - 1.70)	0.70 (0.32 - 1.53)	1.09 (0.46 - 2.57)
Extended family	2.07** (1.13 - 3.77)	2.35 (1.33 - 4.15)***	3.09** (1.72 - 5.55)
Self-reported health			
Good	1.00***	1.00**	1.00*
Fair	1.78*** (1.35 - 2.35)	1.50** (1.13 - 1.99)	1.27 (0.92-1.74)
Poor	3.00*** (1.49 - 6.07)	2.52** (1.31 - 4.84)	2.83*** (1.44-5.56)
Long-standing illness		Not included	
None	1.00		1.00
Yes, not limiting	0.90 (0.65 - 1.23)		1.13 (0.79 - 1.62)
Yes and limiting	0.62 (0.44 - 0.87)		0.91 (0.63 - 1.33)
Difficulties with ADL			
None	1.00	1.00	1.00
1 ADL	0.76 (0.46 - 2.35)	0.84 (0.52 - 1.37)	0.76 (0.45 - 1.30)

2 ADLs	0.65 (0.34 - 1.26)	0.75 (0.40 - 1.42)	0.44 (0.22 - 0.86)
Difficulties with IADL			
None	1.00	1.00	1.00
1 IADL	1.25 (0.81 - 1.95)	1.05 (0.69 - 1.62)	1.22 (0.76 - 1.93)
2 IADLs	1.21 (0.67 - 2.20)	1.47 (0.83 - 2.63)	1.68 (0.92 - 3.10)
Economic activity			
Retired	1.00***	1.00***	1.00***
Employed full-time (>35 hour)	0.69 (0.44 - 1.09)	0.67 (0.41 - 1.09)	0.64 (0.36 - 1.14)
Employed part-time (<35 hour)	0.87 (0.60 - 1.24)	0.78 (0.53 - 1.14)	0.70 (0.44 - 1.09)
Economic inactive	2.68*** (1.66 - 4.30)	2.28*** (1.50 - 3.49)	2.31*** (1.49 - 3.58)
Education			
Less than O-level	1.00	1.00	1.00
O-level	1.14 (0.85 - 1.53)	1.30 (0.96 - 1.74)	1.22 (0.88 - 1.69)
Higher than A-level	0.93 (0.69 - 1.25)	0.99 (0.73 - 1.35)	1.01 (0.72 - 1.73)
Wealth			
Poorest	1.00	1.00*	1.00*
2 nd Quintile	1.20 (0.59 - 2.44)	1.34 (0.66 - 2.71)	0.78 (0.38 - 1.61)
3 rd Quintile	0.92 (0.44 - 1.93)	0.86 (0.41 - 1.82)	0.45 (0.21 - 0.97)
4 th Quintile	0.78 (0.37 - 1.65)	0.68 (0.32 - 1.44)	0.38 (0.17 - 0.82)
Wealthiest	0.82 (0.39 - 1.74)	0.88 (0.41 - 1.89)	0.53 (0.24 - 1.16)
Housing tenure			
Own outright	1.00*	1.00*	1.00
Own with mortgage or loan	0.63* (0.44 - 0.92)	0.52** (0.35 - 0.78)*	0.60* (0.38 - 0.95)
Renting, social	0.76 (0.32 - 1.80)	1.17 (0.50 - 2.76)	1.33 (0.55 - 3.21)
Renting, private	1.82 (0.83 - 3.96)	1.37 (0.64 - 2.93)	0.97 (0.45 - 2.11)
Live rent free	1.22 (0.21 - 7.02)	2.27 (0.39 - 13.36)	0.71 (0.12 - 4.20)
Access to care			
Yes	1.00	1.00***	1.00***
No	1.43 (0.91 - 2.27)	1.87** (1.21 - 2.90)	1.74* (1.11 - 2.73)
Chi-square	145.12, p<0.001	178.68, p<0.001	219.27, p<0.001
-2LLR	1616.82	1586.74	1329.38

*Significant at the 0.05 level, ** Significant at the 0.01 level, *** Significant at the 0.001 level. Source: Author's own analysis of the ELSA Wave 7

Appendix F Percentage of carers by direction of care, gender and self-reported health

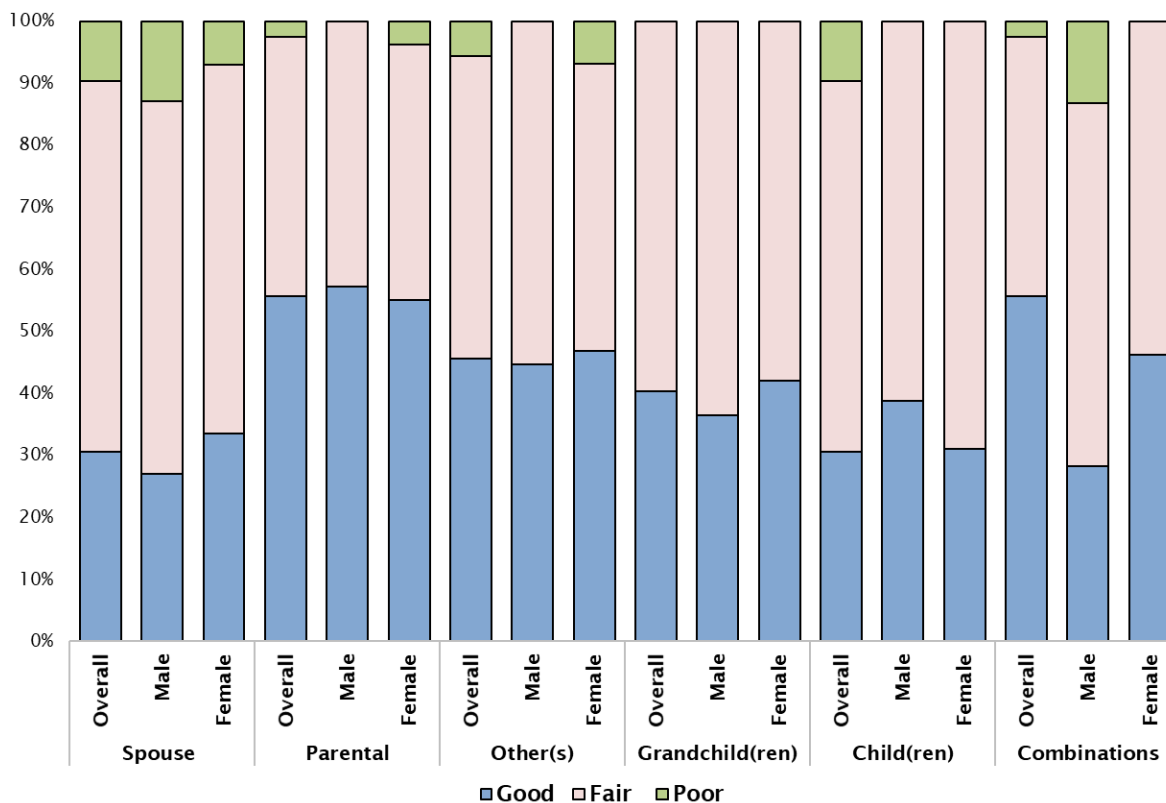


Figure 27 Appendix F: Percentage of carers by direction of care, gender and self-reported health.

Please note weighted data was used and categories with a cell count less than 5 have been omitted. $X^2=32.30$, $p<0.001$. It is important to remember, that the chart was not been controlled for age, which may have confounded the results.

Source: Author's analysis of the ELSA Wave 7.

Appendix G Codebook: regression variables

Table 70 Appendix G: Variable labels for binary logistic regression models

Variable name	Value	Label	Variable name	Value	Label
Age	0	50-59	Wealth	0	Poorest
	1	60-69		1	2 nd Quintile
	2	70-79		2	3 rd Quintile
	3	Over 80		3	4 th Quintile
Gender			4	Wealthiest	
	0	Female	Access to car	0	Yes
1	Male	1		No	
Ethnicity	0	White	SRH	0	Good
	1	Non-white		1	Fair
Marital status	0	Married		2	Poor
	1	Single	LLTI	0	None
	2	Divorced		1	Yes, not limiting
	3	Widowed		2	Yes, limiting
Household type	0	Couple	ADLs	0	None
	1	Couple plus children		1	1 ADL
	2	Single		2	>2 ADLs
	3	Lone plus children	IADLs	0	None
	4	Extended family		1	1 IADL
	5	Other households		2	>2 IADLs
Work	0	Retired	Provision of care	0	No
	1	Employed (full-time)		1	Yes
	2	Employed (part-time)	Number of people cared for	0	1
	3	Economic inactive		1	2
		2		3	
		3		over 4	
Education	0	Less than o-level	Direction of care	0	Spouse
	1	o-level or equivalent		1	Parent(s)
	2	Higher than o-level		2	Others
		3		Grandchildren	
		4		Children	
Region	0	South of England	5	Other combination	
	1	London	Co-residence	0	No
	2	North of England		1	Yes
Housing tenure	0	Own outright			
	1	Own with mortgage			
	2	Renting (social)			
	3	Renting (private)			
	4	Live rent free			

Source: Author's own

Appendix H Codebook: Matrix variables

Table 71 Appendix H: Variable labels for correlation matrices

Variable name	Value	Label	Variable name	Value	Label
Age	N/A	N/A	Access to car		
Gender				0	Yes
	1	Male		1	No
	2	Female	SRH		
Ethnicity				0	Good
	0	White		1	Fair
	1	Non-white		2	Poor
Marital status			LLTI		
	0	Single		0	None
	1	Married		1	Yes, not limiting
	2	Divorced		2	Yes, limiting
	3	Widowed	ADLs		
Household type				0	None
	0	Single		1	1 ADL
	1	Lone plus children		2	>2 ADLs
	2	Couple	IADLs		
	3	Couple plus children		0	None
	4	Extended family		1	1 IADL
	5	Other households		2	>2 IADLs
Work			Provision of care		
	0	Retired		0	No
	1	Employed (full-time)		1	Yes
	2	Employed (part-time)	Number of people cared for		
	3	Economic inactive		0	1
Education				1	2
	0	Less than o-level		2	3
	1	o-level or equivalent		3	over 4
	2	Higher than o-level	Direction of care		
Region				0	Spouse ONLY
	0	South of England		1	Parent(s) ONLY
	1	London		2	Others ONLY
	2	North of England		3	Grandchildren ONLY
Housing tenure				4	Children ONLY
	0	Own outright		5	Other combination
	1	Own with mortgage	Co-residence		
	2	Renting (social)		0	No
	3	Renting (private)		1	Yes
	4	Live rent free			
Wealth					
	0	Wealthiest			
	1	4 th Quintile			
	2	3 rd Quintile			
	3	2 nd Quintile			
	4	Poorest			

Source: Author's own

Appendix I Correlation matrix: Female respondents

Table 72 Appendix I: Correlation matrix females, the ELSA Wave 7

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age	1.00														
2. Ethnicity	-.119**	1.00													
3. Marital	.247**	-0.02	1.00												
4. Household type	-.304**	.073**	-.507**	1.00											
5. Work status	-.530**	.125**	-.165**	.248**	1.00										
6. Education	-.182**	-0.02	-.141**	.090**	.056**	1.00									
7. Tenure	-.260**	.095**	.066**	-0.03	.233**	-.110**	1.00								
8. Wealth	-.056**	.041**	.194**	-.139**	.106**	-.306**	.618**	1.00							
9. Access to car	.133**	0.02	.247**	-.295**	-.057**	-.193**	.246**	.326**	1.00						
10. Region	0.00	0.02	0.01	-0.01	0.02	-0.070**	.040**	.259**	.058**	1.00					
11. SRH	.138**	.067**	.128**	-.093**	-0.02	-.190**	.146**	.270**	.194**	.049**	1.00				
12. LLTI	.180**	-0.01	.120**	-.099**	-.076**	-.117**	.077**	.198**	.168**	.048**	.517**	1.00			
13. Difficulties with ADLs	.139**	0.02	.143**	-.102**	-0.02	-.122**	.109**	.204**	.175**	.054**	.385**	.422**	1.00		
14. Difficulties with IADLs	.138**	.026	.173**	-.138**	-.043**	-.160**	.110**	.211**	.218**	.055**	.411**	.466**	.613**	1.00	
15. Care provided	-.084**	-0.01	-.131**	.140**	.085**	.064**	-0.01	-.032*	-.082**	0.00	-.054**	-0.02	-.077**	-.052**	1.00

*. Correlation significant p<0.05, ** Correlation significant p>0.01. See Appendix C for label values. SHR: Self-reported health, LLTI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living
 Source: Author's own analysis of the ELSA

0.5-1.0	Strong correlation
0.3-0.4.9	Moderate correlation
0.1-0.2.9	Weak correlation
0-0.99	Very weak or no correlation
	Not statistically significant

Appendix J Correlation matrix: Male respondents

Table 73 Appendix J: Correlation matrix males, the ELSA wave 7

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age	1.00														
2. Ethnicity	-.126**	1.00													
3. Marital	.144**	-0.01	1.00												
4. Household type	-.241**	.156**	-.258**	1.00											
5. Work status	-.603**	.116**	-.113**	.153**	1.00										
6. Education	-.063**	0.01	-.059**	.093**	0.00	1.00									
7. Tenure	-.359**	.129**	0.01	.038*	.355**	-.149**	1.00								
8. Wealth	-.129**	.040*	.075**	-.111**	.160**	-.329**	.543**	1.00							
9. Access to car	0.01	.062**	-0.02	-.202**	0.02	-.148**	.225**	.292**	1.00						
10. Region	-0.03	0.00	0.02	-0.02	0.01	-0.066**	0.02	.223**	.050**	1.00					
11. SRH	.160**	.050**	.081**	-.120**	-.045**	-.145**	.112**	.244**	.170**	.057**	1.00				
12. LTLI	.209**	-.031*	.062**	-.146**	-.116**	-.126**	.047**	.201**	.164**	.053**	.503**	1.00			
13. Difficulties with ADLs	.162**	-0.02	.089**	-.097**	-.069**	-.127**	.068**	.162**	.147**	0.03	.343**	.383**	1.00		
14. Difficulties with IADLs	.146**	-.038*	.101**	-.136**	-.050**	-.126**	.066**	.180**	.203**	.052**	.354**	.410**	.573**	1.00	
15. Care provided	.032*	0.01	-.060**	.047**	0.00	0.01	0.00	0.02	-.033*	0.00	.034*	0.02	-.036*	-.011	1.00

*. Correlation significant $p < 0.05$, ** Correlation significant $p < 0.01$. See Appendix H for label values. SHR: Self-reported health, LTLI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living.

Source: Author's own analysis of the ELSA

0.5-1.0	Strong correlation
0.3-0.4.9	Moderate correlation
0.1-0.2.9	Weak correlation
0-0.99	Very weak or no correlation
	Not statistically significant

