**Social participation and health outcomes among caregivers and non-caregivers in Great Britain**

**Athina Vlachantoni a1, a2, Zhixin Feng a3,Ning Wang a1, Maria Evandrou a1,a2**

(a1) Centre for Research on Ageing, Faculty of Social Sciences, University of Southampton, Southampton, UK

(a2) ESRC Centre for Population Change, Faculty of Social Sciences, University of Southampton, Southampton, UK

(a3) School of Primary Care, Population Sciences and Medical Education, Faculty of Medicine, University of Southampton, Southampton, UK

**Corresponding author:**

Zhixin Feng

Primary Care and Population Sciences, Faculty of Medicine, University of Southampton

AB230, Level B, South Academic Block, University Hospital Southampton, Southampton SO16 6YD

Tel: +44 (0)23 8120 6533

Email address: z.feng@soton.ac.uk

**Statement of conflict of interest:**

The Authors declare that there is no conflict of interest.

**Funding:**

This research conducted for this paper was funded by the Economic and Social Research Council’s Secondary Data Analysis Initiative, Grant Number: ES/P001947/1.

**Statement of ethical approval:**

Ethical approval was granted from the University of Southampton’s Research Governance Office (Submission ID: 29758)

**Abstract**

This study investigates the relationship between social participation and health outcomes between caregivers and non-caregivers in Great Britain. Previous studies indicate that the impact of informal caregiving on the carer’s health is complex, and the intensity of care provision have an adverse impact on the caregivers’ health, while social participation could have a protective role in this respect. Using qualitative and quantitative data from wave 8 of the 1958 National Child Development Study, the analysis shows that social participation has a positive effect on the carers’ mental health and subjective wellbeing. Individuals who did not engage in social participation reported lower level of mental health and CASP than those engaged in social participation. The qualitative results showed the barriers to social participation of caregivers to be time, energy and finance. We discuss ways in which the government could address such barriers to improve the level of social participation among caregivers.

**Key words:** social participation, carer, intense carer, mixed methods, UK

**Introduction**

With increasing longevity, individuals are increasingly likely to be involved in informal care provision for their older parents during their life course (Pickard, Wittenberg, Comas-Herrera, Davies & Darton, 2000). According to the Office for National Statistics (2017), eight per cent of the UK's private household population were informal caregivers. At present, it is estimated that there are around seven million people in the UK who are caregivers, accounting for one in ten people; and among caregivers, one in five persons is aged 50-64. The number of caregivers are projected to increase by a further 3.4 million by 2030 (Carers Trust, 2018).

The health of caregivers is important as physical or mental illness developed by the caregiver as a result of their caregiving role could deteriorate the health of both the caregiver and the person they provide care to. However, previous studies show that the impact of informal caregiving on the carer’s health is rather complex (Vlachantoni, Evandrou, Falkingham, & Robards, 2013; Roth, Fredman, & Haley, 2015). In general, the provision of informal care can have negative consequences on the caregivers’ physical, emotional, and mental health as caring could make them physically exhausted. For example, caregivers might be getting up several times in the night as well as provide caring throughout the day; they may need to lift and support an adult who is much heavier than themselves, placing themselves in a vulnerable position. The strain of seeing someone the caregivers care about experiencing distress, pain, or discomfort could make caregivers emotionally exhausted, and lead to stress, depression and other mental health issues (Carers Trust, 2018). Doran and his colleagues (2003) used the UK 2001 Census to illustrate that only 56% of people who provided informal care reported “good health” compared to 70% of people providing no care who reported “good health”. On the other hand, O'Reilly, Connolly, Rosato, & Patterson (2008) found that caregivers were less likely than non-caregivers to report the presence of a Limiting-Long-Term Illness (LLTI) (except males who provided 50 or more hours per week); and caregivers had lower mortality than non-caregivers in Northern Ireland. Vlachantoni, Robards, Falkingham, & Evandrou, (2016) further analysed the UK 2001 and 2011 Censuses and found that individuals who provided informal care in 2011 (regardless of carer status in 2001) show lower odds of poor health in 2011 than those who did not provide care in both 2001 and 2011; while intense caregivers (who spent 20 or more hours on caring per week) in 2001 who were not caring in 2011 showed higher odds of reporting poor health than non-caregivers. Finally, those who were intense caregivers in both 2001 and 2011 were about one-third less likely to report poor health at 2011 than non-caregivers (2001 and 2011). O’Reilly et al (2008) interpreted this phenomenon as the “healthy worker effect” which means that those with physical limitations or poor health would self-select out of the caring role.

Although the impact of informal caregiving on the carer’s health is rather complex, the evidence regarding the adverse impact of intense informal caregiving on the carer’s health is more straightforward. From Hirst’s report (2004), caregivers who were at the highest risk of psychological distress were found in the more demanding care situations; and O’Reilly et al (2008) found that males who provided 50 or more hours per week (intense caregivers) were more likely to report LLTI than non-caregivers. However, there also exists a “healthy worker effect” phenomenon for intense caregivers as intense caring has been shown to reduce the mortality risk (O’Reilly et al, 2008; Vlachantoni et al., 2016).

