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Biographical Compromise When Living with a Chronic Condition and Caring for Someone with Cancer – A Grounded Theory Analysis

by

Daren Chircop

Thesis for the degree of Doctor of Philosophy in Health Sciences

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Abstract

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The number of carers caring for a patient with cancer and at the same time, having a chronic condition is on the rise. These carers are at a higher risk of experiencing health problems and hence, being unable to provide high quality care to the patient. Furthermore, there is a paucity of information on how carers live with their conditions, whilst caring for someone with cancer.

Twenty-seven participants were recruited in this study. In-depth interviewing following an interview guide was the predominant mode of data collection. Constructivist grounded theory methodology was used to guide data collection and analysis. The qualitative data analysis programme NVIVO Version 12 was used to manage the organisation of the data.

The theory of biographical compromise emerged from the data. The core category of this theory is 'Making Concessions', which describes how carers try to reach a compromise between living with their chronic conditions and the caregiving situation. They do so by doing the bare minimum, which allows carers to maintain a sense of control over their conditions and at the same time, do not allow their conditions to interfere with the patient's care. The extent of this compromise depends on three sets of contextual factors: (i) the characteristic features of the caregiving role; (ii) the social context; and (iii) the personal context. This core category relates to three major categories: 'Feeling Obliged', 'Changing Biography', and 'Minimising Interference'.

The study findings contribute to knowledge by merging the two processes of living with a chronic condition and caring for a patient with cancer into one process, that of biographical compromise. The empirical literature tends to explain these processes separately and does not explain how these experiences are intertwined. Furthermore, the theory of biographical compromise highlights which contextual factors impact this process. Hence, it provides important information which can be utilised to develop carer assessment tools to identify those carers who are struggling more and provide the necessary support as early as possible. The study findings also illustrate how all the carers in this study would prefer health care professionals to assist them

directly in the management of their conditions and hence, this emphasises the importance of integrating the care of the carer as part of the overall care plan of the patient with cancer.

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Research Thesis: Declaration of Authorship

Print name: Daren Chircop

Title of thesis: Biographical Compromise When Living with a Chronic Condition and Caring for Someone with Cancer – A Grounded Theory Analysis

I declare that this thesis and the work presented in it are 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;
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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. None of this work has been published before submission.

Signature: .... Date: 10 May 2023

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Abbreviations

ADLs	Activities of Daily Living
AMED	Allied and Complementary Medicine Database
AMSTAR 2	A Measurement Tool to Assess Systematic Reviews 2
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DALYs	Disability-Adjusted Life Years
EU	European Union
FREC	Faculty Research Ethics Committee
GBD	Global Burden of Disease Study
IADLs	Instrumental Activities of Daily Living
INSA	International Narrative Systematic Assessment
NCRI	National Cancer Research Institute
NHS	National Health Service
NHSS	National Health System Strategy
ONS	Oncology Nursing Society
PICOS	Participants, Interventions, Comparators, Outcomes, and Study Design
PRESS	Peer Review of Electronic Search Strategies
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analyses
RAISE Act	Recognize, Assist, Include, Support, and Engage Family Caregivers Act
UK	United Kingdom
US	United States
WHO	World Health Organisation

Chapter 1 Introduction

1.1 Background

Chronic conditions cause 71% of all global deaths each year, with 77% of these deaths occurring in low- and middle-income countries. Chronic conditions are often associated with the elderly however, each year, more than 15 million people die from chronic conditions between the ages of 30 and 69 years, with 85% of these 'premature' deaths occurring in low- and middle-income countries (World Health Organisation, 2021). Consequently, chronic conditions are the main contributor to increasing health loss worldwide as measured by disability-adjusted life years (DALYs), that is, the sum of years lost due to premature mortality and years lived with disability (Global Burden of Disease Study Collaborators, 2020). Furthermore, in addition to the enormous burden of suffering of chronic conditions, it is estimated that the global economic burden of these conditions could reach US$47 trillion by 2030 (Bloom *et al.*, 2011). As a result, due to the burden that chronic conditions pose, especially in low- and middle-income countries, and the effect that this could have on increasing inequalities between countries, the prevention and management of these conditions is considered a global health priority (Hajat and Stein, 2018). Unless immediate action is taken to prevent and manage chronic conditions, the world is heading for financial and health crises.

In 2013, the 66th annual World Health Assembly endorsed the World Health Organisation (WHO) Global Action Plan for the prevention and management of chronic conditions, with the aim of providing countries with a road map of how to reach nine global targets for chronic conditions by 2025. One of these targets is a 25% reduction in 'premature' deaths caused by four major chronic conditions – cancer, cardiovascular diseases, chronic respiratory diseases, and diabetes (WHO, 2013). These four major chronic conditions account for more than 80% of all 'premature' deaths caused by chronic conditions (WHO, 2021). To reach this target, the WHO Global Action Plan emphasised the need to develop new and improve existing interventions for the prevention and management of chronic conditions (WHO, 2013).

Nevertheless, despite a global effort to reach this target, recent data from the Global Burden of Disease (GBD) Study show that the number of deaths from chronic conditions is still on the rise, especially in low- and middle-income countries. Moreover, the authors of the GBD Study also warn that health care systems are not well-equipped to face the challenges posed by the increasing burden of these conditions. They emphasise the need for new and more effective interventions to tackle these challenges (GBD Study Collaborators, 2020). Therefore, using the context of the findings by GBD Study Collaborators (2020), it can be argued that further research is needed on chronic conditions to help develop such interventions.