Appendix K Correlation matrix: Informal carers

Table 74 Appendix K: Correlation matrix Informal carers only, the ELSA Wave 7

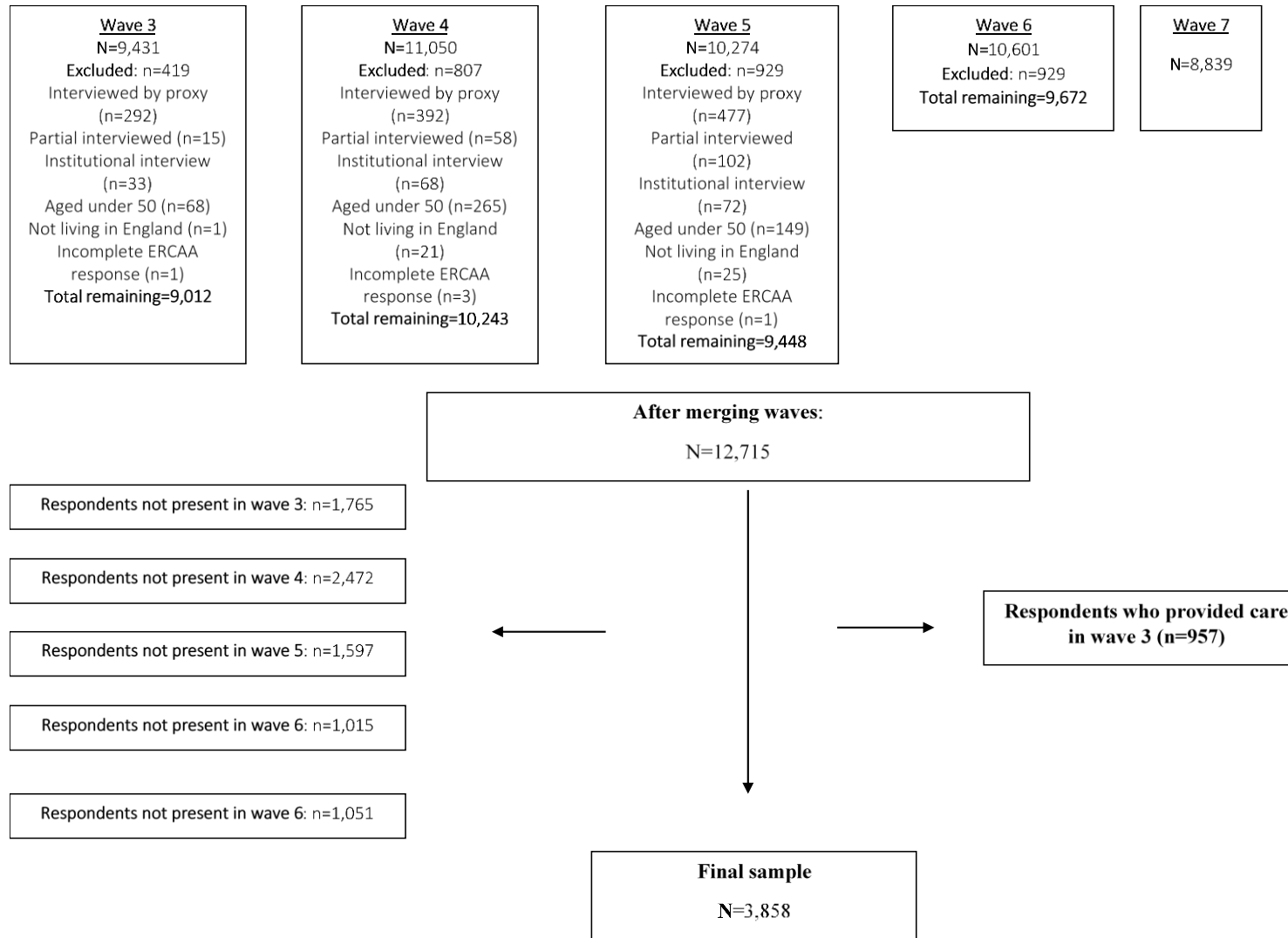
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age	1.00														
2. Sex	-.086**	1.00													
3. Ethnicity	-.079**	-.053*	1.00												
4. Marital	.112**	.146**	-.003	1.00											
5. Household type	-.217**	-.004	.093**	-.367**	1.00										
6. Work status	-.567**	.111**	.068**	-.068**	.158**	1.00									
7. Education	-.108**	-.088**	-.004	0.01	0.03	-.001	1.00								
8. Tenure	-.315**	-.001	.075**	-.003	0.03	.298**	-.159**	1.00							
9. Wealth	-.076**	0.00	0.00	.073**	-.052*	.140**	-.277**	.589*	1.00						
10. Access to car	0.04	.051*	.087**	.071**	-.154**	.060*	-.135**	.260**	.291**	1.00					
11. Region	0.01	0.01	0.01	.065*	-.001	-.001	-.003	0.01	.259**	.079**	1.00				
12. SRH	.080**	-.005	.108**	0.03	-.001	0.02	-.157**	.165**	.274**	.103**	0.01	1.00			
13. LLTI	.141**	0.01	0.01	0.04	-.071**	-.003	-.090**	.066**	.202**	.110**	0.03	.486**	1.00		
14. Difficulties with ADLs	.111**	0.01	-.001	.071**	-.052*	0.00	-.075**	.075**	.149**	.111**	0.02	.325**	.384**	1.00	
15. Difficulties with IADLs	.079**	.064*	-.025	.078**	-.077**	.026	-.129**	.105**	.186**	.145**	.055**	.329**	.395**	.495**	1.00

* Correlation significant p<0.05, ** Correlation is significant p<0.01. See Appendix H for label values. SHR: Self-reported health, LLTI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living. Source: Author's own analysis of the ELSA.

0.5-1.0	Strong correlation
0.3-0.4.9	Moderate correlation
0.1-0.2.9	Weak correlation
0-0.99	Very weak or no correlation
	Not statistically significant

Appendix L Flowchart of sample including Wave 3 to 7

Figure 28 Appendix L: Flowchart of sample including Wave 3 to 7



Appendix M Caring characteristics before and after filter question applied, the ELSA Waves 6 and 7

Table 75 Appendix M: Caring characteristics by filter question Waves 6 and 7

	Wave 6		Wave 7	
	Before filter application	After filter	Before filter application	After filter
Care provision				
No	7,775	8,779	7,235	8,086
Yes	1,897	893	1,604	753
Caring intensity				
Under 19 hours per week	1,133	468	978	408
20 hours or more per week	764	425	626	338
Direction of care				
Spouse	575	263	480	230
Parent or parent-in-law	354	195	315	172
Others	326	132	294	115
Grandchild(ren)	322	111	270	101
Child(ren)	112	54	87	38
Combination	208	138	158	97
Co-residential care				
Yes	821	412	669	334
No	1,075	481	934	419

Source: the author's own analysis of ELSA Waves 6 and 7

Appendix N Correlation matrix: Female future carer

Table 76 Appendix N: Correlation matrix: the FEMALE sample of the ELSA Wave 4

	1	2	3	4	5	6	7	8	9	10
1. Age	1									
2. Marital status	.306***	1								
3. SRH	.128***	.119***	1							
4. ADLs	.149***	.137***	.347***	1						
5. IADLs	.155***	.182***	.352***	.522***	1					
6. LLSI	.133***	.128***	.487***	.381***	.415***	1				
7. Work	-.054***	-.197***	-.039*	-.061***	-.054***	-.038*	1			
8. Education	-.231***	-.106***	-.194***	-.113***	-.127***	-.109***	.062***	1		
9. Tenure	.208***	-.102***	-.142***	-.132***	-.109***	-.097***	-.169***	.080***	1	
10. Wealth	-.074***	-.311***	-.265***	-.220***	-.225***	-.194***	0.004	.305***	.533***	1

0.5-1.0	Strong correlation
0.3-0.4.9	Moderate correlation
0.1-0.2.9	Weak correlation
0-0.99	Very weak or no correlation
	Not statistically significant

*. Correlation significant $p < 0.05$, ** Correlation significant $p < 0.01$ level, *** Correlation significant $p < 0.001$ level.

SHR: Self-reported health, LLTI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living.

Source: author's own analysis of the ELSA Wave 4

Appendix O Correlation matrix: Male future carers

Table 77 Appendix O: Correlation matrix: the MALE sample of the ELSA Wave 4

	1	2	3	4	5	6	7	8	9	10
1. Age	1									
2. Marital status	.044*	1								
3. SRH	.081***	.087***	1							
4. ADLs	.106***	.083***	.325***	1						
5. IADLs	.099***	.088***	.310***	.486***	1					
6. LLSI	.104***	.066***	.482***	.363***	.373***	1				
7. Work	-.556***	-0.018	-0.014	0.009	0.009	-0.013	1			
8. Education	-.118***	-.120***	-.177***	-.140***	-.146***	-.120***	0.038	1		
9. Tenure	.295***	-.163***	-.123***	-.072***	-.087***	-.085***	-.255***	.170***	1	
10. Wealth	0.022	-.272***	-.217***	-.145***	-.160***	-.177***	-.091***	.377***	.475***	1

0.5-1.0	Strong correlation
0.3-0.4.9	Moderate correlation
0.1-0.2.9	Weak correlation
0-0.99	Very weak or no correlation
	Not statistically significant

*. Correlation significant $p < 0.05$, ** Correlation significant $p < 0.01$ level, *** Correlation significant $p < 0.001$ level.

SHR: Self-reported health, LLSI: Limiting long-term illness, ADL: Activities of daily living, IADL: Instrumental activities of daily living.

Source: author's own analysis of the ELSA Wave 4.

Appendix P Description of the socio-demographic characteristics of the overall sample of the ELSA Wave 7

More than half the respondents in Wave 7 were female (53%) and the mean age was 65.4 years (± 10.9). The age distribution of respondents was skewed towards the younger age ranges (i.e. 50 to 59 and 60 to 69). Between genders, the largest differences among the age groups were noted between females and males aged over 80, see Within female respondents, 35% were aged between 50 and 59, Figure 29 30% between 60 and 69, 21% between 70 and 79 and 14% were aged over 80 years. Within males, 38% were aged between 50 and 59, 32% between 60 and 69, 20% between 70 and 79 and 10% were aged over 80 years. Nearly 95% of the overall sample were of white ethnicity.

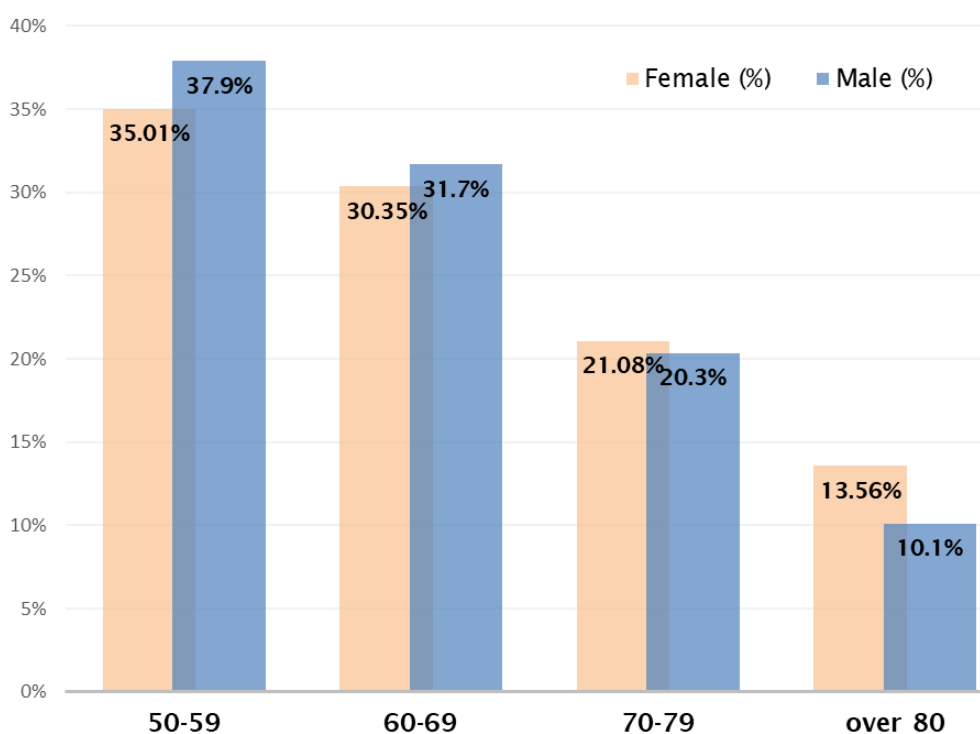


Figure 29 Appendix P: Percentage of all respondents by age and sex, the ELSA Wave 7

Please note that the data was weighted. $\chi^2=25.73$, $p<0.001$.

Source: Author's analysis of the ELSA.

The majority of the respondents were married (or in partnership) (65%), 14% divorced, 12.5% widowed and 8% were single (never married). The household structure of the respondents reflected this as 49% lived in coupled household, 22.4% lived in single household and only 5.5% lived in extended family

Appendix P

households. Households with children (either dependent or non-dependent children) were primarily living with two adults (coupled households with children).

The largest proportion of the sample described their SRH as fair (50%) or good (42%), and only a small number reported their SRH as being poor (8%). As seen from Figure 30, an association between age and poor health was noted, as fewer respondents in the older age groups reported being in good health. For example, in the youngest age groups (i.e. 50-59) 50% reported being in good health and only 7% reported poor health. This pattern was similar for both females and males, however females aged over 80 seemed to be in poorer health than males of the same age, see also Figure 30.

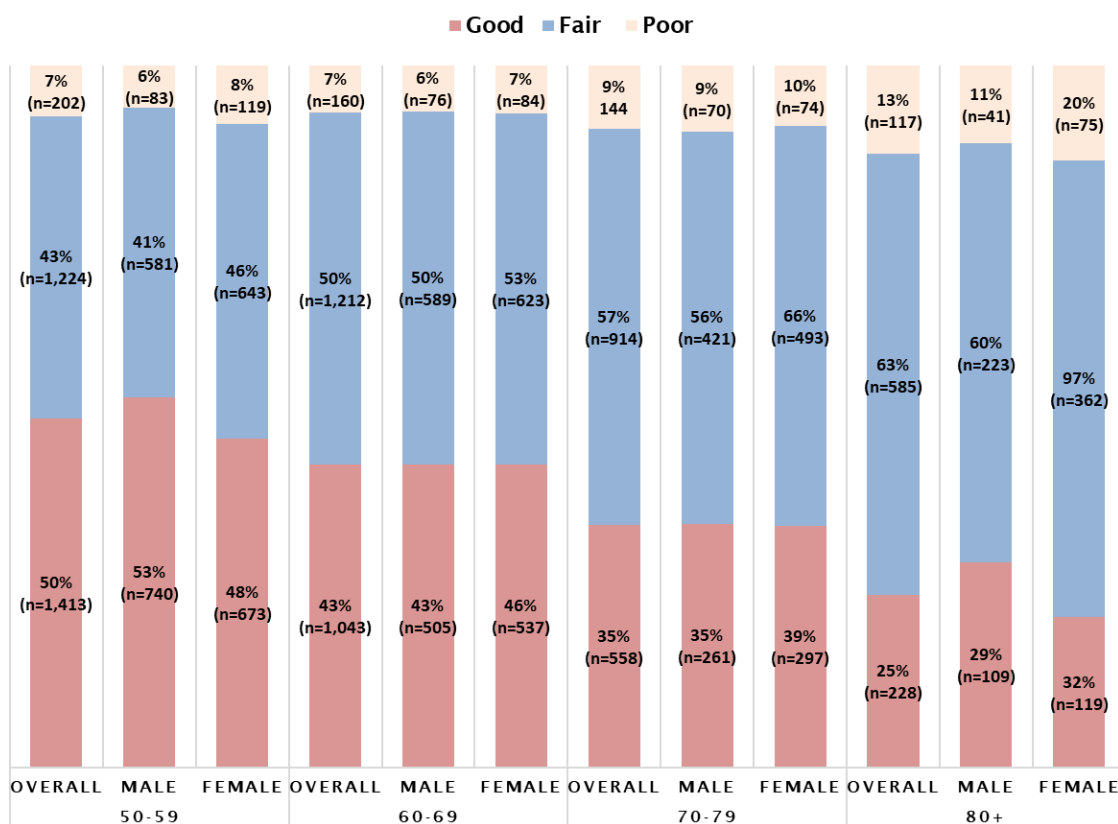


Figure 30 Appendix P: Percentage of all respondents by age, sex and self-reported health, the ELSA Wave 7

Weighted data. Overall: $\chi^2=236.22$, $p<0.001$; male: $\chi^2=107.23$, $p<0.001$; female: $\chi^2=134.11$, $p<0.001$.

Source: Author's analysis of the ELSA

Three other health measures were also used to establish the health outcomes for carers and non-carers, and these included: LLTI, and difficulties with ADLs and IADLs. 48% of the sample reported no LLTI, 84% reported no difficulties with either ADLs and 81% no difficulties with IADLs.

Nearly half (48%) of the respondents were retired, which may be associated with the age structure of the sample population. 25% were employed full-time and 16% part-time. The mean working hours of those in employment was 34 hours per

week. 11% of the respondents were economically inactive, and this included individuals who were either unemployed, permanently sick or disabled, or looking after the home or family.

The education levels were used as a proxy for SES and a quarter of the sample had no education, 21% had NVQ2/GCE/O-level or equivalent, and 16% had the highest education level (NVQ4/NVQ5/degree level or equivalent). The lowest proportion was found among those with NVQ3/GCE/A-level or equivalent (9%) and NVQ1/GSE or grade equivalent (4%). In the subsequent binary logistic regression analysis, the education level will be reduced to a three-category variable.

Most of the respondents owned their house outright (59%), however a large proportion of respondents owned their house with a mortgage or loan (22%). Of those renting, 14% were social renters and only a small proportion were private renters (4.4%). Lastly, 85% of the respondents had access to a car or a van. Wealth was distributed almost equally between the poorest and wealthiest quintiles, with only 0.2% points separating these two groups.

The majority of the respondents resided in the South East (17%), North West (13%) and East of England (12%). The region with the fewest respondents was the North East (5%), followed by the East Midlands (9%).

Appendix Q Detailed description of direction of care by sex

Table 78 Appendix Q: Detailed cross-tabulation of Direction of care by gender

Direction of care	Total	Male	Female
Spouse ONLY	27.0% (480)	33.5% (227)	23.2% (253)
Child(ren) ONLY	5.9% (87)	6.3% (26)	5.7% (61)
Grandchild(ren) ONLY	15.4% (270)	12.7% (83)	17.1% (187)
Parent(s)/Parent(s)-in-law ONLY	22.8% (315)	20.1% (111)	24.5% (204)
Others* ONLY	18.0% (294)	17.2% (95)	18.5% (199)
Spouse & Child(ren)	1.1% (10)	1.4% (3)	1.0% (7)
Spouse & Grandchild(ren)	0.9% (17)	0.6% (7)	1.1% (10)
Parent(s)/Parent(s)-in-law & Child(ren)	1.0% (9)	1.6% (4)	0.6% (5)
Parent(s)/Parent(s)-in-law & Grandchild(ren)	1.8% (32)	1.9% (11)	1.7% (21)
Parent(s)/Parent(s)-in-law & Spouse	1.2% (17)	1.2% (5)	1.2% (12)
Parent(s)/Parent(s)-in-law & others	1.6% (20)	1.2% (2)	1.9% (18)
Spouse and others	1.2% (22)	1.0% (7)	1.3% (15)
Other combinations	1.9% (31)	1.3% (6)	2.2% (25)
Total	100% (1,604)	100% (587)	100% (1,017)

(Unweighted frequencies).