A lack of energy along with health problems due to intense caring could limit the caregivers’ social participation and affect their relationship with their partner, other family members or social network (Hirst, 2004). As a result, intense caregivers may face a double jeopardy from the physical and emotional stresses as well as social isolation that accompanies a demanding caring role (Hirst, 2004; Greenwood, Mezey, & Smith, 2018). Social participation has been found to be an important element of health and wellbeing and it is a potentially modifiable factor which could positively influence depressive symptoms among caregivers (Donkers et al., 2018; Levasseur, Richard, Gauvin, & Raymond, 2000; Sibalija, 2017; Fider, Lee, Gleason, & Jones, 2017). Social participation, such as participating in sport or recreation, or belonging to organizations and clubs, or in other forms of social activities like leisure, recreational, cultural, and spiritual activities, could provide opportunities for people to become involved in their community and for the family to maintain or develop supportive and caring relationships (World Health Organization, 2007). Such social participation may also facilitate individuals’ access to social support, for example, emotional support, companionship, and affection experienced through interpersonal relationships (Sibalija, 2017). On the other hand, individuals who are involved in activities in formal organizations like political parties or trade unions (political participation) may aim at influencing political decision making in their local area and could gain a stronger voice and increase their representation through political participation (Kafkova, Vidovicova & Wija, 2018). Sibalija (2017) found that in Canada both caregivers and non-caregivers who engaged more frequently in community-related activities reported lower depression scores than those who participated less frequently. In addition, when caregivers engage in social activities this may also influence the health of care-recipients. In a study in the US, Kelley et al. (2017) found that social engagement (religious services, went to a support group, visited with friends or family not living in the same home, participated in club meetings or group activities or went out for enjoyment) for caregivers had a direct positive association with the care-recipient’s health.

Research on the relationship between social participation and health outcomes among caregivers and non-caregivers in Great Britain is scarce, whilst research comparing more and less intense care providers is non-existent. This study uses mixed methods in order to examine social participation and health outcomes of caregivers and non-caregivers in the UK. Quantitative analysis distinguishes between intense and non-intense caregivers. The key barriers perceived by caregivers that prevent them from taking part in social activities are then further explored through in-depth interviews on a sub-set of the same respondents.

**Data and Methods**

We integrated two secondary datasets in our study. The quantitative data used in this paper is cross-sectional and comes from wave (8) of the 1958 National Child Development Study (NCDS), a cohort study which begun with more than 17,000 children born in a single week in March 1958 in Great Britain, and who have been followed up through the course of their lives. The wave 8 data collection was conducted in 2008, when 9,789 respondents at age 50 were followed up. In our study, respondents who have no living parents or parents-in-law were excluded as they were not ‘at risk’ of being a caregiver towards the older generation. The final quantitative sample includes a total of 7,333 respondents with valid information. The qualitative data comes from the Social Participation and Identify Study (SPIS), which is a qualitative study which was part of the NCDS wave 8. Stratified by geographic location and social mobility, 220 biographical narratives were collected between 2008 and 2010 through in-depth interviews with an average length of 84.75 minutes (ranging from 25-156 minutes). The topic guide of the interviews covered neighbourhood and belonging, social participation, friendships, life stories and trajectories, identities and membership of the NCDS (Elliott, Miles, Parsons & Savage, 2010). The advantage of the NCDS is that it offers the unique opportunity to combine quantitative data on the provision of informal care in mid-life and a range of individual-level characteristics, with rich qualitative data reflecting the respondents’ views and perspectives on social participation. Since the questions on social participation were changed in wave 9 (the latest wave), and only the wave 8 includes the same questions as the SPIS, therefore we used wave 8 for the analysis in this study.

*Health outcomes measures*

Four health outcomes were considered: self-rated health (SRH), whether the respondent has health problems, mental health and quality of life. SRH is a subjective measure of health. The original five categories have been recoded into three categories: Good (excellent, very good and good), fair, and poor. Burström and Fredlund (2001) found that poor self-rated health is a strong predictor of subsequent mortality in all subgroups studied (young vs old, different social classes), and they concluded that self-rated health may be a useful outcome measure. Respondents were also asked whether they currently suffer from any of sixteen health problems such as asthma or diabetes (the full list of health problems is shown in Table A1 in the appendix). A binary variable was constructed indicating whether the respondent has health problems, with 1 representing reporting at least one health problem, and 0 representing no health problems. The final two health outcomes examined here concern the psychological health outcomes of respondents. The NCDS used the Warwick-Edinburgh Mental Wellbeing Scale (WEMWS) to measure the depression status of respondents, with scores ranging from 14 to 70 (Warwick Medical School, 2015). This variable is not normally distributed, and this research used the cut-off point at 45 following Gremigni’s (2013) suggestions. A binary variable was constructed with 1 indicating “poor mental health” for scores between 14-44, and 0 reflecting “good mental health” for scores above 45. The NCDS also collected the Control, Autonomy, Self-realisation, and Pleasure (CASP) scores (14 items) to indicate the respondents’ subjective quality of life (Wiggins, Netuveli, Hyde, Higgs, & Blane, 2008). Here the range of CASP is from 2 to 42, and the cut-off point was set at 31 (the median point). This variable is not normally distributed. A binary variable was constructed with 1 representing “low CASP” for the scores 2-30, and 0 for “high CASP” and scores from 31 upwards.

*(Intense and non-intense) caregivers and non-caregivers status*

The NCDS asked whether respondents regularly or frequently help parents/ parents-in-law and how many hours they spent caring for parents/ parents-in-law per week. C*aregivers* were defined as those respondents who spend at least 1 hour caring for their parents/ parents-in-law per week; and the rest of the respondents are *non-caregivers.* Although there is no ideal cut-off point for defining caregivers, nevertheless such an approach is appropriate for the size of our sample, and also ensures that any respondent who dedicates time to providing support, often alongside work and other activities, is included in our analysis. Among *caregivers,* we further distinguished as *intense caregivers* those who spend 10 or more hours caring for their parents/ parents-in-law per week, while those who spend fewer than 10 hours caring for their parents/ parents-in-law per week were treated as *non-intense caregivers.* This division is following Gomez-Leon et al’s study (2019).