1.2 Chronic Conditions

WHO (2021) defines chronic conditions as slow progressive diseases that are of long duration. They are often incurable and hence, treatment goals focus on the management of symptoms (Lebel *et al.*, 2020). Types of chronic conditions include arthritis, asthma, diabetes, and hypertension, as well as reoccurring lower back pain, and chronic migraines (Bernell and Howard, 2016). Chronic conditions can limit the ability of the patient to carry out basic self-care tasks, called activities of daily living (ADLs), such as bathing, dressing, or eating. Additionally, chronic conditions can limit the ability of the patient to carry out instrumental activities of daily living (IADLs), such as doing household chores, preparing meals, or managing money (Sharma, Maurya and Muhammad, 2021).

Due to advancements in health care, more people are now living with one or more chronic conditions for longer periods of time (Pizzoli *et al.*, 2019). Consequently, patients with chronic conditions may often need long-term care, which often falls on unpaid, informal carers, such as family members, friends, or neighbours (Berry, Dalwadi and Jacobson, 2017). This care saves health care systems worldwide billions in health care costs. For example, in the United Kingdom (UK), carers save the health care system £132 billion per year, whilst in the United States (US), they save the health care system US$470 billion per year (Adashek and Subbiah, 2020; Buckner and Yeandle, 2015). Therefore, it can be argued that understanding how best to support carers of patients with chronic conditions is vital (Kent *et al.*, 2016). Nevertheless, Jika, Khan and Lawal (2021) highlighted that although there is increasing research, as well as policy development on how to support carers, carers are still not officially recognised as important contributors to the health care system. As a result, further research is still needed in this area to inform policy, especially qualitative research which is lacking. Such research can shed light on carers' experiences and lead to the implementation of interventions which can assist these carers to continue caring for the patient with a chronic condition (Jika *et al.*, 2021).

1.3 Carers of Patients with Chronic Conditions

Caring for someone with a chronic condition brings with it increased responsibilities and demands for the carer. Carers provide physical, emotional, and financial support to the patient with a chronic condition, frequently without training, recognition, or support, and with little to no financial reimbursement (Goldberg and Rickler, 2011). This support may include collecting prescriptions from the pharmacy, shopping, doing housework, accompanying or providing transportation for the patient to hospital appointments, finding information, and talking to health care professionals on the patient's behalf. Additionally, they may provide personal care to the patient, such as feeding, toileting, dressing, and showering, as well as assisting in health care related tasks, such as treatment management. Moreover, they also provide emotional support by listening and talking to the patient, as well as financial support as exemplified by managing the family finances and paying bills (Amir *et al.*, 2012; Lund *et al.*, 2014; Nicholls, Hulbert-Williams and Bramwell, 2014; Partanen, Lemetti and Haavisto, 2018; Soothill *et al.*, 2001; Ullgren *et al.*, 2018; Yabroff and Kim, 2009). Carers also need to take on additional responsibilities which were previously performed by the patient, such as housework, meal preparation, or being the designated family driver (Ussher, Tim Wong and Perz, 2010). Therefore, caring for someone with a chronic condition can be exhausting and stressful. Given the relationship between stress and health, several researchers have studied the relationship between chronic condition caregiving and physical and emotional health problems in the carer using stress process models, as described in the next section.

1.4 Chronic Condition Caregiving and Stress Process Models

The application of stress process models enables researchers to understand the relationship between the responsibilities and demands involved in caring for someone with a chronic condition and stress, and the effect of this stress on the physical and emotional health of carers. The three most widely accepted theoretical models on stress in the field of caregiving are: Lazarus and Folkman's Transactional Stress Theory adapted to caregiving (Haley *et al.*, 1987), Stress Process Model (Pearlin *et al.*, 1990), and Theory of Coherence (Antonovsky, 1987). According to these stress process models, stress is a relationship between the individual and his or her environment. A particular situation becomes stressful for the individual when the demands of the environment exceed his or her resources or jeopardize his or her physical and emotional well-being. The individual determines whether a particular situation is stressful or not through cognitive appraisal. This cognitive appraisal also determines how the individual copes with the stressful situation. Background and contextual variables, such as age or socioeconomic status, impact this cognitive appraisal. Furthermore, other mediators, such as social support and self-efficacy, buffer the effect of the stress on the physical and emotional well-being of the individual (Antonovsky, 1987; Haley *et al.*, 1987; Pearlin *et al.*, 1990).

Considering the increased demands of caregiving and the fact that carers often take up this role without previous experience or training, and with no formal support or financial help, then chronic condition caregiving does qualify as a stressful situation (Cochrane *et al.*, 2021; Goldberg and Rickler, 2011; Kim and Schulz, 2008; Pinquart and Sörensen, 2003). Carers often take on the caregiving role without being aware of the demands of this role and the physical, emotional, social, and financial burden that this may create. Consequently, despite their efforts to manage such demands, these may inadvertently exceed their capabilities and resources resulting in stress for the carers. Therefore, it can be argued that carers are at risk of experiencing physical and emotional health problems which can lead carers to a breaking point, beyond which that they can no longer provide adequate care to the patient (Kim and Schulz, 2008; Pinquart and Sörensen, 2003).