Source: Author's analysis of ELSA Wave 7

*

Direction of care	Frequency
Other relatives	97
Friend and/or Neighbour	235
Others	30

(Unweighted frequencies).

Source: Author's analysis of ELSA Wave 7

Please note that the total adds up to more than the "Others ONLY", as the figure displayed also include combination of care-recipients.

Appendix R Detailed frequencies of the direction of care by age

Table 79 Appendix R: Detailed cross-tabulation of Direction of care by age

	50 - 59	60 - 69	70 - 79	Over 80	Total
No care provided	80.9% (1,510)	80.7% (2,728)	83.3% (1,995)	90.1% (1,002)	7235
Spouse	2.9% (79)	4.1% (143)	8.2% (186)	6.0% (72)	480
Children	1.2% (29)	1.1% (33)	0.9% (19)	0.5% (6)	87
Grandchildren	2.2% (50)	4.4% (154)	2.6% (62)	0.2% (4)	270
Parent (in-law)	7.6% (169)	3.7% (136)	0.4% (10)	0.0% (0)	315
Others	2.7% (51)	3.6% (125)	3.5% (85)	2.8% (33)	294
Spouse & child	0.4% (3)	0.1% (6)	0.1% (1)	0.0% (0)	10
Spouse & grandchild	0.1% (4)	0.2% (8)	0.1% (3)	0.1% (2)	17
Parents & child	0.4% (5)	0.1% (4)	0.0% (0)	0.0% (0)	9
Parent & grandchild	0.3% (10)	0.5% (18)	0.2% (4)	0.0% (0)	32
Spouse & parent	0.3% (6)	0.2% (9)	0.1% (2)	0.0% (0)	17
Parent & others	0.5% (9)	0.3% (9)	0.1% (2)	0.0% (0)	20
Spouse and others	0.2% (4)	0.2% (9)	0.3% (8)	0.1% (1)	22
Other combinations	0.2% (6)	0.6% (20)	0.2% (4)	0.1% (1)	31
Total	100% (1,935)	100% (3,402)	100% (2,381)	100% (1,121)	(8,839)

(Unweighted frequencies).

Source: Author's analysis of ELSA Wave 7

Appendix S Cross-tabulation of care and intensity (hours)

Table 80 Appendix S: Cross-tabulation of direction of care and caring intensity - The **overall** caring subsample of the ELSA Wave 7

	1-19	20-49	50-167	168
<i>Spouse ONLY</i>	14.5% (166)	25.5% (74)	40.3% (37)	62.9% (191)
<i>Child(ren) ONLY</i>	3.5% (32)	6.5% (16)	18.1% (10)	9.8% (28)
<i>Grandchild(ren) ONLY</i>	18.3% (185)	21.2% (65)	11.1% (11)	2.0% (7)
<i>Parent(s)/Parent-in-law(s) ONLY</i>	29.2% (243)	21.2% (46)	4.2% (6)	10.2% (19)
<i>Others (incl. relatives, friend and Neighbours)</i>	26.5% (256)	8.7% (20)	4.2% (5)	3.3% (10)
<i>Spouse & all child(ren)</i>	1.4% (12)	1.7% (5)	4.2% (3)	5.7% (11)
<i>Spouse and others</i>	0.7% (11)	0.4% (1)	2.8% (2)	2.0% (3)
<i>Parent(s)/Parent-in-law(s) & all Child(ren)</i>	2.7% (21)	7.4% (21)	2.8% (2)	1.2% (4)
<i>Parent(s)/Parent-in-law(s) & others</i>	2.1% (20)	0.4% (2)	12.5% (5)	2.4% (3)
<i>Other combinations</i>	1.1% (12)	6.9% (5)		0.4% (1)
	100.0% (958)	100.0% (268)	100.0% (81)	100.0% (277)

Source: author's own analysis

Table 81 Appendix S: Cross-tabulation of direction of care and caring intensity - The **male** caring subsample of the ELSA Wave 7:

	1-19	20-49	50-167	168
<i>Spouse ONLY</i>	17.0% (78)	35.5% (33)	47.6% (17)	72.7% (95)
<i>Child(ren) ONLY</i>	3.0% (10)	9.2% (4)	28.6% (2)	9.1% (9)
<i>Grandchild(ren) ONLY</i>	16.7% (65)	15.8% (15)		1.8% (2)
<i>Parent(s)/Parent-in-law(s) ONLY</i>	28.0% (92)	14.5% (12)	4.8% (1)	6.4% (6)
<i>Others (incl. relatives, friend and Neighbours)</i>	26.7% (85)	7.9% (7)	4.8% (1)	
<i>Spouse & all child(ren)</i>	2.0% (5)	2.6% (3)		3.6% (3)
<i>Spouse and others</i>	0.7% (3)	1.3% (1)		0.9% (1)
<i>Parent(s)/Parent-in-law(s) & all Child(ren)</i>	3.0% (6)	7.9% (7)		1.8% (2)
<i>Parent(s)/Parent-in-law(s) & others</i>	2.0% (6)		14.3% (1)	3.6% (1)
<i>Other combinations</i>	1.0% (4)	5.3% (2)		
	100.0% (354)	100.0% (84)	100.0% (24)	100.0% (119)

Source: author's own analysis

Table 82 Appendix S: Cross-tabulation of direction of care and caring intensity – The **female** caring subsample of the ELSA Wave 7:

	1-19	20-49	50-167	168
<i>Spouse ONLY</i>	13.0% (88)	21.3% (41)	37.3% (20)	54.0% (96)
<i>Child(ren) ONLY</i>	3.9% (22)	5.2% (12)	13.7% (8)	10.9% (19)
<i>Grandchild(ren) ONLY</i>	19.3% (120)	23.9% (50)	15.7% (10)	2.2% (5)
<i>Parent(s)/Parent-in-law(s) ONLY</i>	29.7% (151)	24.5% (34)	3.9% (5)	13.1% (13)
<i>Others (incl. relatives, friend and Neighbours)</i>	26.4% (171)	9.0% (13)	3.9% (3)	5.8% (10)
<i>Spouse & all child(ren)</i>	1.0% (7)	1.3% (2)	5.9% (3)	8.0% (8)
<i>Spouse and others</i>	0.8% (8)		3.9% (2)	2.9% (2)
<i>Parent(s)/Parent-in-law(s) & all Child(ren)</i>	2.4% (15)	6.5% (14)	3.9% (2)	0.7% (2)
<i>Parent(s)/Parent-in-law(s) & others</i>	2.4% (14)	0.6% (2)	11.8% (4)	1.5% (2)
<i>Other combinations</i>	1.2% (8)	7.7% (16)		0.7% (1)
	100.0% (604)	100.0% (184)	100.0% (57)	100.0% (158)

Source: author's own analysis

Appendix X Binary Regression Wave 4 to 7, Female and male future carers

Table 87 Appendix X: Binary logistic model of the odds of becoming a future FEMALE carer

	Block 1	Block 2	Block 11	Final model
Age				
50-59	1.00***	1.00***	1.00***	1.00***
60-69	0.72 (0.58 - 0.90)***	0.73 (0.58 - 0.91)***	0.68 (0.52 - 0.90)***	0.80 (0.65 - 0.98)*
70-79	0.45 (0.34 - 0.61)***	0.47 (0.35 - 0.63)***	0.44 (0.30 - 0.63)***	0.48 (0.36 - 0.64)***
>80	0.41 (0.24 - 0.73)***	0.45 (0.26 - 0.79)***	0.42 (0.23 - 0.76)***	0.46 (0.26 - 0.79)***
Marital Status				
Married	1.00***	1.00***	1.00***	1.00***
Single	0.60 (0.38 - 0.96)*	0.61 (0.38 - 0.99)*	0.58 (0.36 - 0.94)*	0.68 (0.44 - 1.05)
Divorced	0.71 (0.53 - 0.94)*	0.74 (0.56 - 0.98)*	0.72 (0.53 - 0.97)*	0.75 (0.57 - 0.98)*
Widowed	0.48 (0.34 - 0.66)***	0.48 (0.34 - 0.67)***	0.47 (0.33 - 0.66)***	0.49 (0.35 - 0.68)**
Self-reported Health				
Good		1.00*	1.00*	1.00**
Fair		0.76 (0.61 - 0.96)*	0.76 (0.60 - 0.95)**	0.83 (0.69 - 0.99)*
Poor		0.49 (0.27 - 0.92)*	0.47 (0.25 - 0.89)*	0.49 (0.29 - 0.83)**
IADLs				
None		1.00***	1.00	
1 IADL		1.13 (0.8 - 1.6)	1.14 (0.8 - 1.61)	
Over 2 IADLs		0.57 (0.32 - 1)	0.56 (0.31 - 0.99)*	
Employment situation				
Retired			1.00	
Employed (Full-time ≥ 35)			0.69 (0.46 - 1.02)	
Employed (Part-time < 35)			1.02 (0.76 - 1.36)	
Economic inactive			1.16 (0.83 - 1.61)	

*** p<0.001, **p<0.01, *p<0.05. ADL: Activities of Daily Living, IADL: Instrumental Activity of Daily Living Source: Author's own analysis of the ELSA Waves, 4,5,6 and 7.

Table 87 (continued)

	Block 1	Block 2	Block 11	Final model
Education				
Less than O-level or equiv.			1.00	
O-level or equivalent			1.19 (0.93 - 1.52)	
Higher than A-level			1.32 (1.02 - 1.71)	
Wealth Quintiles				
Poorest			1.00	
2nd Quintile			0.94 (0.71 - 1.25)	
3rd Quintile			1.03 (0.45 - 2.32)	
4th Quintile			1.01 (0.54 - 1.91)	
Wealthiest			1.29 (0.5 - 3.35)	
Housing tenure				
Own outright			1.000	
Own with mortgage			1.11 (0.83 - 1.49)	
Renting, social			1.05 (0.77 - 1.42)	
Renting, private			1.2 (0.87 - 1.67)	
Live rent free			1.26 (0.68 - 2.35)	
-2LLR	2586.66	2566.77	2553.566	2917.323
% Change -2LLR		0.77%**	0.06%	- 12.78% ^a
Hosmer & Lemeshow Test	$\chi^2=8.29, p=0.141$	$\chi^2=8.60, p=0.378$	$\chi^2=8.60, p=0.377$	$\chi^2=14.37, p=0.045$
Chi-square overall model	$\chi^2=88.66, p<0.001$	$\chi^2=108.55, p<0.001$	$\chi^2=121.75, p<0.001$	$\chi^2=102.37, p<0.001$

^a change from base block. *** p<0.001, **p<0.01, *p<0.05.

Source: Author's own analysis of the ELSA Waves, 4, 5, 6 and 7.

Appendix X

Table 88 Appendix X: Binary logistic model of the odds of becoming a future MALE carer (filtered)

	Block 1	Block 2	Block 10	Final Model
Age				
50-59 (Ref.)	1.00	1.00	1.00	
60-69	0.86 (0.64 - 1.15)	0.86 (0.64 - 1.15)	0.79 (0.56 - 1.12)	
70-79	0.95 (0.69 - 1.33)	0.95 (0.68 - 1.33)	0.89 (0.57 - 1.39)	
>80	0.70 (0.35 - 1.41)	0.69 (0.34 - 1.41)	0.65 (0.30 - 1.42)	
Marital Status				
Married (Ref.)	1.00***	1.00***	1.00***	1.00***
Single	0.6 (0.35 - 1.03)	0.62 (0.36 - 1.06)	0.58 (0.33 - 1.00)	0.63 (0.37 - 1.07)
Divorced	0.42 (0.25 - 0.70)***	0.43 (0.25 - 0.73)***	0.38 (0.22 - 0.66)***	0.40 (0.23 - 0.68)***
Widowed	0.37 (0.18 - 0.74)***	0.37 (0.18 - 0.75)***	0.34 (0.17 - 0.69)***	0.34 (0.17 - 0.67)***
Self-reported Health				
Good (Ref.)		1.00	1.00	
Fair		0.91 (0.69 - 1.20)	0.91 (0.68 - 1.21)	
Poor		0.45 (0.20 - 1.01)	0.42 (0.18 - 0.96)*	
IADLs				
None (Ref.)		1.00	1.00	
1 IADL		1.16 (0.85 - 1.58)	1.15 (0.84 - 1.57)	
Over 2 IADLs		1.02 (0.70 - 1.46)	0.96 (0.66 - 1.39)	
Employment situation				
Retired (Ref.)			1.00	
Employed (Full-time >=35)			0.96 (0.65 - 1.42)	
Employed (Part-time <35)			1.15 (0.77 - 1.71)	
Economic inactive			1.42 (0.78 - 2.57)	

*** p<0.001, **p<0.01, *p<0.05. ADL: Activities of Daily Living, IADL: Instrumental Activity of Daily Living

Source: Author's own analysis of the ELSA Waves, 4,5,6 and 7.

Table 88 (continued)

	Block 1	Block 2	Block 10	Final Model
Education				
Less than O-level or equivalent (Ref.)			1.00*	1.00*
O-level or equivalent			1.62 (1.15 - 2.28)***	1.58 (1.13 - 2.20)**
Higher than A-level			1.47 (1.05 - 2.06)*	1.41 (1.02 - 1.94)*
Housing tenure				
Own outright (Ref.)			1.00	
Own with mortgage			0.67 (0.47 - 0.96)*	
Renting, social			0.6 (0.22 - 1.65)	
Renting, private			1.03 (0.44 - 2.42)	
Live rent free			1.47 (0.45 - 4.82)	
Wealth Quintiles				
Poorest				
2nd Quintile			1.33 (0.93 - 1.90)	1.24 (0.87 - 1.76)
3rd Quintile			1.71 (1.18 - 2.47)***	1.56 (1.08 - 2.24)*
4th Quintile			1.77 (1.17 - 2.68)***	1.56 (1.05 - 2.32)*
Wealthiest			1.58 (0.70 - 3.58)	1.42 (0.88 - 2.28)
-2LLR	1762.11	1756.027	1731.371	1786.372
% Change -2LLR		0.35%	0.61%*	-1.38% ^a
Hosmer & Lemeshow Test	$\chi^2=0.46, p=0.977$	$\chi^2=3.33, p=0.912$	$\chi^2=5.32, p=0.723$	$\chi^2=6.89, p=0.440$
Chi-square overall model	$\chi^2=26.81, p<0.001$	$\chi^2=32.89, p<0.001$	$\chi^2=57.55, p<0.001$	$\chi^2=38.12, p<0.001$

^a change from base block. *** p<0.001, **p<0.01, *p<0.05.

Source: Author's own analysis of the ELSA Waves, 4,5,6 and 7.

Appendix Y Cross-tabulation of the age by timing of the caring episode

Table 89 Appendix Y: Age and timing of the caring episode

	50-59	60-69	70-79	>80
Did not provide care in any wave				
Age in Wave 4 (2009)	32.5% (1,628)	37.6% (1,884)	24.0% (1,203)	5.8% (291)
Age in Wave 7 (2015)	8.1% (407)	41.8% (2,092)	33.2% (1,664)	16.8% (843)
'Repeating carers'				
Age in Wave 4 (2009)	38.5% (20)	44.2% (23)	15.4% (8)	(-)
Age in Wave 5 (2011)	30.8% (16)	44.2% (23)	21.2% (11)	(-)
Age in Wave 7 (2015)	(-)	55.8% (29)	30.8% (16)	(-)
Provided care in Wave 5 ONLY				
Age in Wave 4 (2009)	39.8% (102)	36.7% (94)	19.9% (51)	3.5% (9)
Age in Wave 5 (2011)	28.5% (73)	41.4% (106)	25.0% (64)	5.1% (13)
Age in Wave 7 (2015)	12.5% (32)	45.3% (116)	31.3% (80)	10.9% (28)
Provided care in Wave 6 ONLY				
Age in Wave 4 (2009)	42.6% (86)	37.6% (76)	16.3% (33)	3.5% (7)
Age in Wave 6 (2013)	19.3% (39)	47.0% (95)	27.7% (56)	5.9% (12)
Age in Wave 7 (2015)	10.9% (22)	52.0% (105)	25.2% (51)	11.9% (24)

Age in Wave 4 (2009) $X^2=23.67$, $p<0.001$, Age in Wave 5 (2011) $X^2=22.97$, $p<0.001$, Age in Wave 6 (2013) $X^2=22.66$, $p<0.01$, Age in Wave 7 (2015) $X^2=29.99$, $p<0.001$. (-): cell count under 5. Source: Author's own analysis of the ELSA waves 4,5,6 & 7.