*Social participation*

Social participation is a key variable in this study. The NCDS asked how often the respondent engages with social activities (the full list of social activities is shown in Table A2 in the appendix). Individuals could access opportunities to become involved in their community and for the family to maintain or develop supportive and caring relationships from their engagement in sport or recreation, or belonging to organizations and clubs, or in terms of leisure, recreational, cultural, and spiritual activities (World Health Organization, 2007). The respondents were asked to rate the frequency of each social participation using a scale from 1 to 4 (1 = At least once a week, 2 = About once a month, 3 = Less often than once a month, 4 = Never/not a member). A binary variable was constructed with respondents who take part in any social participation taking the value of 1, and the rest taking the value 0.

*Covariates*

The demographic and socio-economic status of respondents including their gender, marital status, living arrangements, economic activity, housing tenure, financial situation, regularity of exercise, and whether their household has car(s) were used as control variables in this study (c.f,. Vlachantoni et al., 2016).

**Data analysis**

A convergent mixed-methods design was used where the quantitative and qualitative results were combined to provide a more complete understanding of the research questions (Creswell & Clark, 2017). The analysis strategy included a descriptive analysis of who were the caregivers and intense caregivers, along with statistical models to explore the association between (intense) care, social participation and health outcomes (Pearson’s χ2 test). A multinomial logistic regression model was used to analyse the impact on self-rated health and a binary logistic regression model was applied to analyse whether the respondent has health problems, their mental health and quality of life. Model 1 initially explored the relationship between the respondent’s (*intense*) caregiving status and their health outcomes in order to explore the direct effect of the former on the latter, model 2 incorporated social participation factors, and Model 3 subsequently added all covariates in order to investigate whether the effects of caregiving status and social participation on health outcomes are mediated by these factors. Such a sequence allows us to explore the effect of each set of factors separately, and a similar approach has been used in previous research in the area of caregiving in mid-life (Gomez-leon et al. 2019). Regarding the qualitative data analysis, the 220 interview files were first linked with the quantitative survey data on the same respondents, leading to the identification of 122 caregivers. Among the identified caregivers, there were 13 caregivers who reported providing 10+ hours care per week (defined here as intense caregivers) in the survey data while 109 reported providing less than 10 hours of care per week (non-intense caregivers) to a parent/parent-in-law. As the qualitative study was not purposively designed to address the research questions of this study, only 9 intense caregivers and 39 non-intense caregivers provided information about both their care provision to a parent/parent-in law, and their views on social participation. Thematic analysis was used to explore the themes which relate to the caregivers’ social participation among the 48 caregivers who provided relevant information (Braun & Clarke, 2006). The qualitative analysis was conducted using NVivo 11. All transcripts were read 2-3 times by the researchers and initial coding was conducted by one researcher to generate a codebook; candidate themes were then developed and reviewed by other researchers of the research team (Braun and Clarke, 2006). Three themes were finally confirmed: situations of social participation, type of social participation, and barriers to social participation, addressing the third research question of this study.

**Results**

*Descriptive findings*

Table 1 presents the descriptive statistics between caregivers and non-caregivers, and between intense caregivers and non-intense caregivers. Respondents who were caregivers were significantly more likely to be married (75% vs 72%), living with others (9.3% vs 7.3%), exercise regularly (80% vs 77%), have a car (96% vs 94%), and engage in social participation (53% vs 50%) compared with non-caregivers. Among caregivers, respondents who were intense caregivers were significantly more likely to be females (67% vs 47%), not married (single and never married, separated, divorced, and widowed) (34% vs 24%), living with others (20% vs 7%), economically inactive (25% vs 12%), own outright or by mortgage (78% vs 89%), be in difficult financial situation (10% vs 6%), not exercise regularly (25% vs 19%), and to not have a car (7% vs 3%), compared with non-intense caregivers.

<Table 1 about here>

*Statistical model*

Table 2 presents the multinomial logistic regression model for a) self-rated health (reference group: good health) and the binary logistic regression models for b) having health problems, c) being in poor mental health, and d) low CASP. The results show that there were no significant differences between the caregivers and non-caregivers among the four health outcomes (Model 1 to Model 3); while the results of Model 2 show that respondents who did not engage in social participation were more likely to report fair or poor SRH (ORs=1.43 and 2.42 respectively), poor mental health (ORs=1.63) and CASP (ORs=1.54) than those who engaged in social participation. Model 3 shows that respondents who participated in social activities were still significantly more likely to report poor SRH (ORs=1.26 at 10% level), poor mental health (ORs=1.35) and CASP (ORs=1.24) than those who did not participate in such activities, after controlling for the covariates. In contrast, respondents who did not engage in social participation were still less likely to have health problems (ORs=0.85) than those who did. Table 3 further presents the effect of social participation on health outcomes between caregivers and non-caregivers based on Model 3. Among non-caregivers, respondents who did participate in social activities were significantly more likely to report low mental health than those who participated in social activities (ORs=1.39). Among caregivers, respondents who did not engage in social participation are significantly more likely to report low mental health and CASP than those who engaged in such participation (ORs=1.31 and 1.27 respectively).