1.5 Health Problems in Carers of Patients with Chronic Conditions

The negative effects of caring for someone with a chronic condition have been well documented. In their meta-analysis of 84 papers, Pinquart and Sörensen (2003) found that carers experience significantly higher levels of depression and lower levels of physical health than individuals who are not carers. Other researchers have observed physiological changes, such as escalated reactivity of the sympathetic nervous system and an increased production of circulating inflammatory markers, in carers of patients with chronic conditions when compared to non-carers (Mills *et al.*, 2004; von Känel *et al.*, 2012). These have been associated with an increased diagnoses of cardiovascular problems, such as hypertension and coronary artery disease (von Känel *et al.*, 2008). Additionally, research has also demonstrated that these physiological changes can lead to impaired immunological function and hence, carers have more infectious episodes than non-carers (von Känel *et al.*, 2012). Moreover, it has been demonstrated that carers are more frequently overweight and smokers when compared to individuals who do not have caregiving responsibilities (Laks *et al.*, 2016; Shiue and Sand, 2017).

Considering that carers in good health are at risk of physical and emotional health problems after taking up the caregiving role, then it only makes sense to consider those carers who have existing health problems as being at a higher risk of experiencing health deterioration. In fact, Kenny, King and Hall (2014) found that having a pre-existing chronic condition significantly contributes to carers experiencing a deterioration in their physical health. In their study on carers across Wales, Tommis *et al.* (2009) also found that carers with chronic conditions experienced a decline in their physical health over time. On the other hand, the physical health of carers without pre-existing health problems remained stable (Tommis *et al.*, 2009). In addition, recent studies on the impact of carers' chronic conditions on the caregiving role have demonstrated that carers find it difficult to care for themselves and at the same time, care for the patient, especially when they have multiple chronic conditions that require complex management (Polenick *et al.*, 2020; Polenick *et al.*, 2022). Furthermore, carers have found it even more difficult to live with their chronic conditions during the COVID-19 pandemic. In the study by Polenick *et al.* (2022), carers reported worse physical health, greater pain intensity, and less healthy eating since the pandemic. Additionally, the COVID-19 pandemic made it more difficult for carers to obtain in-home assistance with medical and nursing tasks and thus, carers had to take on the responsibility of these often stressful and challenging tasks. Consequently, carers devoted less time to the management of their chronic conditions leading to detrimental consequences for their health (Polenick *et al.*, 2022). In addition, unhealthy behaviours, such as cigarette smoking, and the psychological distress associated with the caregiving role may further worsen the carer's chronic conditions (Megari, 2013). Therefore, using the context of these findings, it can be argued that carers with pre-existing chronic conditions are at an increased risk of experiencing further health problems, whilst caring for the patient with a chronic condition. This can have strong implications for the carer's health and for the quality of care they provide to the patient, as described below (Polenick *et al.*, 2022).

Firstly, carers may be unable to continue caring for the patient which may require the patient to be admitted to hospital and hence, stretching already limited in-hospital services. Research has demonstrated that carer health and well-being are correlated with the quality of care they provide to the patient. The literature suggests that carers with fair to poor health or having a serious health problem are more likely to have difficulty providing care, especially higher intensity care, to patients when compared to healthy carers (Litzelman *et al.*, 2016; Navaie-Waliser *et al.*, 2002). Furthermore, Segrin and Badger (2014) found that if the carer's quality of life declines, the same is likely to occur to the patient's. Therefore, understanding how to support these carers to live with their chronic conditions and thus, improve their quality of life, may indirectly be beneficial to patients as well (Segrin and Badger, 2014; Streck *et al.*, 2020). Secondly, carers may require emergency hospital admissions and use of health care services themselves because of their chronic conditions and thus, further increasing the financial burden on health care systems. Moreover, carers can continue to care for the patient in the community rather than in an institutional setting, hence further reducing health care costs (Kitrungroter and Cohen, 2006; Partanen *et al.*, 2018).

1.6 Problem Statement

The desire to minimise unnecessary and costly hospital admissions is driving the development of policies that support patients with chronic conditions within their communities. In fact, the WHO Global Action Plan emphasised the need to improve community services for the prevention and management of chronic conditions (WHO, 2013). Nevertheless, although this change in provision of care from inpatient to outpatient settings increases reliance on carers, surprisingly, the WHO

Global Action Plan did not report specifically on carers. In addition, recent research has demonstrated that carers are still not officially recognised as important contributors to health care systems worldwide and new interventions are needed to support these carers (Jika *et al.*, 2021). This is imperative since the number of chronic conditions is increasing and thus, more people will have to take up the caregiving role. Furthermore, considering that before the COVID-19 pandemic, more than 95% of the worldwide population had a health problem, then it is likely that most carers are living with a chronic condition themselves (GBD Study Collaborators, 2015). In fact, in a study on carers of patients with dementia, Wang, Robinson and Carter-Harris (2014) found that 81.5% of the carers reported having at least one chronic condition, whilst 60.5% reported having at least two or more chronic conditions. In another study by Jowsey *et al.* (2013), as many as 96.2% of the carers had at least one chronic condition. Carers with pre-existing chronic conditions are more likely to experience health deterioration and find it difficult to provide high quality patient care when compared to healthy carers (Geng *et al.*, 2018; Litzelman *et al.*, 2016; Navaie-Waliser *et al.*, 2002; Polenick *et al.*, 2020; Polenick *et al.*, 2022; Tommis *et al.*, 2009). In their scoping review of the experiences of older adults with cancer who are caring for their spouses, Donison *et al.* (2021) found that carers often refuse the recommended cancer treatment in order to care for their spouses, jeopardising their health. Moreover, Navaie-Waliser *et al.* (2002) found that carers with fair to poor health or having a serious health problem are less likely to report that their physical health had suffered since becoming a carer than healthy carers.