Appendix Z Phase II: Transitions in the care directions Waves 4 to 7

Table 90 Appendix Z: Transitions in the care directions Waves 4 to 7

Wave 4	Wave 5	Wave 6	Wave 7	(n)
No caring	Spouse	Spouse	Spouse	12
No caring	Spouse	Parent	Spouse	1
No caring	Spouse	Spouse	Other	2
No caring	Parent	Parent	Parent	7
No caring	Parent	Parent	Spouse	1
No caring	Parent	Parent	Combination	1
No caring	Parent	Grandchild	Grandchild	1
No caring	Parent	Grandchild	Other	1
No caring	Parent	Combination	Spouse	1
No caring	Parent	Combination	Parent	2
No caring	Parent	Combination	Grandchild	1
No caring	Parent	Combination	Combination	1
No caring	Other	Other	Other	5
No caring	Other	Spouse	Spouse	1
No caring	Other	Combination	Spouse	1
No caring	Other	Combination	Other	1
No caring	Grandchild	Grandchild	Grandchild	1
No caring	Grandchild	Other	Other	1
No caring	Child	Child	Child	3
No caring	Combination	Combination	Combination	4
No caring	Combination	Spouse	Combination	1
No caring	Combination	Parent	Parent	1
No caring	Combination	Grandchild	Grandchild	1
No caring	Combination	Grandchild	Combination	1
Total				52

Source: Author's own analysis of the ELSA waves 4 to 7

Appendix AA Model 5: Binary regression ‘repeating carers’ compared to ‘discontinued carers’, all blocks

Table 91 Appendix AA: Model 3 binary regression model of the ELSA wave 7, containing all blocks

	Sub sample of individuals who provided care in the ELSA Wave 6 and 7 (Continuous carer = 0, stopped carers=1)																															
	Block 1			Block 2			Block 3			Block 4			Block 5			Block 6			Block 7			Refined model										
	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.	Exp(B)	95% C.I.	Sig.								
Gender	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000					
Female	1.29	1.04	1.80	.019	1.48	1.19	1.84	.000	1.41	1.13	1.78	.000	1.48	1.18	1.88	.000	1.44	1.14	1.81	.002	1.44	1.18	1.82	.000	1.48	1.18	1.84	.001				
Male																																
Age	1.00	0.98	1.01	.884	.99	0.98	1.01	0.92	1.00	.98	1.01	.884	1.00	0.98	1.01	.876	1.00	0.98	1.01	.876	1.00	0.98	1.01	.884	0.98	1.00	0.98	1.014				
Marital Status																																
Married				1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	.000				
Single				1.07	0.85	1.35	.784	1.03	.83	1.25	.859	1.19	0.71	1.58	.814	1.12	0.87	1.48	.887	1.08	0.85	1.48	.798	1.02	0.80	1.33	.842	1.00	0.80	1.07	.989	
Divorced				2.00	1.14	3.84	.018	1.98	1.13	3.45	.022	1.98	1.09	3.48	.028	1.88	1.08	3.38	.038	1.88	1.01	3.28	.048	1.70	0.94	3.08	.082	1.70	0.95	3.06	.075	
Widowed				2.28	1.28	4.14	.008	2.21	1.22	4.02	.009	2.27	1.24	4.18	.008	2.22	1.20	4.08	.011	2.20	1.18	4.08	.012	2.00	1.07	3.73	.038	2.10	1.18	3.82	.018	
Employment situation																																
Retired				1.00		.000	1.00		.011	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000		
Employed (Full-time >=30)				1.25	.87	1.80	0.228	1.28	0.88	1.88	0.182	1.22	0.84	1.77	0.282	1.22	0.84	1.77	0.282	1.24	0.88	1.80	0.287	1.08	0.80	1.40	0.287	1.08	0.79	1.48	0.208	
Employed (Part-time <30)				1.03	.78	1.40	0.837	1.04	0.78	1.41	0.813	1.01	0.74	1.37	0.818	1.02	0.75	1.38	0.811	1.02	0.78	1.40	0.814	1.02	0.78	1.40	0.814	1.14	0.88	1.52	0.878	
Unemployed				.83	.45	.88	0.028	0.88	0.47	0.92	0.014	0.88	0.48	0.87	0.032	0.88	0.48	0.87	0.034	0.70	0.50	0.88	0.041	0.70	0.50	0.88	0.041	0.87	0.42	0.79	0.048	
Direction of care																																
Spouse							1.00		0.000	1.00		0.000	1.00		0.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000		
Parent(s) & parents-in-law				1.34	.87	1.85	0.019	1.11	.78	1.58	0.038	1.11	.78	1.58	0.038	1.11	.78	1.58	0.041	.77	.48	1.20	0.242	.77	.48	1.20	0.242	.77	.48	1.20	0.242	
Others				2.30	1.88	3.18	0.000	1.77	1.28	2.51	0.001	1.88	1.28	2.81	0.001	1.88	1.28	2.82	0.001	1.23	.77	1.87	0.288	1.23	.77	1.87	0.288	1.23	.77	1.87	0.288	
Grandchild(ren)				1.70	1.28	2.40	0.000	1.84	1.18	3.14	0.011	1.88	1.18	3.44	0.008	1.13	.70	1.83	0.813	1.13	.70	1.83	0.813	1.13	.70	1.83	0.813	1.13	.70	1.83	0.813	
Child(ren)				1.33	.83	2.13	0.021	1.23	.78	1.88	0.488	1.22	.78	1.88	0.414	1.22	.78	1.88	0.414	1.07	.88	1.78	0.777	1.07	.88	1.78	0.777	1.07	.88	1.78	0.777	
Combination				.80	.81	1.31	0.088	.84	.87	1.24	0.378	.84	.87	1.24	0.378	1.01	.81	1.88	0.973	.84	.50	1.42	0.511	.84	.50	1.42	0.511	.84	.50	1.42	0.511	
Intensity of care																																
1-19 hrs/wk													1.00		0.000	1.00		0	1.00		0.001	1.00		0.001	1.00		0.001	1.00		0		
20-49 hrs/wk													.80	.44	.77	0.000	.88	.44	.78	0.000	.80	.48	.78	0.000	.80	.48	.78	0.000	.80	.48	.78	0.000
50-187 hrs/wk													.80	.31	.81	0.004	.80	.33	.88	0.008	.88	.38	.81	0.018	.88	.34	.88	0.018	.88	.34	.88	0.018
188 hrs/wk													.88	.43	.81	0.001	.88	.44	.82	0.001	.88	.48	.86	0.022	.88	.47	.88	0.022	.88	.47	.88	0.022
Number of people cared for																																
1																																
2																1.12	.80	1.58	.819	1.10	.78	1.54	0.878	1.08	.81	1.43	.80	1.08	.81	1.43	.80	
3																.87	.42	1.07	.012	.84	.40	1.03	0.084	.84	.42	.86	.08	.84	.42	.86	.08	
over 4																.48	.24	.84	.088	.42	.23	.78	0.001	.42	.24	.74	.08	.42	.24	.74	.08	
Coreidential care																																
Yes																1.00			.000	1.00		.000	1.00		.000	1.00		.000	1.00		.000	
No																1.84	1.12	2.88	.011	1.84	1.12	2.88	.011	1.84	1.12	2.88	.011	1.84	1.12	2.88	.011	
-2LLR	2183.048			2182.881			2148.153			2182.484			2078.444			2088.358			2088.291			2078.548										
% Change -2LLR				1.38%			0.59%			1.78%			5.14%			0.58%			0.32%			4.74% Change from base block										
Significance change to block	y ² =5.58, p<0.081			y ² =30.18, p<0.001			y ² =12.75, p<0.005			y ² =37.84, p<0.001			y ² =24.05, p<0.001			y ² =11.58, p<0.009			y ² =6.57, p<0.010			y ² =122.95, p<0.001										
Hoamer & Lemeshow Test	y ² =15.13, p<0.057			y ² =15.34, p<0.053			y ² =15.98, p<0.043			y ² =18.43, p<0.037			y ² =11.57, p<0.080			y ² =7.87, p<0.488			y ² =9.38, p<0.311			y ² =17.12, p<0.028										
Cox & Snell R squared	0.004			0.022			0.03			0.053			0.067			0.014			0.018			0.014										
Chi-square overall model	y ² =5.58, p<0.081			y ² =35.74, p<0.001			y ² =48.50, p<0.001			y ² =88.13, p<0.001			y ² =110.18, p<0.001			y ² =121.77, p<0.001			y ² =128.33, p<0.001			y ² =122.95, p<0.001										

Numbers in red shows the statistically significant decreased odds of providing care, whilst the blue number are increased off of providing care. Figures in black are none significant.
Source: Author’s own analysis of ELSA wave6 and wave 7

Appendix BB Alternative ‘Sandwiched’ scenarios

Figure 31 used ONS data to predict two comparable family structures of a carer aged 50 years in 2016 a cared aged 50 years in 2036. In the year 2036 a carer aged 50 may potentially have both parents and a grandparent in need of care, whilst their first-born child would be aged 20 years old, and the potential of having second or third younger child as well. The figure is based on average maternal age at firstborn. According to current life expectancy it is not likely that a carer in 2016 has grandparent aged 107 care for, however according to ONS’s high LE projections, in 2036 women could expect to live past 100 years (ONS, 2017), which theoretically would make it possible that the 50 year old carer would be sandwich between multiple care-recipients (i.e. parents and grandparents). This is by no mean to say that all older people aged over 77 is in need of care, this hypothesis rather expands on the future concept of the sandwich generation. Moreover, Figure 31 is based on the assumption that most will follow a ‘predicted’ life cycle, however these individuals actual life course may differ.

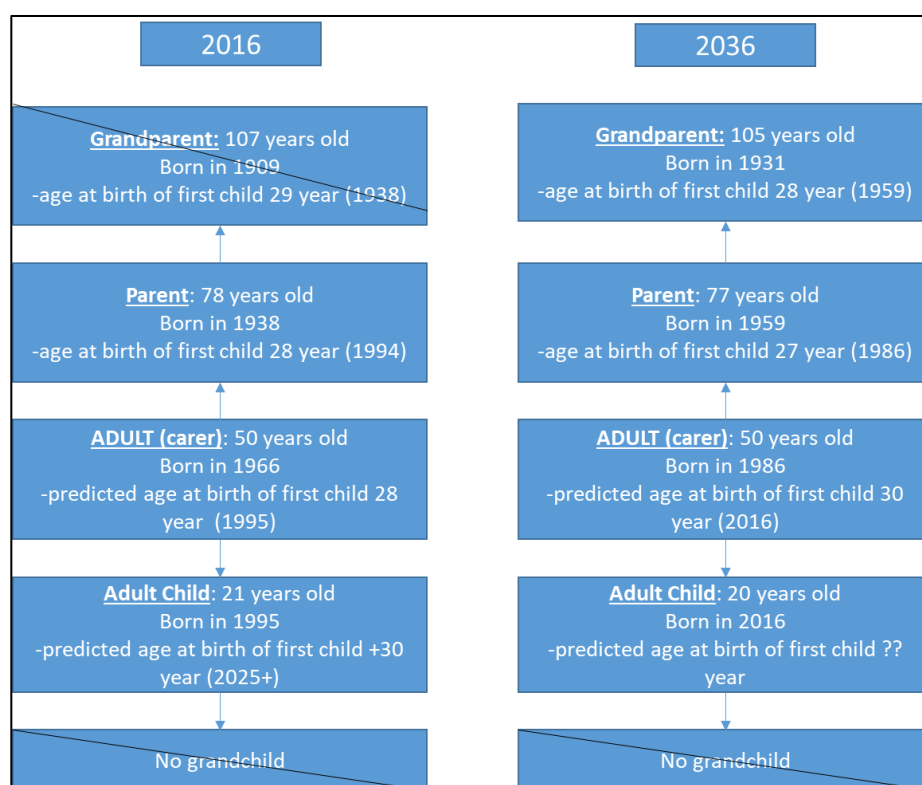


Figure 31 Appendix BB: Comparison of two generations at risk of being sandwiched

Source: author’s own calculation of ONS (2017) ‘Birth by Parents’ Characteristics in England and Wales, 2016.

Appendix CC Cross-tabulation of care provision and age of care-recipient

Table 92 shows the cross-tabulation of informal care provided and age of person cared for. For 711 respondents who had said yes to providing care, the Age of the person cared for was not applicable. This may be due to the carers providing care to a care-recipient of a different age, however 428 respondents answered no to providing care, yes the age of the people cared for was 65 plus; the other age ranges showed similar trends. The variable was therefore dismissed, however, this led to a lack of depth of understanding of the relationship between the carer and the care-recipient.

Table 92 Appendix CC: Informal care provided the past week: age(s) of person/people cared for: 65 years plus

		Age(s) of person/people looked after: 65 years plus			Total
		Item not applicable	Not mentioned	Mentioned	
Provided informal care	Yes	711	182	711	1604
	No	6696	111	428	7235
Total		7407	293	1139	8839

Source: Author's own the ELSA Wave 7

Respite care: ErREsRY3 'Whether there is anyone the respondent could rely on to look after this person (helping person aged 65 or over)' had 8,723 item not applicable and 98 responding 'yes' and 18 responding 'no', however this would not be accurate it is known that more than 116 respondents, provided care to someone aged over 65.

List of References

- Aboderin, I. (2004). Modernisation and ageing theory revisited: Current explanations of recent developing world and historical Western shifts in material family support for older people. *Ageing and Society* 24: 29-50
- Abramson, T.A. (2015). Older Adults: The “Panini Sandwich” Generation. *Clinical Gerontologist* 38(4): 251-67
- Adler, N.E. and Newman, K. (2002). Socioeconomic disparities in health: Pathways and policies. *Health Affairs* 21(2): 60-76
- Adler, N.E. and Ostrove, J.M. (1999). Socioeconomic status and health: What we know and what we don't. *Socioeconomic Status and Health in Industrial Nations: Social, Psychological, and Biological Pathways* 896: 3-15
- AgeUK (2017). *Briefing: Health and Care of Older People in England 2017*. AgeUK. Available from: http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true [Accessed 22/06/17]
- Ahern, K. and Brocque, R.L. (2005). Methodological Issues in the Effects of Attrition: Simple Solutions for Social Scientists. *Field Methods* 17(1): 53-69
- Al-Janabi, H., Carmichael, F. and Oyeboode, J. (2017). Informal care: choice or constraint? *Scandinavian Journal of Caring Sciences* 32(1): 157-67
- Albertini, M., Kohli, M. and Vogel, C. (2007). Intergenerational transfers of time and money in European families: common patterns - different regimes? *Journal of European Social Policy* 17(4): 319-34
- Aldridge, H. and Hughes, C. (2016). *Informal carers & poverty in the UK: An analysis of the Family Resources Survey*. London: New Policy Institute Available from: http://www.npi.org.uk/files/2114/6411/1359/Carers_and_poverty_in_the_UK_-_full_report.pdf [Accessed 22/06/18]
- Allen, K. and Walker, A. (2008). Theorizing About Families and Aging From a Feminist Perspective IN: Silverstein, M., Bengtson, V.L., Putnam, M., Putney, N.M. and Gans, D. (eds) *Handbook of theories of aging* (2nd Edition). Springer Publishing Company 517-30
- Allen, K.R. (2000). A Conscious and Inclusive Family Studies. *Journal of Marriage and Family* 62(1): 4-17
- Allin, S., Masseria, C. and Mossialos, E. (2006). Inequality in health care use among older people in the United Kingdom: an analysis of panel data. *Applied Economics* 43(18): 2229-39
- Alwin, D.F. (2012). Integrating Varieties of Life Course Concepts. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences* 67(2): 206-20
- Appleby, J. (2013). *Spending on health and social care over the next 50 years. Why think long term?* London: The King's Fund Available from:

List of References

- https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Spending%20on%20health%20...%2050%20years%20low%20res%20for%20web.pdf [Accessed 22/08/2017]
- Arber, S. and Ginn, J. (1990). The meaning of informal care: gender and the contribution of elderly people. *Ageing and Society* 10(04): 429-54
- Argyrous, G. (2014). *Statistics for research : with a guide to SPSS*. Los Angeles: SAGE
- Arnsberger, P., Lynch, U. and Li, F.F. (2012). The Effects of Caregiving on Women's Self-Assessed Health Status: An International Comparison. *Health Care for Women International* 33(10): 878-95
- Arrighi, H.M. and Hertz-Picciotto, I. (1994). The Evolving Concept of the Healthy Worker Survivor Effect. *Epidemiology* 5(2): 189-96
- Ayis, S., Gooberman-Hill, R., Bowling, A. and Ebrahim, S. (2006). Predicting catastrophic decline in mobility among older people. *Age and Ageing* 35(4): 382-7
- Bainbridge, H.T.J. and Broady, T.R. (2017). Caregiving responsibilities for a child, spouse or parent: The impact of care recipient independence on employee well-being. *Journal of Vocational Behavior* 101: 57-66
- Balducci, C., Mnich, E., McKee, K.J., Lamura, G., Beckmann, A., Krevers, B., Wojszel, Z.B., Nolan, M., Prouskas, C., Bień, B. and Öberg, B. (2008). Negative Impact and Positive Value in Caregiving: Validation of the COPE Index in a Six-Country Sample of Carers. *The Gerontologist* 48(3): 276-86
- Banks, J., Muriel, A. and Smith, J.P. (2011). Attrition and health in ageing studies: Evidence from ELSA and HRS. *Longitudinal and life course studies* 2(2)
- Barnes, M.P. (2004). Life Expectancy for People with Disabilities. *Journal of Personal Injury Law* 2: 131-55
- Barnett, A.E. (2013). Pathways of Adult Children Providing Care to Older Parents. *Journal of Marriage and Family* 75(1): 178-90
- Barnett, A.E. (2015). Adult Child Caregiver Health Trajectories and the Impact of Multiple Roles Over Time. *Research on Aging* 37(3): 227-52
- Barrett, P., Butler, M. and Hale, B. (2014). *Family Care and Social Capital: Transitions in Informal Care*. Dordrecht [u.a.]: Springer Netherlands
- Bastawrous, M., Gignac, M.A., Kapral, M.K. and Cameron, J.I. (2015). Factors that contribute to adult children caregivers' well-being: a scoping review. *Health and Social Care Community* 23(5): 449-66
- Batty, G.D. and Steptoe, A. (2016). Introduction IN: Banks, J., Batty, G.D., Nazroo, J. and Steptoe, A. (eds) *The Dynamics of Ageing, Evidence from the English Longitudinal Study of Ageing 2002-15 (WAVE 7)*. London: The Institute for Fiscal Studies Available from: https://www.ifs.org.uk/uploads/elsa/docs_w7/ELSA%20Wave%207%20report.pdf [Accessed 13/12/2017]
- Bauer, J.M. and Sousa-Poza, A. (2015). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family. *Journal of Population Ageing* 8(3): 113-45