<Table 2 about here>

<Table 3 about here>

Among caregivers, the results of reporting fair or poor SRH in the multinomial regression models in Table 3 show that intense caregivers were more likely to report fair or poor SRH (ORs=1.72 and 2.23 respectively) (Model 1), and such patterns remained similar when the social participation variables were added into Model 2. Again, respondents who did not take part in social activities were more likely to report fair or poor SRH (ORs=1.42 and 2.29 respectively) than those who did (Model 2). After controlling for covariates, intense caregivers were still more likely to report fair SRH than non-intense caregivers (ORs=1.34 at 10% level); while, the effect of social participation on SRH appeared to become not statistically significant. In terms of reporting health problems, there were no significant differences between intense caregivers and non-intense-caregivers (Model 1 to Model 3); while, respondents who did not take part in social activities were still less likely to have health problems (ORs=0.84) and 0.75 in Model 2 and Model 3 respectively). For mental health outcomes, again, there were no significant differences between intense caregivers and non-intense-caregivers (Model 1 to Model 3). Respondents who did not engage in social participation were more likely to report low mental health than those who did (ORs=1.52 and 1.31 in Model 2 and Model 3 respectively). The results of reporting low CASP were similar to those reporting fair or poor SRH, intense caregivers were significantly more likely to report low CASP even when the social participation variables were controlled for (ORs=1.32 for Model 1 & 2); and respondents who did not take part in social activities were more likely to report fair or poor SRH (ORs=2.29) (Model 2). After controlling for covariates, there were no significant differences between intense caregivers and non-intense-caregivers on CASP; respondents who did not engage in social participation were more likely to report low CASP than those who did (ORs=1.27) (Table 4).

<Table 4 about here>

In order to better understand the effect of social participation on health outcomes between intense caregivers and non-intense caregivers, Table 5 presents the effect of social participation on health outcomes based on Model 3. Among non-intense caregivers, respondents who did not take part in social events are significantly more likely to report low mental health and CASP than those who did (ORs=1.28 and 1.26 respectively); among intense caregivers, respondents who did not engage in social participation are significantly more likely to report low mental health than those who did engage (ORs=1.62).

<Table 5 about here>

Qualitative analysis

The qualitative analysis found that caring had a detrimental effect on caregivers’ social life, as the caring activity is demanding and time-consuming, however a very low percentage of caregivers use respite services (Jones and Peters, 1992; Van Exel, de Graaf, & Brouwer, 2008). Consistent with the existing literature, this study found that time and energy were the two main barriers preventing the caregivers’ social participation. In addition, as caregivers were found to have a disadvantaged economic status, financial issues were the third factor which prevents caregivers from social participation (Arksey and Glendinning, 2008).

Theme 1: Time issue. Fifteen caregivers revealed that time is the barrier for them to be engaged in social participation. For those working caregivers, they have to juggle between work and caregiving and seldom had any spare time for social participation. The interviews also showed that; even for those who frequently conducted charity work, taking on the caring responsibility may squeeze their time for such social participation. For example, Case 026 worked full-time and had experienced her father’s health deterioration and death in the past year; she made a difficult decision to accommodate her mother who had severe dementia in a nursing home, but visited her daily to help with feeling “guilty”. When talking about her social participation, she mentioned that she “had done plenty of things with the church on a voluntary basis” before, but “since mother and father have become ill and things, I’ve had to just ease off and just concentrate on them really”.

A respondent (Case 187) who lived with and spent 7-24 hours caring his father also highlighted a similar time issue:

Q: And do you do any voluntary or charitable work?

A: I’ve not got time to do that [laughs].

Q: No, [laughs], I know after what you said.

A: I’m not saying I wouldn’t like to, but I just don’t have enough time for myself to devote a day or hours to do such a thing, you know. (Case 187)

Another respondent (Case 175) who also provided more than 20 hours of care per week for her parents mentioned that being at the “sandwich generation” stage of life, she has a responsibility to both parents and adult children, where her time after work was mainly spent:

Q: So over and above what you do to your--, for your mum, do you do any voluntary or charitable work?

A: Not really, no.

Q: No, any reason why you don’t do any?

A: I don’t think I’ve got the time, everything’s down to time. Because I am, what is it they call it, sandwich generation, I’ve got my mum on one side and then I’m quite close to my stepdaughter and, you know, I never ever thought that we would--, ‘cause I always thought that her mum would have more to do with {STEPDAUGHTER1}, but {STEPDAUGHTER1} comes here nine times out of ten, so you end up--, you don’t like to say no. (Case 175)

Theme 2: Energy issue

Most of the carers who were still in full-time employment had very busy lives juggling paid work and caregiving. When it came to weekends, they seldom had the energy to take on extra social participation especially when the activity was time-consuming. Case 052 was a single woman who worked full-time. Because her mother was vulnerable at the moment, she usually visited her mum every day after work and spent the Saturday helping her. She gave up her charitable work because “it was every Saturday” and so that she “only get Sunday off”. She constantly mentioned that she “felt really tired and drained” during the time “mum was not well” and that she herself did not “have a social life”. Likewise, Case 082 who reported caring for his parents-in-law in the quantitative data, but reported nearly no social participation in the qualitative data, explained that most of his jobs took place in another location and he had to commute for a long time; for his current job, he got the train just around seven in the morning and got home around seven in the evening on most days. He felt that other than his work and family, he did not have any energy for other activities.