Therefore, using the context of these findings, it can be argued that further research is needed on the experiences of carers with pre-existing chronic conditions. Such research can help health care professionals to develop interventions to support these carers so that they can continue caring for the patient with a chronic condition, whilst at the same time care for themselves and hence, continue to alleviate the financial burden on health care systems worldwide.

1.7 Cancer

WHO (2021) lists cancer as one of the four major types of chronic conditions worldwide. During the past decade, cancer has remained one of the main contributors to total global DALYs, rising from third place in 2010 to second place in 2019, remaining second only to cardiovascular diseases. However, in high-income countries, cancer has surpassed cardiovascular disease in relation to DALYs and has become the leading cause of total disease burden in 2019 (GBD Study Collaborators, 2020). This means that patients with cancer are now living more years in poor health and hence, may require long-term care. As advances in cancer treatments and the need to decrease the financial toll on health care systems shift the provision of treatment from inpatient to outpatient settings, most of this long-term care falls on carers (Adashek and Subbiah, 2020;

Berry *et al.*, 2017; Given, Given and Kozachik, 2001). In fact, the steady move to outpatient settings means that patients have fewer points of contact with the clinical team and hence, the majority of the care falls on carers, which leaves carers with less time for caring for their own health problems (Adashek and Subbiah, 2020). Considering that the global cancer burden is expected to be 28.4 million cases in 2040, a 47% rise from 2020, it makes sense to consider that more carers will need to take up the cancer caregiving role (Sung *et al.*, 2021). Therefore, further research is needed to develop and improve existing interventions to support carers, especially those already living with a pre-existing chronic condition.

1.8 Carers of Patients with Cancer

Macmillan Cancer Support (2016a) defines a ‘carer of a patient with cancer’ as someone who provides unpaid support to a family member or friend with cancer and this support is not part of paid work or voluntary service. At present, in the UK, 1.5 million carers who are 16 years or older are providing unpaid care to someone with cancer. This number is increasing at a rate of 3% per year, as the number of patients diagnosed with cancer increases (Macmillan Cancer Support, 2016b).

The care provided by carers of patients with cancer can add up to a considerable number of hours per week. In the UK, the average amount of care provided by carers of patients with cancer is estimated at 17.5 hours per week (Macmillan Cancer Support, 2016b). In addition to this care, it is likely that these carers also have to spend time caring for their own health problems. In fact, in their study on chronic conditions among advanced cancer patients and their spouse carers, Ketcher, Otto and Reblin (2019) found that 36% of the carers reported having at least one chronic condition, whilst 41% reported having at least two chronic conditions. The most common chronic conditions among carers of patients with cancer include arthritis, cancer, chronic back pain, diabetes, heart disease, high cholesterol, and hypertension (Ketcher *et al.*, 2019; Kim *et al.*, 2013). However, due to the high burden of the cancer caregiving role, carers often neglect their own health which often leads to health complications and decreases their ability to continue caring for the patient with cancer (Stenberg, Ruland and Miaskowski, 2010). Ipsos MORI and Macmillan Cancer Support (2011) reported that more than half of the carers (51%) in the UK report that they have let a health care problem go untreated whilst caring for someone with cancer. Therefore, with the expected growth in the number of carers, the substantial burden endured, and the fact that carers are critical for the delivery of sustainable cancer care, then cancer caregiving is considered as a public health priority (Harrison *et al.*, 2021; Lambert, Levesque and Girgis, 2016). In fact, The Five Year Forward View report by the National Health Service (NHS) (2014, p.13) highlights the “*underappreciated contribution*” of carers to both patients and the sustainability of

NHS services. Hence, it is imperative that further research is conducted on the experience of these carers to help health care professionals develop interventions that can assist these carers in continuing to care for the patient with cancer and at the same time, living with their chronic conditions. Such research would be mostly important for nurses who are often at the forefront of care delivery to the patient with cancer, as seen by the increase in nurse-led clinics in recent years and who would therefore, be in the best position to identify carers who are struggling and assist them (Farrell *et al.*, 2011).

1.9 Cancer Versus Other Chronic Conditions

The decision to focus on cancer carers in this doctoral research did not only rest on the fact that cancer is becoming the leading cause of total disease burden worldwide, but it also rested on the debate that exists about whether cancer should be considered a chronic condition or not. Whilst WHO (2021) lists cancer as a type of chronic condition since cancer is often treated over a number of months, sometimes even years, researchers argue that it may not be appropriate to label cancer as a chronic condition (Pizzoli *et al.*, 2019; Tritter and Calnan, 2002). Firstly, chronic conditions are diseases of long duration and slow progression, which require ongoing treatment and impact the patient's quality of life (Lebel *et al.*, 2020; WHO, 2021). This definition may apply to some types of cancers, such as chronic leukaemias, where patients must adhere to life-long treatment which impacts their quality of life (Schwarz, Roeder and Seifert, 2022). On the other hand, other types of cancers, such as acute leukaemias and pancreatic cancer, do not fall under this definition because of their rapid progression and high mortality rates within the first few months of diagnosis (Rawla, Sunkara and Gadaputi, 2019; Thakral *et al.*, 2020). Therefore, the significant variability that exists between different types of cancers makes it difficult to label cancer as 'chronic', especially since the term 'cancer' is an umbrella term for a group of diseases, rather than a single disease (Tritter and Calnan, 2002). Secondly, Tritter and Calnan (2002) highlight that there are both chronic and acute phases in the cancer trajectory. They argue that, although the treatment and survivorship phases of the cancer trajectory may be considered as chronic phases due to their long duration, the initial cancer diagnosis is clearly acute because the patient is referred immediately for treatment. This contrasts the diagnosis of chronic conditions which is often characterised by a gradual onset and progression (Tritter and Calnan, 2002). Therefore, these researchers argue that the label 'chronic' should be used with caution when referring to cancer (Pizzoli *et al.*, 2019; Tritter and Calnan, 2002).