- Beesley, L. (2006). *Informal Care in England, Wanless social care review*. London: King's Fund Available from: <https://www.kingsfund.org.uk/sites/default/files/informal-care-england-wanless-background-paper-lucinda-beesley2006.pdf> [Accessed 22/08/2017]
- Ben-Galim, D. and Silim, A. (2013). *The sandwich generation: older women balancing work and care*. London: Institute for Public Policy Research
- Bengtson, V.L. (2001). Beyond the nuclear family: The increasing importance of multigenerational bonds. *Journal of Marriage and Family* 63(1): 1-16
- Bengtson, V.L., Elder, G. and Putney, N. (2005a). The Lifecourse Perspective on Ageing: Linked Lives, Timings, and History IN: Johnson, M.L. (ed) *The Cambridge handbook of age and ageing*. Cambridge ; New York: Cambridge University Press
- Bengtson, V.L., Gans, D., Putney, N.M. and Silverstein, M. (2009). Theories About Age and Aging IN: Bengtson, V.L., Gans, D., Putney, N.M. and Silverstein, M. (eds) *Handbook of theories of aging* (2nd Edition). New York: Springer
- Bengtson, V.L., Putney, N.M. and Johnson, M.L. (2005b). The Problem of Theory in Gerontology Today IN: Johnson, M.L. (ed) *The Cambridge handbook of age and ageing*. Cambridge: New York: Cambridge University Press
- Bengtson, V.L. and Roberts, R.E.L. (1991). Intergenerational solidarity in aging families - an example of formal theory construction. *Journal of Marriage and the Family* 53(4): 856-70
- Berecki-Gisolf, J., Lucke, J., Hockey, R. and Dobson, A. (2008). Transitions into informal caregiving and out of paid employment of women in their 50s. *Social Science and Medicine* 67(1): 122-7
- Berrington, A., Stone, J. and Beaujouan, E. (2015). Educational differences in timing and quantum of childbearing in Britain: A study of cohorts born 1940 - 1969. *Demographic Research* 33(26): 733-64
- Bianchi, S.M., Hotz, V.J., McGarry, K.M. and Seltzer, J.A. (2006). Intergenerational ties: Alternative theories, empirical findings and trends, and remaining challenges. *California Center for Population Research*
- Blundell, R., Crawford, R., French, E. and Tetlow, G. (2016). Comparing Retirement Wealth Trajectories on Both Sides of the Pond. *Fiscal Studies* 37(1): 105-30
- Bongaarts, J. (2009). Human population growth and the demographic transition. *Philosophical Transactions of the Royal Society B: Biological Sciences* 364(1532): 2985-90
- Bonsang, E. (2009). Does informal care from children to their elderly parents substitute for formal care in Europe? *Journal of Health Economics* 28(1): 143-54
- Börsch-Supan, A., Brandt, M., Hunkler, C., Kneip, T., Korbmacher, J., Malter, F., Schaan, B., Stuck, S. and Zuber, S. (2013). Data Resource Profile: The

List of References

- Survey of Health, Ageing and Retirement in Europe (SHARE). *International Journal of Epidemiology* 42(4): 992-1001
- Boslaugh, S. (2007). An introduction to secondary data analysis *Secondary data sources for public health: a practical guide (Practical Guides to Biostatistics and Epidemiology)*. Cambridge: Cambridge University Press Available from: <https://cyfar.org/sites/default/files/Boslaugh,%202007.pdf>
- Brandt, M., Haberkern, K. and Szydlik, M. (2009). Intergenerational Help and Care in Europe. *European Sociological Review* 25(5): 585-601
- Breeze, E. and Stafford, M. (2010). Receipt and giving of help and care IN: Banks, J., Breeze, E., Crawford, R., Demakakos, P., Oliveira Cd, G.E., Green, R., Hussey, D., Kumari, M., Lessof, C. and Marmot, M. (eds) *Financial circumstances, health and well-being of the older population in England. The 2008 English Longitudinal Study of Ageing (Wave 4)*. London: Institute for Fiscal Studies
- Bridges, S., Hussey, D., Blake, M. and Philo, D. (2014). Methodology IN: Banks, J., Nazroo, J. and Steptoe, A. (eds) *The dynamics of ageing: Evidence from the English Longitudinal Study of Ageing 2002-12 (wave 6)*. London: The Institute for Fiscal Studies, Available from: https://www.ifs.org.uk/uploads/elsa/docs_w6/ELSA%20Wave%206%20report.pdf
- Brimblecombe, N., Fernández, J.-L., Knapp, M., Rehill, A. and Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. *Journal of Long-term Care* 2018:25-40 Available from: https://www.ilpnetwork.org/wp-content/media/2018/09/JLTCSeptember2018_Brimblecombe.pdf [Accessed 16/11/2018]
- Brimblecombe, N., Pickard, L., King, D. and Knapp, M. (2017). Barriers to Receipt of Social Care Services for Working Carers and the People They Care For in Times of Austerity. *Journal of Social Policy* 47(2): 215-33
- Bristow, J. (2016). The making of 'Boomergeddon': the construction of the Baby Boomer generation as a social problem in Britain. *The British Journal of Sociology* 67(4): 575-91
- Broese van Groenou, M.I. and De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing* 13(3): 271-9
- Brown, G.C. (2015). Living too long: the current focus of medical research on increasing the quantity, rather than the quality, of life is damaging our health and harming the economy. *EMBO reports* 16(2): 137-41
- Brown, R.M. and Brown, S.L. (2014). Informal Caregiving: A Reappraisal of Effects on Caregivers. *Social Issues and Policy Review* 8(1): 74-102
- Brown, S.L., Bulanda, J.R. and Lee, G.R. (2012). Transitions Into and Out of Cohabitation in Later Life. *Journal of Marriage and Family* 74(4): 774-93
- Brown, S.L. and Lin, I.F. (2012). The Gray Divorce Revolution: Rising Divorce Among Middle-Aged and Older Adults, 1990-2010. *The Journals of Gerontology: Series B* 67(6): 731-41

- Brown, S.L., Smith, D.M., Schulz, R., Kabeto, M.U., Ubel, P.A., Poulin, M., Yi, J., Kim, C. and Langa, K.M. (2009). Caregiving Behavior Is Associated With Decreased Mortality Risk. *Psychological Science* 20(4): 488-94
- Bryan, M.L. (2012). Access to flexible working and informal care. *Scottish Journal of Political Economy* 59(4): 361-89
- Buckner, L. and Yeandle, S. (2015). *Valuing carers 2015: The rising value of carers' support*. London: Carers UK Available from: https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf [Accessed 22/08/2017]
- Bucx, F., van Wel, F. and Knijn, T. (2012). Life Course Status and Exchanges of Support Between Young Adults and Parents. *Journal of Marriage and Family* 74(1): 101-15
- Burchardt, T., Jones, E. and Obolenskaya, P. (2018). Formal and Informal Long-Term Care in the Community: Interlocking or Incoherent Systems? *Journal of Social Policy* 47(3): 479-503
- Burton, L.C., Zdaniuk, B., Schulz, R., Jackson, S. and Hirsch, C. (2003). Transitions in spousal caregiving. *Gerontologist* 43(2): 230-41
- Cahill, K.E., Giandrea, M.D. and Quinn, J.F. (2011). Reentering the labor force after retirement. *Monthly Labor Review* 134(6): 34-42
- Calasanti, T.M. (1993). Bringing in Diversity - Toward an Inclusive Theory of Retirement. *Journal of Aging Studies* 7(2): 133-50
- Capistrant, B.D., Moon, J.R. and Glymour, M.M. (2012). Spousal Caregiving and Incident Hypertension. *American Journal of Hypertension* 25(4): 437-43
- Caputo, J., Pavalko, E.K. and Hardy, M.A. (2016). The Long-Term Effects of Caregiving on Women's Health and Mortality. *Journal of Marriage and Family* 78(5): 1382-98
- Care, D.o.H.a.S. (2018). *Carers Action Plan 2018 - 2020. Supporting carers today*. Strategy and Project Team. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf [Accessed 10/08]
- Carers Trust (2014). *Husband, Partner, Dad, Son, Carer? A survey of the experiences and needs of male carers*. London: Carers Trust and Men's Health Forum Available from: https://professionals.carers.org/sites/default/files/husband_partner_dad_son_carer_a_survey_of_the_experiences_and_needs_of_male_carers.pdf [Accessed 16/12/2018]
- Carers Trust (2015). *Caring About Older Carers, Providing Support for People Caring Later in Life*. 2015 Available from: https://professionals.carers.org/sites/default/files/caring_about_older_carers.pdf [Accessed 19/11/2018]

List of References

- Carers Trust (2017). *Money and Benefits*. Available from: https://carers.org/article/money-and-benefits?gclid=CNqd7KqTnNOCFVQ_GwodI31BMw [Accessed 01/06/2017]
- Carers UK (2012). *In Sickness and in Health*. Carers UK. Available from: <https://www.carersuk.org/for-professionals/policy/policy-library/in-sickness-and-in-health> [Accessed 07/08]
- Carers UK (2015). *Facts about Carers: Who are carers?* London: Carers UK
Available from: https://www.carersuk.org/images/Facts_about_Carers_2015.pdf [Accessed 03/12/2018]
- Carers UK (2018). *State of Caring 2018*. 2018 Available from: <https://www.carersuk.org/images/Downloads/SoC2018/State-of-Caring-report-2018.pdf> [Accessed 20/11/2018]
- Carmichael, F., Charles, S. and Hulme, C. (2010). Who will care? Employment participation and willingness to supply informal care. *Journal of Health Economics* 29(1): 182-90
- Carmichael, F. and Ercolani, M.G. (2014). Overlooked and undervalued: The caring contribution of older people. *International Journal of Social Economics* 41(5): 397-419
- Carmichael, F. and Ercolani, M.G. (2016). Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes. *Social Science & Medicine* 156: 1-11
- Carr, E., Murray, E.T., Zaninotto, P., Cadar, D., Head, J., Stansfeld, S. and Stafford, M. (2016). The Association Between Informal Caregiving and Exit From Employment Among Older Workers: Prospective Findings From the UK Household Longitudinal Study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 73(7): 1253-62
- Cheng, H.G. and Phillips, M.R. (2014). Secondary analysis of existing data: opportunities and implementation. *Shanghai archives of psychiatry* 26(6): 371
- Community and Local Government (2010). *Household Projections, 2008 to 2033, England*. National Statistics Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6395/1780763.pdf [Accessed 22/08/2017]
- Connidis, I.A. and McMullin, J.A. (2002). Sociological ambivalence and family ties: A critical perspective. *Journal of Marriage and Family* 64(3): 558-67
- Connolly, S. (2012). Housing tenure and older people. *Reviews in Clinical Gerontology* 22(4): 286-92
- Connolly, S., O'Reilly, D. and Rosato, M. (2010). House value as an indicator of cumulative wealth is strongly related to morbidity and mortality risk in older people: a census-based cross-sectional and longitudinal study. *International Journal of Epidemiology* 39(2): 383-91
- COPNI (2014). *Supporting Older Carers 2014* Available from: https://www.copni.org/media/1127/supporting_older_carers_-_commissioners_report.pdf [Accessed 22/11/2018]

- Cronin, P., Hynes, G., Breen, M., McCarron, M., McCallion, P. and O'Sullivan, L. (2015). Between worlds: the experiences and needs of former family carers. *Health Soc Care Community* 23(1): 88-96
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A. and Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology* 11: 100-
- Dahlberg, L., Demack, S. and Bambra, C. (2007). Age and gender of informal carers: a population-based study in the UK. *Health & Social Care in the Community* 15(5): 439-45
- Dannefer, D. (2003). Cumulative advantage/disadvantage and the life course: Cross-fertilizing age and social science theory. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 58(6): S327-S37
- Dannefer, D. and Settersten, R., A. (2013). The Study of the Life Course: Implications for Social Gerontology IN: Dannefer, D. and Phillipson, C. (eds) *The SAGE handbook of social gerontology*. London: SAGE
- Davis, L.L., Gilliss, C.L., Deshefy-Longhi, T., Chestnutt, D.H. and Molloy, M. (2011). The Nature and Scope of Stressful Spousal Caregiving Relationships. *Journal of Family Nursing* 17(2): 224-40
- Del Bono, E., Sala, E. and Hancock, R. (2009). Older carers in the UK: are there really gender differences? New analysis of the Individual Sample of Anonymised Records from the 2001 UK Census. *Health & Social Care in the Community* 17(3): 267-73
- Demakakos, P., Nazroo, J., Breeze, E. and Marmot, M. (2008). Socioeconomic status and health: the role of subjective social status. *Social Science & Medicine* 67(2): 330-40
- Demey, D., Berrington, A., Evandrou, M. and Falkingham, J. (2013). Pathways into living alone in mid-life: Diversity and policy implications. *Advances in Life Course Research* 18(3): 161-74
- Deng, Y.T., Hillygus, D.S., Reiter, J.P., Si, Y.J. and Zheng, S.Y. (2013). Handling Attrition in Longitudinal Studies: The Case for Refreshment Samples. *Statistical Science* 28(2): 238-56
- Department for Work & Pensions (2015). *Employment statistics for workers aged 50 and over, by 5-year age bands and gender. From 1984 to 2015*. Department for Work & Pensions Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/568240/employment-stats-workers-aged-50-and-over-1984-2015.pdf [Accessed 22/08/2017]
- Department of Health (1999). *Caring about carers: a national strategy for carers*. Stationary Office London
- Department of Health (2006). *Our health, our care, our say: a new direction for community services*. The Stationery Office Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf [Accessed 03/12/2018]

List of References

- Department of Health (2010). *Recognised, Valued and Supported: Next steps for the Carers Strategy*. London: HM Government Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf [Accessed 22/08/2017]
- Department of Health (2014). *Carers Strategy: Second National Action Plan 2014-2016*. London: HM Government Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_-_2016.pdf [Accessed 22/08/2017]
- DeSa, U.N. (2017). World population prospects: The 2017 Revision. *Population division of the department of economic and social affairs of the United Nations Secretariat, New York* Volume II: Demographic Profiles
- Di Gessa, G., Glaser, K. and Tinker, A. (2016). The impact of caring for grandchildren on the health of grandparents in Europe: A lifecourse approach. *Social Science & Medicine* 152: 166-75
- Doebler, S., Ryan, A., Shortall, S. and Maguire, A. (2017). Informal care-giving and mental ill-health - differential relationships by workload, gender, age and area-remoteness in a UK region. *Health and Social Care in the Community* 25(3): 987-99
- Doyle, M. (2012). Social care provision IN: Craig, R. and Mindell, J. (eds) *Health Survey for England 2012*. London: The Health and Social Care Information Centre
- Drinkwater, S. (2015). Informal Caring and Labour Market Outcomes Within England and Wales. *Regional Studies* 49(2): 273-86
- Dykstra, P. (2010). *Intergenerational family relationships in ageing societies*. United Nations. Available from: <https://www.unece.org/fileadmin/DAM/pau/docs/age/2010/Intergenerational-Relationships/ECE-WG.1-11.pdf> [Accessed 25/08]
- Elder, G.H. (1994). Time, human agency, and social-change - perspectives on the life-course. *Social Psychology Quarterly* 57(1): 4-15
- Elder, G.H. and Rockwell, R.C. (1979). The life-course and human development: An ecological perspective. *International Journal of Behavioral Development* 2(1): 1-21
- ELSA (2018). *What we do*. The Institute for Fiscal Studies. Available from: <https://www.elsa-project.ac.uk/about-ELSA> [Accessed 18/11]
- Eurocarers (2017). *The gender dimension of informal care - 2017*. Eurocarers. Available from: <https://eurocarers.org/userfiles/files/The%20gender%20dimension%20of%20informal%20care.pdf> [Accessed 26.09.2018]
- Evandrou, M. and Falkingham, J. (2006). Will the Baby-boomers be better off than their Parents in Retirement? IN: Vincent, J.A., Phillipson, C., Downs, M. and British Society of, G. (eds) *The futures of old age*. London: Sage Publications
- Evandrou, M., Falkingham, J., Gomez-Leon, M., Robards, J. and Vlachantoni, A. (2015a). Local Government and the Demography of Ageing. IN: Local