Theme 3: Financial issues

Three caregivers revealed that finance is a barrier for them to engage in social participation. The high cost of being a member of clubs and associations has prevented some care-givers from continuing their social participation. As the two participants explained:

 “I’d say, yeah, it’s this Cardiff ex-servicemen’s club which I’ve been a member there for over 20 years, I used to work there for 12 years as a barman, doorman, cellar man, all sorts of work there, but it was great, but it was costing me money. I was having to leave my day job early just to make their start time by seven o’clock. I thought, well, this is stupid, it’s costing me money, although I was enjoying myself, it wasn’t work, it was a social event. I had to pack it in because it was costing me money.’” (Case042)

Q: Have you ever sort of, I don’t know, been in a music club or a gym or, I don’t know, evening classes?

A1: I was going to gym for some time actually. I had to give it up because it started to get a bit expensive with money being a bit tight and being a single parent of two teenage boys. (Case 152)

**Discussion and Conclusion**

This study investigated social participation and health outcomes among caregivers and non-caregivers in Great Britain and further examined social participation and health outcomes among intense and non-intense caregivers. The results show that there are no significant differences in the health outcomes between caregivers and non-caregivers. These are partly consistent with previous studies showing that caregivers are healthier or that there are no differences in the health outcomes among non-caregivers, reflecting the “healthy worker effect” whereby healthier individuals are more likely to be involved in a caring role (Vlachantoni et al., 2013; Vlachantoni et al., 2016; O’Reilly et al., 2008). In terms of health outcomes between intense caregivers and non-intense caregivers, intense caregivers were more likely to report fair or poor self-rated health and low CASP, which is consistent with Hirst’s (2005) findings. After controlling for demographic, socio-economic and social participation factors, apart from intense caregivers being still more likely to report fair SRH, there are no significant differences in the four health outcomes between intense caregivers and non-intense caregivers. This could reflect that the poor health outcomes among intense caregivers are explained by their potentially more vulnerable position (economically inactive, in ‘other’ house tenure, being in difficult financial situation, and do not have a car) (Vlachantoni et al., 2013).

After controlling for demographic and socio-economic effects on the carers’ health outcomes, there remain significantly positive effects of social participation on non-caregivers, caregivers, intense caregivers and non-intense caregivers’ mental health or CASP. People who did not engage in social participation were more likely to have low mental health or CASP, which is consistent with Sibalija’s study (2017) showing that social participation could influence the caregivers’ mental health. Social participation could provide emotional support, companionship, and affection for caregivers and protect them against health risks (Pinto, 2016). On the other hand, caregivers who participate in social activities could reflect that they have more time or resources to be engaged in these types of activities. This could be a proxy of proximal or family support in terms of the care provision, or a potential protective factor by itself. In addition, the qualitative results have provided new evidence in that time, energy and finance are considered to be barriers to social participation among carers in Great Britain, which enriched Pinto’s review (2016) and Innes et al’s (2016) study on barriers to leisure participation for people with dementia and their carers.

It is important to consider the paper’s limitations. Firstly, the survey lacks information about the health status of the respondent’s parents or parents-in-law and as such, it is not possible to explore how the health status of parents or parents-in-law could affect the health of caregivers. Secondly, the NCDS lacks information about how long the respondent has been a caregiver and whether they are in receipt of support with their caring role. Thirdly, NCDS is a cohort study which only followed respondents who were born in 1958, therefore it may not fully capture the experiences of the whole caregiving v/s non-caregiving population. This may have led to a degree of bias in the analysis as the samples compared do not have similar characteristics in critical variables. Nevertheless, the findings in this paper provide additional insight into the effects of social participation on health outcomes among caregivers in Great Britain.

The findings in this study have important policy implications. The health inequalities between intense caregivers and non-intense caregivers have been explained by potentially more vulnerable position of intense caregivers (economically inactive, being in difficult financial situation, and do not have a car) which reflect that the current carer’s allowance needs to be improved (Tostevin, 2015). Currently (April 2019), this benefit stands at £66.15 per week and only carers who provide at least 35 hours of care per week and do not earn over a certain threshold are eligible to receive it. Intense caregiving is associated with lower working hours and lower levels of labour force participation (Lilly, Laporte, & Coyte, 2007) which could place caregivers in a difficult financial situation, as the lack of financial resources could result in poor health outcomes of caregivers and thus influence the health of the care-recipient. Social participation has a potential protective effect against one’s mental health and CASP. It is important to ensure that caregivers (both intense caregivers and non-intense caregivers) in Great Britain are able to engage in social participation. To address the three main barriers to social participation (time, energy and finance) which the caregivers mentioned would need to place carers and these issues at the centre of the government policy agenda. For instance, having a break from the caring role through respite care could affect the caregiver’s receipt of the Carer’s Allowance, with specialist advice being critical (Age UK, 2018). Approach could be to simplify the rules relating to respite from care provision and provide guidelines for caregivers to engage in social participation, or develop home-based aerobic and resistance exercise programmes in order to improve individuals’ physical function and caregiving perceptions among caregivers (Gary, Dunbar, Higgins, Butts, Corwin, Hepburn, Butler, and Miller, 2018)

In conclusion, this is the first British study on the relationship between social participation and health outcomes between caregivers and non-caregivers, and the relationship between social participation and health outcomes between intense and non-intense caregivers. The population-level cohort analysis provides insight into how social participation influences health outcomes in Great Britain. Another unique contribution of the study is that the study identifies the view of social participation from the caregivers. The present study highlights the importance of social participation in improving caregivers’ mental health. Policy strategies and programmes must consider the three main barriers to social participation to encourage caregivers to engage in social participation, which could improve caregivers’ mental health.