There are other features which distinguish cancer from chronic conditions. Often times, patients with cancer have to start treatment immediately and this treatment is often more complex and intensive than the treatment for other chronic conditions, involving different treatment modalities, such as chemotherapy and radiotherapy amongst others. Such treatments may be provided at different sites and may require the patient to be admitted to hospital or attend day ward clinics (Tritter and Calnan, 2002). Additionally, carers may be required to perform complex medical tasks due to the side effects of cancer treatment, such as catheter care, or managing patients' emesis or fatigue symptoms (Kim and Schulz, 2008). Moreover, the rapid progression of some types of cancers do not allow carers to prepare for the upheavals that a cancer diagnosis and its treatment bring to their daily life and physical and mental well-being (Rajaei *et al.*, 2022). It can be argued that cancer and chronic conditions can actually be considered as two separate substantial areas of interest. Hence, taking into consideration this debate, it was decided to focus on cancer caregiving and exclude other carers who provide care to patients with other chronic conditions or functional limitations.

The decision to focus on cancer caregiving was further justified by the several research priorities in cancer care published by various organisations and researchers after the commencement of this research. In 2018, the RAISE Act (Recognize, Assist, Include, Support, and Engage Family Caregivers Act (S. 1028 / H.R. 3759)) was passed by both the US House and Senate with the aim of developing a national strategy to assist carers (Kent *et al.*, 2019). In 2019, the National Cancer Research Institute (NCRI) together with the James Lind Alliance identified the top ten research priorities for living with and beyond cancer. One of these research priorities states that emphasis should be given to identify ways to deliver long-term cancer care, and makes reference to carer involvement (NCRI, 2019). Furthermore, in 2019, the NHS (2019, p.42) Long Term Plan reported that "*carers are twice as likely to suffer from poor health compared to the general population*" and encouraged improved carer support. Additionally, in 2020, the Oncology Nursing Society (ONS) conducted a rapid review to identify research priorities for cancer care in the context of the COVID-19 pandemic and highlighted the importance of exploring the experiences of carers related to cancer and COVID-19 (Zanville *et al.*, 2021). Therefore, these publications make the development of this research timely.

1.10 Presentation of Report

Chapter Two will describe a systematic review of reviews conducted to identify gaps in the literature on the experiences of carers of patients with cancer. The findings of this review eventually led to formulating the research question and choosing an appropriate methodology. Chapter Three will describe the principles of grounded theory and why constructivist grounded theory was adopted as the methodological framework for this research (Charmaz, 2014). Chapter Four will provide a discussion of the approach to this research, where the processes of recruitment and data collection are described in detail. Chapter Five will describe the data analysis process. Chapters Six to Nine will describe the research findings. Chapter Ten will discuss the research findings in relation to the extant literature. Chapter Eleven will describe the grounded theory developed in this research and its implications. Chapter Twelve will provide a conclusion to this research. However, before moving on to the next chapter, it is appropriate to discuss three important issues in this research: (i) the approach taken to reviewing the literature; (ii) the use of the term ‘carer’; and (iii) the Maltese health care system.

1.11 Reviewing the Literature

To keep in line with the tenets of constructivist grounded theory (Charmaz, 2014), two literature reviews were conducted in this research. As described in the previous section, the systematic review of reviews on the experiences of carers of patients with cancer was conducted to enable the researcher to identify a gap in the literature and assist him in preparing his Ethics proposal. On the other hand, a more detailed literature review was conducted later in the research process once the researcher started developing some categories from the data. This review was informed by the emerging categories and aimed to identify extant theories. These extant theories were then compared with the emerging categories to determine whether they fitted the data and hence, could be considered to enhance further the developing theory.

1.12 Using the Term ‘Carer’

Debates exist on how carers of patients with cancer define themselves. Macmillan Cancer Support (2016b) states that only 2 out of 5 people who are taking care of a patient with cancer define themselves as a ‘carer’. Therefore, the term ‘carer’ is a contested term and there are lots of people who do not identify with it. In addition, this research is being conducted in Malta. There is no single word in the Maltese language which describes the term ‘carer’. Instead, the Maltese use a phrase to describe this term: ‘persuna li qed tieħdu ħsieb lill-persuna oħra bil-kanċer’ which means ‘a person taking care of another person with cancer’. Therefore, the researcher was at first undecided on whether to use the term ‘carer’ in this doctoral research. In fact, he avoided using this term during the interviews because one would then be assuming that the participants identify themselves with this term. However, analysis of the data revealed that some of the Maltese participants made use of the English term ‘carer’ even though their interviews were conducted in Maltese. Hence, for the purpose of this research, using the term ‘carers’ was deemed appropriate.

1.13 The Maltese Context

The Maltese archipelago is located in the centre of the Mediterranean Sea and is made up of three main islands: Malta, Gozo and Comino. At the end of 2021, the total Maltese population was estimated at 519,000 and in fact, Malta remains the smallest country in the European Union. However, although it has the smallest population size, Malta by far ranks first among all European Union (EU) Member States in terms of population density (National Statistics Office of Malta, 2022).