- Government Knowledge Navigator and Local Government Association (ed) *Need to Know*. Centre for population change
- Evandrou, M., Falkingham, J., Gomez-Leon, M. and Vlachantoni, A. (2016). Intergenerational flows of support between parents and adult children in Britain. *Ageing and Society*: 1-31
- Evandrou, M., Falkingham, J., Robards, J. and Vlachantoni, A. (2015b). Who cares? Continuity and change in the prevalence of caring, and characteristics of informal carers, in England and Wales 2001-2011. 2015b Working Paper 68 Available from: https://eprints.soton.ac.uk/381035/1/2015_WP68_Who_cares_Continuity_and_change_in_the_prevalence_of_caring.pdf [Accessed 22/08/2017]
- Feeney, J.A. and Hohaus, L. (2001). Attachment and spousal caregiving. *Personal Relationships* 8(1): 21-39
- Feld, S., Dunkle, R.E., Schroepfer, T. and Shen, H.-W. (2010). Does Gender Moderate Factors Associated with Whether Spouses Are the Sole Providers of IADL Care to Their Partners? *Research on Aging* 32(4): 499-526
- Fernandez, J.-L., Snell, T., Forder, J. and Wittenberg, R. (2013). Implications of setting eligibility criteria for adult social care services in England at the moderate needs level. Personal Social Services Research Unit, London: PSSRU Discussion Paper
- Ferrucci, L., Guralnik, J.M., Simonsick, E., Salive, M.E., Corti, C. and Langlois, J. (1996). Progressive versus catastrophic disability: a longitudinal view of the disablement process. *The journals of Gerontology. Series A, Biological sciences and medical sciences* 51(3): M123-30
- Field, A.P. (2005). *Discovering statistics using SPSS*. London: SAGE
- Fingerman, K.L., Pitzer, L., Lefkowitz, E.S., Birditt, K.S. and Mroczek, D. (2008). Ambivalent Relationship Qualities Between Adults and Their Parents: Implications for the Well-Being of Both Parties. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences* 63(6): P362-P71
- Fredman, L., Cauley, J.A., Hochberg, M., Ensrud, K.E. and Doros, G. (2010). Mortality Associated with Caregiving, General Stress, and Caregiving-Related Stress in Elderly Women: Results of Caregiver-Study of Osteoporotic Fractures (SOF). *Journal of the American Geriatrics Society* 58(5): 937-43
- Friedman, E.M., Park, S.S. and Wiemers, E.E. (2015). New Estimates of the Sandwich Generation in the 2013 Panel Study of Income Dynamics. *The Gerontologist*: 1-6
- Galobardes, B., Shaw, M., Lawlor, D.A. and Lynch, J.W. (2006). Indicators of socioeconomic position (part 1). *Journal of Epidemiology and Community Health* 60(1): 7-12
- Ganong, L.H., Coleman, M. and Rothrauff, T. (2009). Patterns of assistance between adult children and their older parents: Resources, responsibilities, and remarriage. *Journal of Social and Personal Relationships* 26(2-3): 161-78

List of References

- Gans, D. and Silverstein, M. (2006). Norms of filial responsibility for aging parents across time and generations. *Journal of Marriage and Family* 68(4): 961-76
- Gibson, D. (1996). Broken down by age and gender - "The problem of old women" redefined. *Gender & Society* 10(4): 433-48
- Glaser, K., Evandrou, M. and Tomassini, C. (2005). The health consequences of multiple roles at older ages in the UK. *Health & Social Care in the Community* 13(5): 470-7
- Glaser, K. and Grundy, E. (2002). Class, caring and disability: evidence from the British Retirement Survey. *Ageing and Society* 22: 325-42
- Glaser, K., Ribé Montserrat, E., Waginger, U., Price, D., Stuchbury, R. and Tinker, A. (2010). *Grandparenting in Europe*. London: Grandparents Plus Available from: <https://www.bl.uk/britishlibrary/~media/bl/global/social-welfare/pdfs/non-secure/g/r/a/grandparenting-in-europe-summary.pdf> [Accessed 22/08/2017]
- Glauber, R. (2016). Gender Differences in Spousal Care Across the Later Life Course. *Research on Aging*: 1-26
- Gomez-Leon, M., Evandrou, M., Falkingham, J. and Vlachantoni, A. (2017). The dynamics of social care and employment in mid-life. *Ageing and Society*: 1-28
- Gonzales, E., Lee, Y. and Brown, C. (2017). Back to Work? Not Everyone. Examining the Longitudinal Relationships Between Informal Caregiving and Paid Work After Formal Retirement. *The Journals of Gerontology: Series B* 72(3): 532-9
- GOV.UK (2018). Record NHS funding to give patients a better alternative to hospital. *New funding for primary and community healthcare by 2023/4 under the NHS Long Term Plan*. London: Prime Minister's Office, 10 Downing Street, Department of Health and Social Care, NHS England, The Rt Hon Matt Hancock MP, and The Rt Hon Theresa May MP
- GOV.UK (2019). *Carers and disability benefits*. Available from: <https://www.gov.uk/browse/benefits/disability> [Accessed 26/03/2019]
- Government Office for Science (2016). *Future of an Ageing Population*. London: Government Office for Science Available from: http://www.ageing.ox.ac.uk/files/Future_of_Ageing_Report.pdf [Accessed 22/08/2017]
- Graf, C. (2008). The Lawton instrumental activities of daily living scale. *AJN The American Journal of Nursing* 108(4): 52-62
- Gray, A. (2005). The Changing Availability of Grandparents as Carers and its Implications for Childcare Policy in the UK. *Journal of Social Policy* 34(4): 557-77
- Greenwood, N. and Smith, R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. *Maturitas* 82(2): 162-9
- Grundy, E. (2005). Reciprocity in relationships: socio-economic and health influences on intergenerational exchanges between Third Age parents and

- their adult children in Great Britain. *British Journal of Sociology* 56(2): 233-55
- Grundy, E. and Henretta, J.C. (2006). Between elderly parents and adult children a new look at the intergenerational care provided by the 'sandwich generation'. *Ageing & Society* 26: 707-22
- Grundy, E. and Holt, G. (2001). The socioeconomic status of older adults: How should we measure it in studies of health inequalities? *Journal of Epidemiology and Community Health* 55(12): 895-904
- Grundy, E. and Read, S. (2012). Social contacts and receipt of help among older people in England: are there benefits of having more children? *The Journals of Gerontology Series B* 67(6): 742-54
- Haberkern, K., Schmid, T. and Szydlik, M. (2015). Gender differences in intergenerational care in European welfare states. *Ageing & Society* 35(2): 298-320
- Haberkern, K. and Szydlik, M. (2010). State care provision, societal opinion and children's care of older parents in 11 European countries. *Ageing and Society* 30(2): 299-323
- Haines, S. and Wetton, Y. (2016). Carer's Assessments in Essex: what do carers say? 2016 Available from: <https://www.healthwatchessex.org.uk/wp-content/uploads/2016/01/Carers-Assessments-in-Essex-FINALv2.pdf>
- Hajek, A. and Konig, H.H. (2016). The Effect of Intra- and Intergenerational Caregiving on Subjective Well-Being - Evidence of a Population Based Longitudinal Study among Older Adults in Germany. *Plos One* 11(2)
- Hancock, R. (1998). Housing wealth, income and financial wealth of older people in Britain. *Ageing and Society* 18(1): 5-33
- Hank, K., Cavrini, G., Di Gessa, G. and Tomassini, C. (2018). What do we know about grandparents? Insights from current quantitative data and identification of future data needs. *European Journal of Ageing* 15(3): 225-35
- Hanratty, B., Drever, F., Jacoby, A. and Whitehead, M. (2007). Retirement age caregivers and deprivation of area of residence in England and Wales. *European Journal of Ageing* 4(1): 35-43
- Hareven, T.K. (1996a). *Aging and Generational Relations: Life-course and Cross-cultural Perspectives*. New York: Aldine de Gruyter
- Hareven, T.K. (1996b). Historical Perspectives on the Family and Aging. IN: Blieszner, R. and Bedford, V.H. (eds) *Aging and the family: Theory and Research*. Praeger Publishers
- Harper, S. (2006). *Ageing societies: myths, challenges and opportunities*. London: Hodder Arnold
- He, D. and McHenry, P. (2016). Does Formal Employment Reduce Informal Caregiving? *Health Economics* 25(7): 829-43

List of References

- Heath, A., Carey, L.B. and Chong, S. (2018). Helping Carers Care: An Exploratory Study of Factors Impacting Informal Family Carers and Their Use of Aged Care Services. *Journal Religion and Health* 57(3): 1146-67
- Heiss, F. (2011). Dynamics of self-rated health and selective mortality. *Empirical Economics* 40(1): 119-40
- Heitmueller, A. (2007). The chicken or the egg?: Endogeneity in labour market participation of informal carers in England. *Journal of Health Economics* 26(3): 536-59
- Henz, U. (2004). The effects of informal care on paid-work participation in Great Britain: a lifecourse perspective. *Ageing and Society* 24: 851-80
- Hiel, L., Beenackers, M.A., Renders, C.M., Robroek, S.J.W., Burdorf, A. and Croezen, S. (2015). Providing personal informal care to older European adults: Should we care about the caregivers' health? *Preventive Medicine* 70: 64-8
- Hill, P., Thomson, C. and Cass, B. (2011). The costs of caring and the living standards of carers. Australia, New South Wales: Department of Families, Housing, Community Services and Indigenous Affairs
- Hirst, M. (2002). Transitions to informal care in Great Britain during the 1990s. *Journal of Epidemiology and Community Health* 56(8): 579
- HM Government (2008). *Carers at the Heart of 21st Century Families and Communities "A Caring System on Your Side, a Life of Your Own"*. HM Government, Available from: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/document_s/digitalasset/dh_085338.pdf [Accessed 22/08/2017]
- HM Government and Carers UK (2013). Supporting Working Carers: The Benefits to Families, Business and the Economy. 2013 Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/232303/Supporting_Working_Carers_Final_Report_accessible_.pdf
- Hoff, A. (2015). *Current and future challenges of family care in the UK: future of an ageing population. Evidence review*. London: Government Office for Science Available from: <http://dera.ioe.ac.uk/24148/1/gs-15-18-future-ageing-family-care-er09.pdf> [Accessed 22/08/2017]
- Hogerbrugge, M.J.A. and Komter, A.E. (2012). Solidarity and Ambivalence: Comparing Two Perspectives on Intergenerational Relations Using Longitudinal Panel Data. *The Journals of Gerontology: Series B* 67B(3): 372-83
- Holman, D., Foster, L. and Hess, M. (2018). Inequalities in women's awareness of changes to the State Pension Age in England and the role of cognitive ability. *Ageing and Society*: 1-18
- Hosseinpour, A.R., Bergen, N. and Chatterji, S. (2013). Socio-demographic determinants of caregiving in older adults of low- and middle-income countries. *Age and Ageing* 42(3): 330-8

- Hughes, N., Locock, L. and Ziebland, S. (2013). Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social Science & Medicine* 96: 78-85
- Hutton, S. and Hirst, M. (2010). Caring relationships over time. End of Project Report. York, England: Social Policy Research Unit, The University of York
- IBM (2013a). *IBM SPSS Regression 22*. IBM Corporation Available from: http://www.sussex.ac.uk/its/pdfs/SPSS_Regression_22.pdf [Accessed 28/12/2017]
- IBM (2013b). *IBM SPSS Statistics Base 22*. IBM Corporation Available from: http://www.sussex.ac.uk/its/pdfs/SPSS_Statistics_Base_22.pdf [Accessed 09/05/2018]
- Idler, E.L. and Benyamini, Y. (1997). Self-rated health and mortality: a review of twenty-seven community studies. *Journal of Health and Social Behavior* 38(1): 21-37
- IRISS (2012). *Rest assured? A study of unpaid carers' experiences of short breaks*. Scotland: Institute for Research and Innovation in Social Services Available from: <https://www.iriss.org.uk/sites/default/files/2016-03/iriss-rest-assured-full-report-2012-07.pdf> [Accessed 07/08/2018]
- Ismail, S., Thorlby, R. and Holder, H. (2014). *Focus On: Social care for older people. Reductions in adult social services for older people in England*. London: The Health Foundation and Nuffield Trust Available from: <https://www.nuffieldtrust.org.uk/files/2018-10/qualitywatch-social-care-older-people.pdf> [Accessed 22/08/2017]
- Jacobs, J.C., Laporte, A., Van Houtven, C.H. and Coyte, P.C. (2014). Caregiving intensity and retirement status in Canada. *Social Science & Medicine* 102: 74-82
- Jarrett, T. (2015). Social care: Direct Payments from a local authority (England). *House of Commons Library. Briefing paper* (03735)
- Jenkins, K.R., Kabeto, M.U. and Langa, K.M. (2009). Does caring for your spouse harm one's health? Evidence from a United States nationally-representative sample of older adults. *Ageing & Society* 29: 277-93
- Jeune, B. and Christensen, K. (2005). Biodemography and Epidemiology of Longevity IN: Johnson, M.L. (ed) *The Cambridge handbook of age and ageing*. Cambridge ; New York: Cambridge University Press
- Johansson, L., Sundstrom, G. and Hassing, L.B. (2003). State provision down, offspring's up: the reverse substitution of old-age care in Sweden. *Ageing and Society* 23: 269-80
- Joloza, T. (2009). *Non-Household Groups: Position Paper*. London: Office of National Statistics
- Jones, R. (2007). A journey through the years: Ageing and social care. *Ageing Horizons* 6: 42-51
- Kahn, R.L. and Antonucci, T.C. (1980). Convoys over the life course: Attachment, roles, and social support. *Life-span Development and Behavior* 3: 253-86

List of References

- Kalmijn, M. and Saraceno, C. (2008). A comparative perspective on intergenerational support - Responsiveness to parental needs in individualistic and familialistic countries. *European Societies* 10(3): 479-508
- Kalwij, A., Pasini, G. and Wu, M. (2014). Home care for the elderly: the role of relatives, friends and neighbors. *Review of Economics of the Household* 12(2): 379-404
- Kang, H. (2013). The prevention and handling of the missing data. *Korean Journal of Anesthesiology* 64(5): 402-6
- Kanji, S. (2017). Grandparent Care: A Key Factor in Mothers' Labour Force Participation in the UK. *Journal of Social Policy* 47(3): 523-42
- Kaschowitz, J. and Brandt, M. (2017). Health effects of informal caregiving across Europe: A longitudinal approach. *Social Science & Medicine* 173: 72-80
- Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A. and Jaffe, M.W. (1963). Studies of illness in the aged: The index of adl: a standardized measure of biological and psychosocial function. *JAMA* 185(12): 914-9
- Keating, N. and Eales, J. (2017). Social consequences of family care of adults: a scoping review. *International Journal of Care and Caring* 1(2): 153-73
- Keating, N., Kwan, D., Hillcoat-Nalletamby, S. and Burholt, V. (2015). Intergenerational relationships: Experiences and attitudes in the new millennium. Foresight: Government Office for Science
- Keene, J.R., Yamashita, T. and Prokos, A.H. (2017). The effect of work hours and workplace policies on sandwiched caregivers IN: Burke, R.J. and Calvano, L.M. (eds) *The Sandwich Generation: Caring for Oneself and Others at Home and at Work*. Cheltenham: Edward Elgar Publishing
- Kim, M.H., Dunkle, R.E., Lehning, A.J., Shen, H.W., Feld, S. and Perone, A.K. (2016). Caregiver stressors and depressive symptoms among older husbands and wives in the United States. *Journal of Women & Aging*: 1-11
- King, D. and Pickard, L. (2013). When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England. *Health & Social Care in the Community* 21(3): 303-14
- King, D. and Wittenberg, R. (2015). *Data on adult social care*. School for Social Care Research. Available from: http://eprints.lse.ac.uk/65149/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_NIHR%20School%20for%20Social%20Care%20Research_SSCR_Scoping%20Review_12_web.pdf
- Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N. and Sanders, C. (2015). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community* 24(2): 203-13
- Kohli, M. and Künemund, H. (2003). Intergenerational transfers in the family: What motivates giving IN: Bengtson, L., Vern and Lowenstein, A. (eds) *Global aging and challenges to families*. New York: Aldine de Gruyter
- Kruijswijk, W., Da Roit, B. and Hoogenboom, M. (2015). Elasticity of care networks and the gendered division of care. *Ageing & Society* 35(4): 675-703