**References**

Age UK. (2018). Respite care: having a break from caring. Webpage. Retrieved from: https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/respite-care/.

Arksey, H., & Glendinning, C. (2008). Combining work and care: Carers' decision-making in the context of competing policy pressures. *Social Policy & Administration, 42*(1), 1-18.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Burström, B., & Fredlund, P. (2001). Self rated health: Is it as good a predictor of subsequent mortality among adults in lower as well as in higher social classes? . *Journal of Epidemiology and Community Health, 55*(11), 836-840.

Creswell, J. W., & Clark, V. L. P. (2017). Designing and conducting mixed methods research: Sage publications.

Carers Trust. (2018). Key facts about carers and the people they care for. Online article. Retrieved from: https://carers.org/key-facts-about-carers-and-people-they-care.

Creswell, J.W. and Clark, V.L.P. (2017) *Designing and conducting mixed methods research*. London, UK: Sage publications.

Doran, T., Drever, F., & Whitehead, M. (2003). Health of young and elderly informal carers: analysis of UK census data. *British Medical Journal, 327*(7428), 1388-1388.

Elliott, J., Miles, A., Parsons, S., & Savage, M. (2010). The design and content of the ‘social participation study’: A qualitative sub-study conducted as part of the age 50 (2008) sweep of the national child development study. London: Centre for Longitudinal Studies.

Gomez-Leon, M., Evandrou, M., Falkingham, J., & Vlachantoni, A. (2019). The dynamics of social care and employment in mid-life. Ageing & Society, 39(2), 381-408.

Gremigni, P. (2013). Measurement Invariance of the Warwick-Edinburgh Mental Well-Being Scale and its Short form across UK and Italy. Online thesis. Retrieved from: *https://**[www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&ved=2ahUKEwiuu\_35x8LeAhWIW8AKHRWIBL4QFjACegQIBhAC&url=https%3A%2F%2Fpdfs.semanticscholar.org%2F628c%2Fc68159913d5e60f12a415a60f4af1c577346.pdf&usg=AOvVaw1-gc0-\_89WClHdOmfPSEZb](http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&ved=2ahUKEwiuu_35x8LeAhWIW8AKHRWIBL4QFjACegQIBhAC&url=https%3A%2F%2Fpdfs.semanticscholar.org%2F628c%2Fc68159913d5e60f12a415a60f4af1c577346.pdf&usg=AOvVaw1-gc0-_89WClHdOmfPSEZb)*.

Donkers,H., Vernooij-Dassen, M., Van Der Veen, d. & N. V. D., S., M. & Graff, M. (2018). Social participation perspectives of people with cognitive problems and their care-givers: a descriptive qualitative study. *Ageing and Society*. Online article. Retrieved from <https://www.cambridge.org/core/journals/ageing-and-society/article/social-participation-perspectives-of-people-with-cognitive-problems-and-their-caregivers-a-descriptive-qualitative-study/B52668495E1C37FA615F49B30065DF13#fndtn-information>.

Fider, C. R. A., Lee, J. W., Gleason, P. C., & Jones, P. (2017). Influence of Religion on Later Burden and Health of New Black and White Caregivers. *Journal of Applied Gerontology, 38*(9), 1282–1303.

Gary, R., Dunbar, S. B., Higgins, M., Butts, B., Corwin, E., Hepburn, K., Miller, A. H. (2018). An Intervention to Improve Physical Function and Caregiver Perceptions in Family Caregivers of Persons With Heart Failure *Journal of Applied Gerontology*, ﻿1–23.

Greenwood, N., Mezey, G., & Smith, R. (2018). Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas,* 112, 39-45.

Hirst, M. (2004). Health inequalities and informal care: end of project report *Social Policy Reearch Unit*. Online report. Retrieved from: <https://www.york.ac.uk/inst/spru/pubs/pdf/healthinequalities.pdf>.

Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science & Medicine, 61*(3), 697-708.

Innes, A., Page, S. J., & Cutler, C. (2016). Barriers to leisure participation for people with dementia and their carers: An exploratory analysis of carer and people with dementia's experiences. *Dementia-International Journal of Social Research and Practice, 15*(6), 1643-1665.

Jones, D. A., & Peters, T. J. (1992). Caring for Elderly Dependents - Effects on the Carers Quality-of-Life. *Age and Ageing, 21*(6), 421-428.

Kafkova, M. P., Vidovicova, L., & Wija, P. (2018). Older Adults and Civic Engagement in Rural Areas of the Czech Republic. *European Countryside, 10*(2), 247-262. doi: 10.2478/euco-2018-0015

Kelley, D., Lewis, M., & Southwell, B. (2017). Perceived support from a caregiver's social ties predicts subsequent care-recipient health. *Preventive Medicine Reports*, 108-111.

Levasseur, M., Richard, L., Gauvin, L., & Raymond, E. (2010). Inventory and analysis of definitions of social participation found in the aging literature: Proposed taxonomy of social activities. *Social Science & Medicine, 71*(12), 2141-2149.

Lilly, M. B., Laporte, A., & Coyte, P. C. (2007). Labor market work and home care's unpaid caregivers: A systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *Milbank Quarterly, 85*(4), 641-690.

O'Reilly, D., Connolly, S., Rosato, M., & Patterson, C. (2008). Is caring associated with an increased risk of mortality? A longitudinal study. *Social Science & Medicine, 67*(8), 1282-1290.

Office of National Statustics (ONS). (2017). Unpaid carers provide social care worth £57 billion In ONS (Ed.). Online article, Retrieved from: https://[www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10).