The health care system in the Maltese Islands is based on the NHS system in the UK. There are both private and public health services (Scerri, 2014). Scerri (2014) explains that public health services are funded from taxation and cover almost any treatment, such as hospitalisation, medications, and rehabilitation. There are two main hospitals and one oncology centre on the Maltese Islands. On the other hand, several Health Centres across Malta and Gozo provide primary health care. Nevertheless, some patients choose to use the private services due to convenience and continuity of care (Azzopardi Muscat *et al.*, 2014).

Despite Malta having a comprehensive health care provision, there are challenges which include: (i) an aging population; (ii) increase in chronic conditions; and (iii) a shortage of health care professionals (National Health System Strategy, 2014). Therefore, considering the fact that the number of chronic conditions is on the rise, then it is likely that many Maltese carers are not only managing the patient’s cancer, but they are also coping with their own chronic conditions. Moreover, the National Health System Strategy (NHSS) (Ministry for Energy and Health, 2014) in Malta advocates that action needs to be taken to encourage, educate, and support carers. However, in order to support these carers, the NHSS acknowledges the importance of conducting further research in this area, in both public and private health settings, in order to identify the needs of these carers so as to implement interventions to address these needs (Ministry for Energy and Health, 2014). Therefore, taking into consideration these notions, further research is needed on the experiences of Maltese carers, especially those already living with a pre-existing chronic condition.

1.14 Conclusion

This chapter highlights that there is a gap in the literature on the experiences of carers with pre-existing chronic conditions and who are caring for a patient with cancer and hence, the need to conduct further research on this topic. In summary, considering the fact that the global cancer burden is on the rise and that the majority of the world’s population has a health problem, then it is likely that the number of carers caring for a patient with cancer and at the same time, having a chronic condition is also increasing. These carers are at a higher risk of experiencing physical and emotional problems which can have several implications. Firstly, these carers may experience a deterioration in their health and hence, the need to be admitted to hospital and use health care services. Furthermore, they may find it difficult to continue providing high quality patient care. These implications may significantly impact both the patient’s and carer’s quality of life and increase the financial toll on health care systems worldwide. Therefore, it is imperative that further research is conducted on the experiences of these types of carers. The next chapter will describe the systematic review of reviews, the findings of which corroborate the conclusions drawn in Chapter One.

Chapter 2 Systematic Review of Reviews

2.1 Introduction

This chapter describes the systematic review of reviews. This review was conducted to identify gaps in the literature on the experiences of carers of patients with cancer. This led to the formulation of a research question focussing on an area which previously had been largely overlooked. Furthermore, the findings of this review aided the researcher to choose the appropriate methodology for this doctoral research.

2.2 The Systematic Review

An exploratory search conducted in the electronic database DelphiS (accessed through the University of Southampton website on 13 September 2017) identified several literature reviews on the experiences of carers of patients with cancer. Therefore, a systematic review of reviews was conducted to provide an overall examination of the body of research evidence that is available on the experiences of carers at different points along the cancer trajectory. Review of reviews are useful tools to summarise existing literature and to highlight the absence of evidence (Hunt *et al.*, 2018). The aim of this review was to highlight literature gaps and hence, aid in the formulation of a research question for this research. To identify these gaps, it is important to first and foremost show evidence from existing literature about the experience of carers. Therefore, the question for this review was: What are the lived experiences of carers of patients with cancer? This review was designed using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) Guidelines (Shamseer *et al.*, 2015).

2.3 Inclusion and Exclusion Criteria

The eligibility criteria for study inclusion were developed using the PICOS (Participants, Interventions, Comparators, Outcomes and Study design) framework. Papers were included if they met the PICOS criteria, illustrated in Table 1. No language restriction was applied. However, only articles written in English language were eventually included in this review due to a lack of translation facilities. Therefore, for articles not published in the English language, the corresponding authors were contacted to see if there are any English translations available. Methodological quality was not used as a basis to exclude articles since the aim of this review was to provide an overall examination of the body of research evidence that is available on the studied topic.

Table 1: PICOS criteria for including papers.

PICOS Framework	Inclusion and Exclusion Criteria
Population	Patients aged ≥18 years diagnosed with all types of cancer and carers aged ≥18 years. Reviews on carers of children with cancer were excluded due to the distinct experiences these carers may face.
Intervention	Experience of providing unpaid care for someone with cancer at any stage of the cancer trajectory, including at diagnosis, during active treatment, post-treatment, palliative phase, and end-of-life phase.
Comparator	This review was not limited to comparator studies.
Outcomes	Different dimensions of the lived experience of carers, including quality of life, well-being, self-management, health status and perceived continuity, and quality of care were included. Reviews that examined the experience of carers receiving interventions, or the effectiveness of implementing interventions for this population, or the barriers and facilitators to implementation of interventions were excluded. Intervention studies are often restricted to a single centre where the available specialists and technologies differ from those found in most general practice settings. Furthermore, intervention studies also have a monitoring bias linked to a higher frequency of assessments and visits when compared to usual clinical practice. Therefore, the findings of intervention studies may not be representative of the real-life situation (Saturni *et al.*, 2014).
Study Design	Both narrative and systematic reviews were included. Both qualitative and quantitative reviews were included. Reviews which examined the experiences of both carers and patients with cancer where the data for carers could not be extracted separately were excluded. Reviews of published opinions were also excluded.