- Langan, M. (1990). Community care in the 1990s: the community care White Paper: 'Caring for People'. *Critical Social Policy* 10(29): 58-70
- Langner, L.A. and Furstenberg, F.F. (2018). Gender Differences in Spousal Caregivers' Care and Housework: Fact or Fiction? *The Journals of Gerontology: Series B*
- Lapierre, T.A. and Keating, N. (2012). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing and Society* 33(8): 1442-68
- Larkin, M. (2008). Life after caring: the post-caring experiences of former carers. *British Journal of Social Work* 39(6): 1026-42
- Larkin, M. and Milne, A. (2014). Carers and empowerment in the UK: a critical reflection. *Social Policy and Society* 13(1): 25-38
- Larkin, M. and Milne, A. (2017). What do we know about older former carers? Key issues and themes. *Health & Social Care in the Community* 25(4): 1396-403
- Lee, Y. and Tang, F. (2013). More Caregiving, Less Working: Caregiving Roles and Gender Difference. *Journal of Applied Gerontology* 34(4): 465-83
- Lee, Y., Tang, F.Y., Kim, K.H. and Albert, S.M. (2015). The Vicious Cycle of Parental Caregiving and Financial Well-being: A Longitudinal Study of Women. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences* 70(3): 425-31
- Legislation.gov.uk. (2014). *Care Act 2014*. Available from: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted> [Accessed 21/11/2018]
- Leinonen, A.M. (2011). Adult children and parental care-giving: making sense of participation patterns among siblings. *Ageing & Society* 31: 308-27
- Lendon, J.P., Silverstein, M. and Giarrusso, R. (2014). Ambivalence in Older Parent-Adult Child Relationships: Mixed Feelings, Mixed Measures. *Journal of Marriage and the Family* 76(2): 272-84
- Leopold, T., Raab, M. and Engelhardt, H. (2014). The Transition to Parent Care: Costs, Commitments, and Caregiver Selection Among Children. *Journal of Marriage and Family* 76(2): 300-18
- Lima, J.C., Allen, S.M., Goldscheider, F. and Intrator, O. (2008). Spousal caregiving in late midlife versus older ages: Implications of work and family obligations. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences* 63(4): S229-S38
- Littleford, C., Hussey, D., Begum, N. and Oskala, A. (2016). Methodology IN: Banks, J., Barry, D.G., Nazroo, J. and Steptoe, A. (eds) *The dynamics of ageing: Evidence from the English Longitudinal Study of Ageing 2002-15 (wave 7)*. London: The Institute for Fiscal Studies, Available from: https://www.ifs.org.uk/uploads/elsa/docs_w7/ELSA%20Wave%207%20report.pdf

List of References

- Lloyd, L. (2010). The Individual in Social Care: The Ethics of Care and the 'Personalisation Agenda' in Services for Older People in England. *Ethics and Social Welfare* 4(2): 188-200
- Lowenstein, A. (2007). Solidarity-conflict and ambivalence: Testing two conceptual frameworks and their impact on quality of life for older family members. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences* 62(2): S100-S7
- Lowenstein, A. and Katz, R. (2013). Family and Age in a Global Perspective IN: Dannefer, D. and Phillipson, C. (eds) *The SAGE handbook of social gerontology*. London: SAGE 190 - 201
- Lugtig, P. (2014). Panel Attrition. *Sociological Methods & Research* 43(4): 699-723
- Lumsdaine, R.L. and Vermeer, S.J.C. (2015). Retirement Timing of Women and the Role of Care Responsibilities for Grandchildren. *Demography* 52(2): 433-54
- Lundholm, E. and Malmberg, G. (2009). Between Elderly Parents and Grandchildren—Geographic Proximity and Trends in Four-Generation Families. *Journal of Population Ageing* 2(3): 121-37
- Lynn, P. (2012). The problem of nonresponse IN: de Leeuw, E.D., Hox, J. and Dillman, D. (eds) *International Handbook of Survey Methodology*. Routledge
- Lyons, J.G., Cauley, J.A. and Fredman, L. (2015). The Effect of Transitions in Caregiving Status and Intensity on Perceived Stress Among 992 Female Caregivers and Noncaregivers. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences* 70(8): 1018-23
- Macintyre, S., Ellaway, A., Der, G., Ford, G. and Hunt, K. (1998). Do housing tenure and car access predict health because they are simply markers of income or self esteem? A Scottish study. *Journal of Epidemiology and Community Health* 52(10): 657-64
- Manor, O., Matthews, S. and Power, C. (2001). Self-rated health and limiting longstanding illness: inter-relationships with morbidity in early adulthood. *International Journal of Epidemiology* 30(3): 600-7
- Marmot, M. (2010). Fair society, healthy lives: the Marmot Review: strategic review of health inequalities in England post-2010. London: The Marmot Review
- Marmot, M., Oldfield, Z., Clemens, S., Blake, M., Phelps, A., Nazroo, J., Steptoe, A., Rogers, N., Banks, J. and Oskala, A. (2017). Longitudinal Study of Ageing: Waves 0-7, 1998-2015. [data collection]. 27th Edition Edition: UK Data Service
- Marmot, M.G., Bobak, M. and Smith, G.D. (1995). *Explanations for social inequalities in health*. Oxford University Press Oxford, 1995
- Martinez-Marcos, M. and De la Cuesta-Benjumea, C. (2014). How women caregivers deal with their own long-term illness: a qualitative study. *Journal of Advanced Nursing* 70(8): 1825-36
- Mason, K.O. (1997). Explaining fertility transitions. *Demography* 34(4): 443-54

- McCann, J.J., Hebert, L.E., Bienias, J.L., Morris, M.C. and Evans, D.A. (2004). Predictors of beginning and ending caregiving during a 3-year period in a biracial community population of older adults. *American Journal of Public Health* 94(10): 1800-6
- McDonald, P. (2000). Gender Equity in Theories of Fertility Transition. *Population and Development Review* 26(3): 427-39
- McGarrigle, C.A., Leahy, S. and Kenny, R.A. (2018). OP85 Investigating the health of older carers within different social care systems in Ireland and England: evidence from the Irish Longitudinal Study on Ageing (TILDA) and the English Longitudinal Study of Ageing (ELSA). BMJ Publishing Group Ltd
- McHugh, M.C. (2012). Aging, Agency, and Activism: Older Women as Social Change Agents. *Women & Therapy* 35(3-4): 279-95
- Mentzakis, E., McNamee, P. and Ryan, M. (2009). Who cares and how much: exploring the determinants of co-residential informal care. *Review of Economics of the Household* 7(3): 283-303
- Meyler, D., Stimpson, J.P. and Peek, M.K. (2007). Health concordance within couples: a systematic review. *Social Science and Medicine* 64(11): 2297-310
- Midi, H., Sarkar, S.K. and Rana, S. (2010). Collinearity diagnostics of binary logistic regression model. *Journal of Interdisciplinary Mathematics* 13(3): 253-67
- Miller, R.B. and Hollist, C.S. (2007). Attrition Bias. *Faculty Publications, Department of Child, Youth, and Family Studies*. 45
- Miller, R.L., Acton, C., Fullerton, D. and Maltby, J. (2002). *SPSS for social scientists*. Basingstoke: Palgrave Macmillan
- Milligan, C. and Morbey, H. (2016). Care, coping and identity: Older men's experiences of spousal care-giving. *Journal of Aging Studies* 38: 105-14
- Monden, C. (2007). Partners in health? Exploring resemblance in health between partners in married and cohabiting couples. *Sociology of Health & Illness* 29(3): 391-411
- Mortensen, J., Dich, N., Lange, T., Alexanderson, K., Goldberg, M., Head, J., Kivimaki, M., Madsen, I.E., Rugulies, R., Vahtera, J., Zins, M. and Rod, N.H. (2017). Job strain and informal caregiving as predictors of long-term sickness absence: A longitudinal multi-cohort study. *Scandinavian Journal of Work, Environment and Health* 43(1): 5-14
- Mulder, C.H. and van der Meer, M.J. (2009). Geographical Distances and Support from Family Members. *Population Space and Place* 15(4): 381-99
- Naldini, M., Pavolini, E. and Solera, C. (2016). Female employment and elderly care: the role of care policies and culture in 21 European countries. *Work Employment and Society* 30(4): 607-30
- Natcen Social Research (2016). *English Longitudinal Study of Ageing (ELSA). Wave 1 to Wave 7. User Guide to the core datasets*. London: Natcen Social Research Available from:

List of References

- http://doc.ukdataservice.ac.uk/doc/5050/mrdoc/pdf/5050_elsa_user_guide_waves_1-7.pdf [Accessed 22/08/2017]
- National Audit Office (2014). *Adult Social Care in England: Overview*. London: Department of Health and Department for Communities and Local Government Available from: <https://www.nao.org.uk/wp-content/uploads/2015/03/Adult-social-care-in-England-overview.pdf> [Accessed 22/08/2017]
- NCRM (2011). *Using statistical regression methods in education research: Module 4 - Binary Regression*. National Centre for Research Methods. Available from: <http://www.restore.ac.uk/srme/www/fac/soc/wie/research-new/srme/modules/mod4/index.html> [Accessed 12/05]
- NHS (2018). *Carers' breaks and respite care*. NHS. Available from: <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/> [Accessed 12/12]
- NHS England (2014). *NHS England's commitment to carers*. NHS England Available from: <https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf> [Accessed 21/11/2018]
- NHS England (2017). *The Economics of Caring: A Scoping Review*. The Strategy Unit and ICF, NHS Midlands and Lancashire Communication Support Unit Available from: <https://www.strategyunitwm.nhs.uk/sites/default/files/2017-12/Caring%20scoping%20study%20-%20final%20report.pdf> [Accessed 16/11/2018]
- NHSDigital (2017). *Community Care Statistics, Social Services Activity, England - 2015-26*. NHS Digital. Available from: <http://digital.nhs.uk/catalogue/PUB21934> [Accessed 16/11/2017]
- Nocon, A. and Pearson, M. (2000). The roles of friends and neighbours in providing support for older people. *Ageing and Society* 20(3): 341-67
- Noël-Miller, C.M. (2011). Partner caregiving in older cohabiting couples. *The journals of gerontology. Series B, Psychological Sciences and Social Sciences* 66(3): 341-53
- Norman, P. and Purdam, K. (2013). Unpaid Caring Within and Outside the Carer's Home in England and Wales. *Population Space and Place* 19(1): 15-31
- Norton, E.C., Nicholas, L.H. and Huang, S.S.H. (2013). Informal Care and Inter-vivos Transfers: Results from the National Longitudinal Survey of Mature Women. *B E Journal of Economic Analysis & Policy* 14(2): 377-400
- O'Reilly, D., Connolly, S., Rosato, M. and Patterson, C. (2008). Is caring associated with an increased risk of mortality? A longitudinal study. *Social Science & Medicine* 67(8): 1282-90
- O'Loughlin, K., Loh, V. and Kendig, H. (2017). Carer Characteristics and Health, Wellbeing and Employment Outcomes of Older Australian Baby Boomers. *Journal of Cross-Cultural Gerontology* 32(3): 339-56
- OECD (2003). *Health at a Glance 2003: OECD Indicators*. Paris: OECD Publishing Available from: <http://www.oecd.org/site/worldforum/33703760.pdf> [Accessed 15/07/2017]

- OECD (2011). *The Impact of Caring on Family Carers Help Wanted? Providing and Paying for Long-Term Care*. Paris: OECD Publishing Available from: <https://www.oecd.org/els/health-systems/47884865.pdf>
- OECD (2017). Informal Carers IN: OECD (ed) *Health at a Glance 2017: OECD indicators*. Paris: OECD Available from: https://www.oecd-ilibrary.org/docserver/health_glance-2017-78-en.pdf?expires=1532506609&id=id&accname=guest&checksum=D1707D4B58BAB7C7FA9E4D0B93A2CFE0
- ONS (2005a). *Focus on Ethnicity and Identity*. London: Office for National Statistics Available from: <http://webarchive.nationalarchives.gov.uk/20160128145240/http://www.ons.gov.uk/ons/rel/ethnicity/focus-on-ethnicity-and-identity/index.html> [Accessed 27/06/17]
- ONS (2005b). *The National Statistics Socio-economic Classification*. Office for National Statistics. Available from: <https://www.ons.gov.uk/methodology/classificationsandstandards/otherclassifications/thenationalstatistics socioeconomicclassificationnssecrebasedonsoc2010> [Accessed 21/07/2017]
- ONS (2012). *Ethnicity and National Identity in England and Wales: 2011*. Office for National Statistics. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11> [Accessed 13/07/2017]
- ONS (2013a). 2011 Census analysis: Unpaid care in England and Wales, 2011 and comparison with 2001. 2013a 2013 Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15> [Accessed 16/07/2017]
- ONS (2013b). *Ethnic Variations in General Health and Unpaid Care Provision, 2011*. Office for National Statistics. Available from: <http://webarchive.nationalarchives.gov.uk/20160105204917/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/ethnic-variations-in-general-health-and-unpaid-care-provision/rpt-ethnic-variations-in-general-health-and-unpaid-care-provision.html> [Accessed 17/01/2018]
- ONS (2013c). Full story: The gender gap in unpaid care provision: is there an impact on health and economic position? 2013c Available from: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171776_310295.pdf [Accessed 25/08/2017]
- ONS (2013d). *The number of people age 60 and over getting divorced has risen since the 1990s*. Office for National Statistics. Available from: <http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/family-demography/older-people-divorcing/2011/style-divorce.html> [Accessed 22/06/2017]
- ONS (2016a). *Birth Summary Tables, England and Wales: 2014. Live births, stillbirths, and the intensity of childbearing measured by the total fertility rate*. Office for National Statistics. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsand>

List of References

- [marriages/livebirths/bulletins/birthsummarytablesenglandandwales/2016](#)
[Accessed 16/08/2017]
- ONS (2016b). *Childbearing by socio-economic status and country of birth of mother:2014*. Office for National Statistics Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/articles/anoteonchildbearingbysocioeconomicstatusandcountryofbirthofmother/2016> [Accessed 06/09/2018]
- ONS (2016c). *Dataset: Health state life expectancy at birth and at age 65 by local areas, UK*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/healthstatelifeexpectancyatbirthandage65bylocalareasuk> [Accessed 05/12/2017]
- ONS (2016d). *Healthy life expectancy at birth and age 65 by upper tier local authority and area deprivation: England , 2012- 2014*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthylifeexpectancyatbirthandage65byuppertierlocalauthorityandareadeprivation/england2012to2014>
[Accessed 22/08/2017]
- ONS (2016e). Home produced 'adultcare' services *Household satellite accounts: 2005 to 2014*. Office of National Statistcis Available from:
<https://www.ons.gov.uk/economy/nationalaccounts/satelliteaccounts/compendium/householdsatelliteaccounts/2005to2014/chapter3homeproducedadultcareservices> [Accessed 16/11/2017]
- ONS (2017a). *Births by Parents' Characteristics in England and Wales: 2016*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsbyparentscharacteristicsinenglandandwales/2016> [Accessed 04/09/2018]
- ONS (2017b). *Labour market economic commentary: August 2017*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/articles/labourmarketeconomiccommentary/august2017> [Accessed 19/01/2018]
- ONS (2017c). *Marriage and divorce on the rise at 65 and over*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/marriagecohabitationandcivilpartnerships/articles/marriageanddivorceontheriseat65andover/2017-07-18> [Accessed 25/07/2018]
- ONS (2017d). *Past and projected data from the period and cohort life tables, 2016-based, UK: 1981 to 2066*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/pastandprojecteddatafromtheperiodandcohortlifetables/2016baseduk1981to2066> [Accessed 14/09/2018]
- ONS (2017e). *Population Estimations for the UK, England and Wales, Scotland and Northern Ireland: Mid-2016 Population Estimates*. Office for National Statistics. Available from:
<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandm>

- [igration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland](#) [Accessed 27/06/2017]
- ONS (2017f). *Time series: Female employment rate (aged 16 to 64, seasonally adjusted)*. Available from: <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/timeseries/lf25/lms> [Accessed 21/11/2017]
- ONS (2017g). *Unpaid carers provide social care worth £57 billion*. Office for National Statistics. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10> [Accessed 25/02/2019]
- ONS (2018a). *Health state life expectancies, UK: 2015 to 2017*. Office for National Statistics. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2015to2017> [Accessed 02/01]
- ONS (2018b). *Living longer: how our population is changing and why it matters*. Office of National Statistics. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13> [Accessed 12/12]
- ONS (2018c). *UK labour market: October 2018*. Office for National Statistics. Available from: <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/bulletins/uklabourmarket/october2018> [Accessed 12/11/2018]
- Orzeck, P. and Silverman, M. (2008). Recognizing post-caregiving as part of the caregiving career: implications for practice. *Journal of Social Work Practice* 22(2): 211-20
- Österle, A. and Rothgang, H. (2010). Long-Term Care IN: Castles, F.G., Leibfried, S., Lewis, J., Obinger, H. and Pierson, C. (eds) *The Oxford Handbook of the Welfare State*. Oxford University Press
- Pannell, J. and Blood, I. (2012). Supported housing for older people in the UK: An evidence review. *Joseph Rowntree Foundation, York*. Available at: <http://www.jrf.org.uk/publications/supported-housing-older-people-evidence-review> (accessed on 11/11/2014)
- Parrott, T.M. and Bengtson, V.L. (1999). The effects of earlier intergenerational affection, normative expectations, and family conflict on contemporary exchanges of help and support. *Research on Aging* 21(1): 73-105
- Peel, E. and Harding, R. (2013). 'It's a huge maze, the system, it's a terrible maze': Dementia carers' constructions of navigating health and social care services. *Dementia* 13(5): 642-61
- Pickard, L. (2002). The decline of intensive intergenerational care of older people in Great Britain, 1985-1995. *Population trends* 110: 31-41