Pickard, L., Wittenberg, R., Comas-Herrera, A., Davies, B., & Darton, R. (2000). Relying on informal care in the new century? Informal care for elderly people in England to 2031. *Ageing and Society, 20*, 745-772.

Pinto, J. M. (2016). Barriers to social participation in caregivers of older people: A systematic review. *Research in Health Science, 1*(2), 78-84.

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies. *Gerontologist, 55*(2), 309-319.

Sibalija, J. (2017). *Social Support, Social Participation, and Depression among Caregivers and Non-Caregivers in Canada: A Population Health Perspective.* PhD thesis, The University of Western Ontario, Western Ontario.

Tostevin, A. (2015). Carer’s Allowance – pleased to say it’s not perfect. It can be improved. Online article. Retrieved from: <https://dwpdigital.blog.gov.uk/2015/06/12/carers-allowance-its-not-perfect-it-can-be-improved/>.

Van Exel, J., de Graaf, G., & Brouwer, W. (2008). Give me a break! Informal caregiver attitudes towards respite care. *Health Policy*, 88(1), 73-87.

Vlachantoni, A., Evandrou, M., Falkingham, J., & Robards, J. (2013). Informal care, health and mortality. Maturitas, 74(2), 114-118. doi: 10.1016/j.maturitas.2012.10.013

Vlachantoni, A., Robards, J., Falkingham, J., & Evandrou, M. (2016). Trajectories of informal care and health. Social science & Medicine: Population Health, 2, 495-501.

Warwick Medical School (2015). Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). Webpage. Retrieved from: <https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/>.

Wiggins, R. D., Netuveli, G., Hyde, M., Higgs, P., & Blane, D. (2008). The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches. *Social Indicators Research, 89*(1), 61-77.

World Health Organization. (2007). Global age-friendly cities: A guide. Online report. Retrieved from: <http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf>.

**Table 1 Descriptive analysis between intense and non-intense caregivers (N=7,333)**

|  |  |  |
| --- | --- | --- |
|   | Whether a caregiver | Whether an intense caregiver  |
|   | No | Yes | Non-intense caregiver | Intense caregiver |
| Total N | 3,360 | 3,973 | 3,509 | 464 |
| **Gender** |   | \*\*\* |
| Male | 48.5% | 50.1% | 52.4% | 32.8% |
| Female | 51.5% | 49.9% | 47.7% | 67.2% |
| **Marital status** | \*\* | \*\*\* |
| Single never married | 8.9% | 9.1% | 7.9% | 18.1% |
| Married | 72.4% | 74.8% | 76.1% | 64.9% |
| Separated/Divorced | 17.4% | 15.0% | 15.0% | 15.5% |
| Widowed | 1.4% | 1.1% | 1.1% | 1.5% |
| **Living arrangements** | \*\*\* | \*\*\* |
| Living with partner | 84.0% | 84.0% | 85.6% | 72.0% |
| Living with others | 7.3% | 9.3% | 7.8% | 20.5% |
| Living alone | 8.7% | 6.6% | 6.5% | 7.5% |
| **Economic activity** |   | \*\*\* |
| Full-time employment | 69.2% | 68.4% | 70.5% | 53.0% |
| Part-time employment | 17.6% | 17.9% | 17.4% | 22.0% |
| Others | 13.2% | 13.7% | 12.2% | 25.0% |
| **Housing tenure** | \*\*\* | \*\*\* |
| Own outright | 23.9% | 25.3% | 24.8% | 29.5% |
| Own with mortgage | 61.8% | 61.7% | 63.4% | 48.5% |
| Rent | 12.8% | 10.8% | 10.0% | 16.8% |
| Others | 1.6% | 2.2% | 1.8% | 5.2% |
| **Financial situation** |   | \*\*\* |
| Living comfortably | 42.2% | 41.1% | 41.6% | 37.7% |
| Doing all right | 30.1% | 31.6% | 31.9% | 29.3% |
| Just about getting by | 19.7% | 20.6% | 20.3% | 23.1% |
| Finding it difficult | 8.0% | 6.7% | 6.3% | 9.9% |
| **Exercises regularly** | \*\*\* | \*\*\* |
| Yes | 77.1% | 79.7% | 80.4% | 74.6% |
| No | 23.0% | 20.3% | 19.6% | 25.4% |
| **Whether household has access to car/van** | \*\*\* | \*\*\* |
| No | 6.1% | 3.9% | 3.5% | 7.3% |
| Yes | 93.9% | 96.1% | 96.6% | 92.7% |
| **Whether takes part in the activities of the organisation (Social participation)** | \*\*\* |   |
| No | 50.2% | 47.1% | 46.9% | 48.5% |
| Yes | 49.8% | 52.9% | 53.1% | 51.5% |

Source: Authors’ analysis of NCDS wave 8**. Pearson’s χ2 test was applied for this descriptive analysis.**\*\*\*p<0.01, \*\*p<0.05, \*p<0.1