2.4 Searches and Information Sources

Nine electronic databases were searched from inception until 30 November 2017 (host sites given in parenthesis): Academic Search Complete (EBSCOhost), Allied and Complementary Medicine Database (AMED, EBSCOhost), Cochrane Database of Systematic Reviews, Cumulative Index to Nursing and Allied Health Literature (CINAHL, EBSCOhost), Embase (Ovid), Medline (EBSCOhost), PubMed, Prospero Register, and PsycINFO (EBSCOhost). The search strategies for the electronic databases were developed using the Peer Review of Electronic Search Strategies (PRESS) Guidelines (McGowan *et al.*, 2016). The search strategy for the database Embase (Ovid) is illustrated in Appendix A. A search for grey literature was also conducted in OpenGrey and PsycEXTRA databases from inception until 30 November 2017, using the search terms ‘caregiver’ and ‘cancer’, combined with the Boolean operator AND.

In addition, the reference lists of all included articles were searched for further relevant reviews. Moreover, experts in the field were also identified from the included articles and contacted to inquire whether they were aware of other relevant reviews on the topic. Additionally, the search strategies revealed that most of the literature on carers was published in the journals Psycho-Oncology and European Journal of Cancer Care, and hence, issues of these journals were hand searched for further relevant reviews.

2.5 Screening and Data Extraction

A three-step screening process was undertaken to achieve the final set of included articles. Firstly, all titles were read and those that did not meet the inclusion criteria were excluded. Secondly, the abstracts of the remaining articles were examined against the inclusion and exclusion criteria. Finally, the full text copies of potentially relevant articles were obtained and examined for inclusion in the review.

Data were extracted using a standard data extraction form in a Microsoft Excel Spreadsheet, as described by Aromataris *et al.* (2015). The following data were extracted: citation details; objectives of included review; type of review; participant details; setting and context; number of databases sourced and searched; date range of database searching; number of studies, types of studies; instrument used to appraise the primary studies; outcomes relevant to the present review; method of synthesis/analysis employed to synthesise the evidence; and comments or notes the review authors may have had regarding any included study.

2.6 Methodological Quality

Methodological quality was assessed using instruments appropriate to the type of review. The methodological quality of narrative reviews was assessed using the International Narrative Systematic Assessment (INSA). INSA is a 7-item checklist and presents methodological quality as either ‘good’ or ‘poor’ (La Torre, Backhaus and Alice, 2015). The methodological quality of systematic reviews was assessed using A Measurement Tool to Assess Systematic Reviews 2 (AMSTAR 2). AMSTAR 2 is a 16-items checklist and presents methodological quality as either ‘high’, ‘moderate’, ‘low’, or ‘critically low’ (Shea *et al.*, 2017). Items 11, 12 and 15 of the AMSTAR 2 tool were not considered in this review since none of the included reviews were meta-analyses.