List of References

- Pickard, L. (2004). The effectiveness and cost-effectiveness of support and services to informal carers of older people. *Audit Commission, London*
- Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society* 35(01): 96-123
- Pickard, L. (2018). Good Value for Money? Public Investment in 'Replacement Care' for Working Carers in England. *Social Policy and Society*: 1-18
- Pickard, L., Wittenberg, R., Comas-Herrera, A., King, D. and Malley, J. (2007). Care by Spouses, Care by Children: Projections of Informal Care for Older People in England to 2031. *Social Policy and Society* 6(3): 353-66
- Pillemer, K. and Suitor, J.J. (2014). Who provides care? A prospective study of caregiving among adult siblings. *The Gerontologist* 54(4): 589-98
- Plaisier, I., van Groenou, M.I.B. and Keuzenkamp, S. (2015). Combining work and informal care: the importance of caring organisations. *Human Resource Management Journal* 25(2): 267-80
- Pope, N.D., Kolomer, S. and Glass, A.P. (2012). How Women in Late Midlife Become Caregivers for Their Aging Parents. *Journal of Women & Aging* 24(3): 242-61
- Prohaska, V., Brown, N.R. and Belli, R.F. (1998). Forward telescoping: the question matters. *Memory* 6(4): 455-65
- Rafnsson, S.B., Shankar, A. and Steptoe, A. (2015). Informal caregiving transitions, subjective well-being and depressed mood: Findings from the English Longitudinal Study of Ageing. *Aging & Mental Health*: 1-9
- Ramsay, S., Grundy, E. and O'Reilly, D. (2013). The relationship between informal caregiving and mortality: an analysis using the ONS Longitudinal Study of England and Wales. *Journal of Epidemiology and Community Health* 67(8): 655-60
- Reinharz, S. (1986). Friends or foes: Gerontological and feminist theory. *Women's Studies International Forum* 9(5): 503-14
- Riley, N.E. (1999). Challenging demography: Contributions from feminist theory. *Sociological Forum* 14(3): 369-97
- Robards, J., Vlachantoni, A., Evandrou, M. and Falkingham, J. (2015). Informal caring in England and Wales - Stability and transition between 2001 and 2011. *Advances in Life Course Research* 24: 21-33
- Roth, D.L., Fredman, L. and Haley, W.E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist* 55(2): 309-19
- Rutherford, A.C. and Bu, F. (2017). Issues with the measurement of informal care in social surveys: evidence from the English Longitudinal Study of Ageing. *Ageing and Society*: 1-19
- Schmidt, A.E., Ilinca, S., Schulmann, K., Rodrigues, R., Principi, A., Barbabella, F., Sowa, A., Golinowska, S., Deeg, D. and Galenkamp, H. (2016). Fit for caring: factors associated with informal care provision by older caregivers

- with and without multimorbidity. *European Journal of Ageing* 13(2): 103-13
- Schneider, U., Trukeschitz, B., Mühlmann, R. and Ponocny, I. (2013). "Do I stay or do I go?"—job change and labor market exit intentions of employees providing informal care to older adults. *Health economics* 22(10): 1230-49
- Schulz, R., Beach, S.R., Cook, T.B., Martire, L.M., Tomlinson, J.M. and Monin, J.K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging and Mental Health* 16(6): 712-21
- Scott, J. and Clery, E. (2013). Gender roles: an incomplete revolution IN: Park, A., Bryson, C., Clery, E., Curtice, J. and Philips, M. (eds) *British social attitudes: the 30th report*. London: NatCen Social Research
- Scrutton, J. and Creighton, H. (2015). The emotional wellbeing of older carers. 2015 Available from: http://www.ilcuk.org.uk/index.php/publications/publication_details/the_emotional_wellbeing_of_older_carers
- Searle, B.A. and Köppe, S. (2014). *Assets, savings and wealth, and poverty: A review of evidence. Final report to the Joseph Rowntree Foundation*. Bristol: Personal Finance Research Centre. Bristol: Personal Finance Research Centre Available from: <http://www.bristol.ac.uk/media-library/sites/geography/pfrc/pfrc1405-assets-savings-wealth-poverty.pdf> [Accessed 16/08/2017]
- Seltzer, M.M. and Li, L.W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *Gerontologist* 40(2): 165-78
- Shavers, V.L. (2007). Measurement of socioeconomic status in health disparities research. *Journal of the National Medical Association* 99(9): 1013-23
- Shaw, M. and Dorling, D. (2004). Who cares in England and Wales? The Positive Care Law: cross-sectional study. *The British Journal of General Practice* 54(509): 899-903
- Silverstein, M., Gans, D. and Yang, F.M. (2006). Intergenerational support to aging parents - The role of norms and needs. *Journal of Family Issues* 27(8): 1068-84
- Simpson, P. (2017). Public spending on adult social care in England. IFS Briefing Note BN200. London, Institute for Fiscal studies: Nuffield Foundation
- Singer, J.D. and Willett, J.B. (2003). *Applied Longitudinal Data Analysis : Modeling Change and Event Occurrence*. Oxford: Oxford University Press
- Singh-Manoux, A., Adler, N.E. and Marmot, M.G. (2003). Subjective social status: its determinants and its association with measures of ill-health in the Whitehall II study. *Social Science & Medicine* 56(6): 1321-33
- Smith, G.D., Shipley, M.J. and Rose, G. (1990). Magnitude and causes of socioeconomic differentials in mortality: further evidence from the Whitehall Study. *Journal of Epidemiology and Community Health* 44(4): 265-70

List of References

- Solomi, V.L. and Casiday, R.E. (2016). In sickness and in health: The strains and gains of caring for a chronically ill or disabled spouse. *Chronic Illness* 13(2): 75-87
- Sovinsky, M. and Stern, S. (2016). Dynamic modelling of long-term care decisions. *Review of Economics of the Household* 14(2): 463-88
- Steinbach, A. (2012). Intergenerational relations across the life course. *Advances in Life Course Research* 17(3): 93-9
- Stephoe, A., Breeze, E., Banks, J. and Nazroo, J. (2013). Cohort Profile: The English Longitudinal Study of Ageing. *International Journal of Epidemiology* 42(6): 1640-8
- Stone, J., Evandrou, M., Falkingham, J. and Vlachantoni, A. (2015). Women's economic activity trajectories over the life course: implications for the self-rated health of women aged 64+ in England. *Journal of Epidemiology and Community Health* 69(9): 873-9
- Stuifbergen, M.C. (2011). *Filial obligations today: Moral practice, perception and ethical theory*. Utrecht: Utrecht University Available from: <https://dspace.library.uu.nl/bitstream/handle/1874/204051/stuifbergen.pdf?sequence=2> [Accessed 06/09/2018]
- Stuifbergen, M.C., Van Delden, J.J.M. and Dykstra, P.A. (2008). The implications of today's family structures for support giving to older parents. *Ageing & Society* 28: 413-34
- Suanet, B., Van Groenou, M.B. and Van Tilburg, T. (2012). Informal and formal home-care use among older adults in Europe: can cross-national differences be explained by societal context and composition? *Ageing & Society* 32: 491-515
- Sullivan, A.B. and Miller, D. (2015). Who is Taking Care of the Caregiver? *Journal of patient experience* 2(1): 7-12
- Szinovacz, M.E. and Davey, A. (2013). Changes in adult children's participation in parent care. *Ageing & Society* 33: 667-97
- Thabane, L., Mbuagbaw, L., Zhang, S., Samaan, Z., Marcucci, M., Ye, C., Thabane, M., Giangregorio, L., Dennis, B., Kosa, D., Debono, V.B., Dillenburg, R., Fruci, V., Bawor, M., Lee, J., Wells, G. and Goldsmith, C.H. (2013). A tutorial on sensitivity analyses in clinical trials: the what, why, when and how. *BMC Medical Research Methodology* 13(1): 92
- The Health Foundation and the Nuffield Trust (2014). Cause for Concern – Qualitywatch Annual Statement, 2014. IN: The Health Foundation and the Nuffield Trust (ed) *QualityWatch*. London: The Health Foundation and the Nuffield Trust
- The Lancet (2017). Who cares for the carer? *The Lancet* 389(10071): 763
- The Social Progress Imperative (2017). *2017 Social Progress Index*. Available from: <http://www.socialprogressindex.com/> [Accessed 01/12/2017]
- Thomas, K. (2006). Community palliative care. *ABC of palliative care* 56: 68
- Thomese, F., Van Tilburg, T., Van Groenou, M.B. and Knipscheer, K. (2005). Network Dynamics in Later Life IN: Johnson, M.L. (ed) *The Cambridge*

- handbook of age and ageing*. Cambridge: New York: Cambridge University Press
- Thurley, D. and Keen, R. (2017). State Pension age increases for women born in the 1950. Briefing Paper. House of Commons Library
- Tomassini, C. (2005). The demographic characteristics of the oldest old in the United Kingdom. *Population trends* (120): 15-22
- Tudor Hart, J. (1971). The Inverse care law. *The Lancet* 297(7696): 405-12
- Turner, M., King, C., Milligan, C., Thomas, C., Brearley, S.G., Seamark, D., Wang, X., Blake, S. and Payne, S. (2016). Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences. *Age and Ageing* 45(3): 421-6
- UK Data Archive (2017). *UK Data Archive: Important Study Information*. Available from: <http://doc.ukdataservice.ac.uk/doc/5050/read5050.htm> [Accessed 11/05/2017]
- UK Data Archive (Unknown). *Financial derived variables user guide*. Available from: http://doc.ukdataservice.ac.uk/doc/5050/mrdoc/pdf/5050_user_guide_financial_derived_vars.pdfUK [Accessed 06/06/2017]
- UK Data Service (2014). *Data analysis. Explore key variables, examine relationships between variables, data manipulation. Survey weights*. Available from: <https://www.ukdataservice.ac.uk/using-survey-data/data-analysis/survey-weights> [Accessed 04/12/2017]
- UK Data Service (2016). *Terms and conditions of access*. UK Data Service. Available from: <https://www.ukdataservice.ac.uk/get-data/how-to-access/conditions> [Accessed 10/06/2016]
- University College London (2019). *What is a Community Navigator?* University College London,. Available from: <https://www.ucl.ac.uk/psychiatry/research/epidemiology/community-navigator-study/about/what-is-a-community-navigator> [Accessed 05/03/2019]
- University of Essex (2016). *Understanding Society. The UK Household Longitudinal Study. Waves 1-5. Quality Profile*. Institute for Social and Economic Research
- Van Bavel, J. and De Winter, T. (2013). Becoming a Grandparent and Early Retirement in Europe. *European Sociological Review* 29(6): 1295-308
- Verbakel, E. (2017). How to understand informal caregiving patterns in Europe? The role of formal long-term care provisions and family care norms. *Scandinavian Journal of Public Health* 46(4): 436-47
- Victor, C. (2006). Will our old age be healthier? IN: Vincent, J.A., Phillipson, C., Downs, M. and British Society of, G. (eds) *The futures of old age*. London: Sage Publ. in assoc. with BSG

List of References

- Victor, C.R. (2002). Using existing research and statistical data: secondary data analysis IN: Jamieson, A. and Victor, C.R. (eds) *Researching ageing and later life : the practice of social gerontology* (1st Edition). Buckingham, UK; Philadelphia, PA: Open University Press
- Vlachantoni, A. (2010). The demographic characteristics and economic activity patterns of carers over 50: evidence from the English Longitudinal Study of Ageing. *Population trends* (141): 54
- Vlachantoni, A., Evandrou, M., Falkingham, J. and Robards, J. (2013). Informal care, health and mortality. *Maturitas* 74(2): 114-8
- Vlachantoni, A., Robards, J., Falkingham, J. and Evandrou, M. (2016). Trajectories of informal care and health. *SSM - Population Health* 2: 495-501
- Vlachantoni, A., Shaw, R., Willis, R., Evandrou, M., Falkingham, J. and Luff, R. (2011). Measuring unmet need for social care amongst older people. *Population trends* 145(1): 60-76
- Vlachantoni, A., Shaw, R.J., Evandrou, M. and Falkingham, J. (2015). The determinants of receiving social care in later life in England. *Ageing & Society* 35(2): 321-45
- Wagner, M. and Brandt, M. (2018). Long-term Care Provision and the Well-Being of Spousal Caregivers: An Analysis of 138 European Regions. *The Journals of Gerontology: Series B* 73(4): e24-e34
- Walsh, E. and Murphy, A. (2018). Investigating the causal relationship between employment and informal caregiving of the elderly. *BMC research notes* 11(1): 570
- Wanless, D., Forder, J., Fernández, J.-L., Poole, T., Beesley, L., Henwood, M. and Moscone, F. (2006). *Wanless social care review: securing good care for older people, taking a long-term view*. King's Fund
- Wasserman, C. and Ossiander, E. (2018). Department of Health Agency Standards for reporting data with small numbers. 2018 Available from: <https://www.doh.wa.gov/Portals/1/Documents/1500/SmallNumbers.pdf> [Accessed 18/11/2018]
- Watts, J.H. and Cavaye, J. (2016). Being a Former Carer: Impacts on Health and Well-Being. *Illness, Crisis & Loss* 26(4): 330-45
- Westermeier, C. and Grabka, M. (2015). *Longitudinal Wealth Data and Multiple Imputation: An Evaluation Study*. Berlin: The German Socio-Economic Panel (SOEP) Available from: http://EconPapers.repec.org/RePEc:diw:diwsop:diw_sp790 [Accessed 22/08/2017]
- Wiener, J.M., Hanley, R.J., Clark, R. and Van Nostrand, J.F. (1990). Measuring the Activities of Daily Living: Comparisons Across National Surveys. *Journal of Gerontology* 45(6): S229-S37
- Willis, R., Price, D. and Glaser, K. (2013). Ethnicity as a Determining Factor for Instrumental Support in Mid and Later Life in England and Wales. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences* 68(2): 278-89

- Willson, A.E., Shuey, K.M. and Elder, G.H. (2003). Ambivalence in the relationship of adult children to aging parents and in-laws. *Journal of Marriage and Family* 65(4): 1055-72
- Windle, G.S., Burholt, V. and Edwards, R.T. (2006). Housing related difficulties, housing tenure and variations in health status: evidence from older people in Wales. *Health Place* 12(3): 267-78
- Wittenberg, R., Hu, B. and Hancock, R. (2018). *Projections of demand and expenditure on adult social care 2015 to 2040*. London: Personal Social Services Research Unit Available from: <https://www.pssru.ac.uk/publications/pub-5421/> [Accessed 20/09/2018]
- Wood, C. and Vibert, S. (2017). Public attitudes to the role of the state and the individual in achieving financial security in later life. 2017 Available from: <https://www.demos.co.uk/wp-content/uploads/2017/12/A-Good-Retirement.pdf>
- World Health Organisation (2003). *WHO definition of Health*. Available from: <http://www.who.int/about/definition/en/print.html> [Accessed 26/04]
- World Health Organisation (2017). *Gender and Genetics*. World Health Organisation. Available from: <http://www.who.int/genomics/gender/en/> [Accessed 24/10/2017]
- World Health Organization (2008). *Home care in Europe: the solid facts*. Copenhagen: World Health Organization, Available from: http://www.euro.who.int/_data/assets/pdf_file/0005/96467/E91884.pdf [Accessed 16/10/2017]
- Wu, S., Wang, R., Zhao, Y., Ma, X., Wu, M., Yan, X. and He, J. (2013). The relationship between self-rated health and objective health status: a population-based study. *BMC Public Health* 13: 320-
- Yin, R.K. (2003). *Case study research : design and methods*. Thousand Oaks, California: Sage Publications
- Young, A., Powers, J. and Wheway, V. (2007). Working with longitudinal data: Attrition and retention, data quality, measures of change and other analytical issues. *International Journal of Multiple Research Approaches* 1(2): 175-86
- Young, H. and Grundy, E. (2008). Longitudinal perspectives on caregiving, employment history and marital status in midlife in England and Wales. *Health & Social Care in the Community* 16(4): 388-99
- Young, H., Grundy, E. and Jitlal, M. (2006). Care providers, care receivers. A *longitudinal perspective*. York, United Kingdom: Joseph Rowntree Foundation
- Železná, L. (2016). Care-giving to grandchildren and elderly parents: role conflict or family solidarity? *Ageing and Society*: 1-21
- Zuccotti, C.V. (2018). *Does ethnic concentration influence gender role views? A study across ethnic groups in England and Wales*. European University Institute. Workign Paper RSCAS Available from: <http://diana->

List of References

n.iue.it:8080/bitstream/handle/1814/52164/RSCAS_2018_11.pdf?sequence=1&isAllowed=y [Accessed 05/09/2018]