**Table 2 Logistic regression for health outcomes between caregivers and non-caregivers (N=7,333)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|   |   | A1 Fair SRH | A2 Poor SRH | B Has health problem | C Has low mental health | D Has low CASP |
|   |   | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI |
| Model 1 | Non-caregivers (ref: caregivers) | 1.02 | (0.88-1.18) | 1.20 | (0.97-1.50) | 0.90 | (0.79-1.02) | 1.08 | (0.97-1.20) | 1.00 | (0.91-1.10) |
| Model 2 | Non-caregivers (ref: caregivers) | 1.01 | (0.87-1.17) | 1.17 | (0.94-1.46) | 0.90 | (0.79-1.03) | 1.06 | (0.95-1.18) | 0.99 | (0.90-1.08) |
| Did not engage in social participation (ref: Yes) | 1.43\*\*\* | (1.23-1.65) | 2.42\*\*\* | (1.91-3.06) | 0.93 | (0.82-1.06) | 1.63\*\*\* | (1.47-1.81) | 1.54\*\*\* | (1.40-1.69) |
| Model 3  | Non-caregivers (ref: caregivers) | 0.97 | (0.83-1.13) | 1.13 | (0.89-1.45) | 0.88 | (0.78-1.01) | 1.04 | (0.93-1.16) | 0.97 | (0.88-1.08) |
| Did not engage in social participation (ref: Yes) | 0.97 | (0.82-1.14) | 1.26\* | (0.97-1.64) | 0.85\*\* | (0.74-0.97) | 1.35\*\*\* | (1.20-1.51) | 1.24\*\*\* | (1.12-1.38) |

Notes: Model 3 controlled for the following variables: gender, marital status, living arrangements, economic activity, housing tenures, financial situation, regularity of exercise, household access to car/ van. \*\*\*p<0.01, \*\*p<0.05, \*p<0.1;Source: Authors’ analysis of NCDS wave 8

**Table 3 Logistic regression of the effect of social participation on health outcomes, (by non-carers and carers, based on Model 3) (N= 3,360 Non-carers; 3,973 carers)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|   |   | A1 Fair SRH | A2 Poor SRH | B Has health problem | C Has low mental health | D Has low CASP |
|   |   | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI |
| Non-carers | Did not take part in social participation (ref: Yes) | 0.92 | (0.72-1.17) | 1.01 | (0.76-1.69) | 0.98 | (0.80-1.19) | 1.39\*\*\* | (1.17-1.64) | 1.20\*\* | (1.03-1.40) |
| Carers | Did not take part in social participation (ref: Yes) | 1.13 | (0.82-1.25) | 1.34 | (0.93-1.92) | 0.75\*\*\* | (0.62-0.90) | 1.31\*\*\* | (1.12-1.53) | 1.27\*\* | (1.11-1.46) |

\*\*\*p<0.01, \*\*p<0.05, \*p<0.1

Source: Authors’ analysis of NCDS wave 8

**Table 4 Among caregivers, logistic regression for health outcomes between intense of care and non- intense of care (N=3,973)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|   |   | A1 Fair SRH | A2 Poor SRH | B Has health problem | C Has low mental health | D Has low CASP |
|   |   | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI |
| Model 1 | Intense caregivers (ref: Non- intense caregivers) | 1.72\*\*\* | (1.31-2.25) | 2.23\*\*\* | (1.52-3.29) | 1.10 | (0.82-1.45) | 1.22 | (0.97-1.50) | 1.32\*\*\* | (1.09-1.60) |
| Model 2 | Intense caregivers (ref: Non- intense caregivers) | 1.71\*\*\* | (1.30-2.25) | 2.23\*\*\* | (1.51-3.29) | 1.10 | (0.83-1.46) | 1.21 | (0.97-1.50) | 1.32\*\*\* | (1.08-1.60) |
| Did not engage in social participation (ref: Yes) | 1.42\*\*\* | (1.16-1.73) | 2.29\*\*\* | (1.65-3.17) | 0.84\* | (0.70-1.01) | 1.52\*\*\* | (1.32-1.76) | 1.49\*\*\* | (1.32-1.69) |
| Model 3  | Intense caregivers (ref: Non- intense caregivers) | 1.34\* | (0.99-1.80) | 1.42 | (0.91-2.23) | 1.08 | (0.80-1.45) | 1.00 | (0.79-1.27) | 1.13 | (0.91-1.40) |
| Did not engage in social participation (ref: Yes) | 1.02 | (0.82-1.26) | 1.35 | (0.94-1.95) | 0.75\*\*\* | (0.62-0.90) | 1.31\*\*\* | (1.12-1.53) | 1.27\*\* | (1.11-1.46) |

Notes: In Model 3, the controlled variables: gender, marital status, living arrangements, economically active, house tenures, financial situation, exercises regularly, household has car(s).

\*\*\*p<0.01, \*\*p<0.05, \*p<0.1

Source: Authors’ analysis of NCDS wave 8

**Table 5 Among caregivers, logistic regression of the effect of social participation on health outcomes, (by Non- intense caregivers and intense caregivers) (Based on Model 3) (N=3,973)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|   |   | A1 Fair SRH | A2 Poor SRH | B Has health problem | C Has low mental health | D Has low CASP |
|   |   | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI | ORs | 95% CI |
| Non-intense caregivers | Did not engage in social participation (ref: Yes) | 1.08 | (0.85-1.36) | 0.70 | (0.95-2.16) | 0.77\*\* | (0.64-0.94) | 1.28\*\*\* | (1.08-1.51) | 1.26\*\* | (1.09-1.46) |
| Intense caregivers | Did not engage in social participation (ref: Yes) | 1.44 | (0.39-1.26) | 0.98 | (0.42-2.26) | 0.55\*\* | (0.31-0.99) | 1.62\*\* | (1.03-2.55) | 1.37 | (0.91-2.09) |

\*\*\*p<0.01, \*\*p<0.05, \*p<0.1

Source: Authors’ analysis of NCDS wave 8