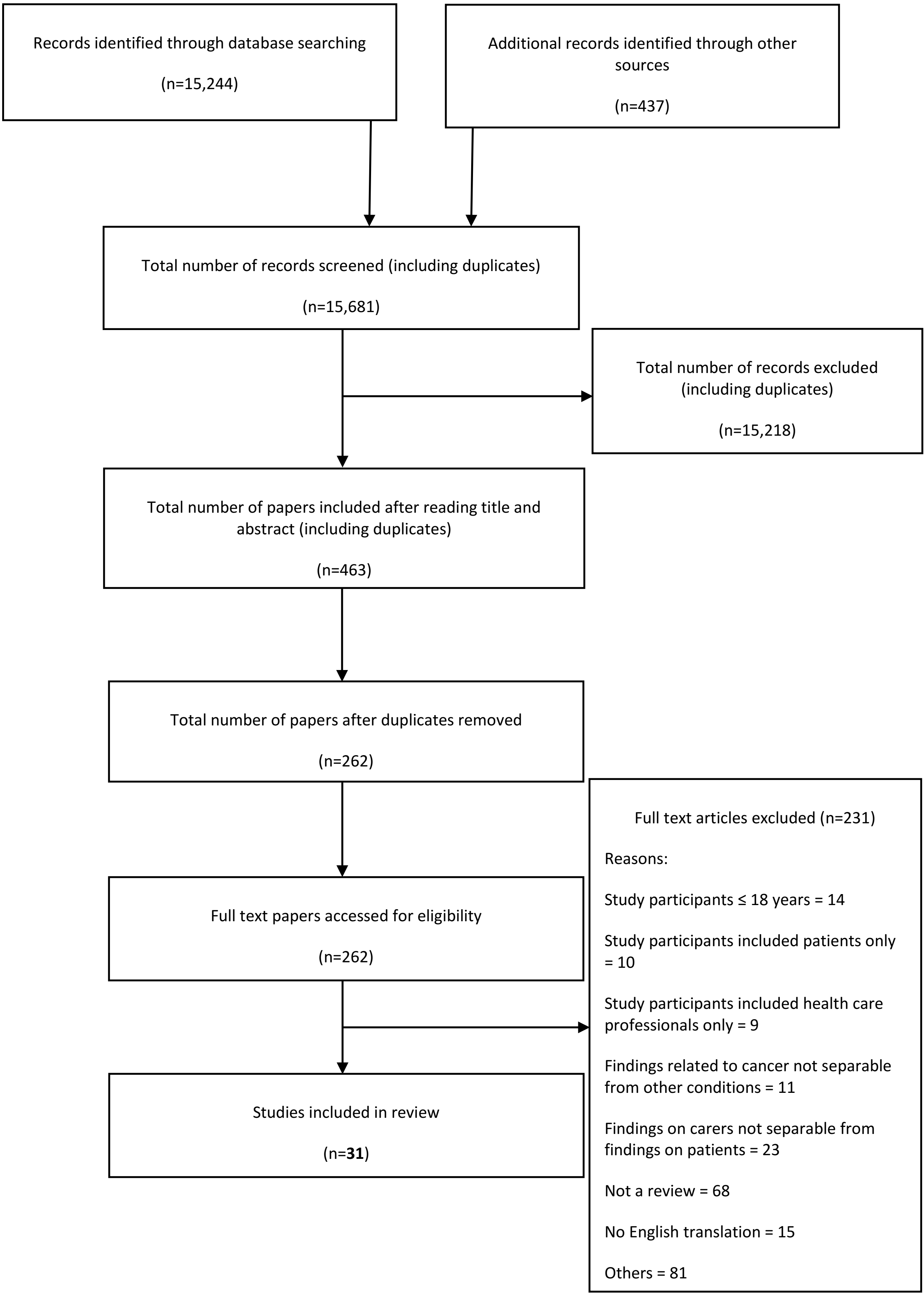
2.7 Data Analysis and Synthesis

Data analysis was carried out using thematic analysis (Braun and Clarke, 2006). Firstly, the results, discussion, and conclusions sections of each included article were read to identify the main findings. These findings were then examined for similarity and grouped into themes. Each theme provided a summarised description of the findings. The findings of quantitative reviews were not analysed using formal statistical meta-analysis methods because of the considerable heterogeneity with regards to populations and outcome measures among the included reviews.

2.8 Results of the Searches

The review process is shown in Figure 1. 15,681 possible articles were identified through database searching and other sources, such as reading through reference lists and issues of the journals Psycho-Oncology and European Journal of Cancer Care. After reading through the titles and abstracts, 463 potentially eligible articles were identified according to the inclusion and exclusion criteria. 262 articles remained after removing duplicates. Further screening was carried out by reading the full-texts of these 262 papers. Finally, this led to 31 reviews that fully met the inclusion criteria, being included in this systematic review. Of these, 21 reviews focused on aspects of the everyday experiences of carers of patients with cancer. 6 reviews focused specifically on the psychosocial aspects of caring for the patient with cancer, 2 reviews focused on the informational needs of carers, whilst another 2 reviews focused on the positive aspects of cancer caregiving. 19 reviews were narrative reviews whilst 12 reviews were systematic reviews.

Figure 1: PRISMA flow chart.



2.9 Methodological Quality of Included Reviews

As illustrated in Table 2, 63% of the included narrative reviews did not provide a clear description of how the studies were selected. On the other hand, 32% of the reviews did not clearly describe the characteristics of the included studies, whilst 68% of the reviews did not report a conflict of interest. Overall, 7 out of the 19 (37%) included narrative reviews were found to have poor methodological quality (Kim and Given, 2008; Kotkamp-Mothes *et al.*, 2005; Mosher and Danoff-Burg, 2005; Northfield and Nebauer, 2010; Obaidi and Al-Atiyyat, 2013; Resendes and McCorkle, 2006; Romito *et al.*, 2013).

Table 2: Description of narrative reviews based on INSA items.

INSA items	**Yes (%)**	**No (%)**
Background of study is clearly described	18 (95)	1 (5)
Objective is clear	16 (84)	3 (16)
Description of selection of studies is clear	7 (37)	12 (63)
Description of the characteristics of included studies is clear	13 (68)	6 (32)
Presentation of results is clear (paragraphs, tables, synthesising of data)	18 (95)	1 (5)
Conclusion is clear	18 (95)	1 (5)
Conflict of interest is stated	6 (32)	13 (68)

After assessment of methodological quality using AMSTAR 2, it was found that all the included systematic reviews had a critically low methodological quality (Aamotsmo and Bugge, 2014; Bee, Barnes and Luker, 2009; Duggleby *et al.*, 2016; LeSeure and Chongkham-ang, 2015; Lopes *et al.*, 2018; Madsen and Poulsen, 2011; Nicholls *et al.*, 2014; Stenberg *et al.*, 2010; Stenberg *et al.*, 2014; Sterckx *et al.*, 2013; Wheelwright *et al.*, 2015; Young and Snowden, 2017). As illustrated in Table 3, the main problems in the reviews were that the authors failed to report (i) whether a review protocol existed (item 2); (ii) whether an adequate search strategy was carried out (item 4); and (iii) whether critical appraisal of the individual studies was carried out (item 9). A lack of a pre-defined protocol prior to the conduct of the review increases the risk of bias. Conversely, important studies could have been missed if an inadequate search strategy was carried out. Additionally, failing to report the critical appraisal of the individual studies means that it is difficult to determine whether the findings of these reviews are based on robust studies or not (Shea *et al.*, 2017).

Table 3: Description of systematic reviews based on AMSTAR 2 items.

AMSTAR 2 items	**Yes (%)**	**No (%)**	**Partially Yes (%)**
Research questions and inclusion criteria include components of PICO	11 (92)	1 (8)	
Reported a review protocol	1 (92)	11 (8)	
Justified selection of the study designs for inclusion in the review	6 (50)	6 (50)	
Performed a comprehensive literature search strategy		7 (58)	5 (42)
Performed study selection in duplicate	8 (67)	4 (33)	
Performed data extraction in duplicate	6 (50)	6 (50)	
Provided a list of excluded studies and justified the exclusions	4(33)	8 (67)	
Described the included studies in adequate detail	5 (42)	2 (16)	5 (42)
Used a satisfactory technique for assessing the Risk of Bias	1 (8)	10 (84)	1 (8)
Reported sources of funding for the primary studies included in the review		12 (100)	
Accounted for Risk of Bias in the primary studies when interpreting/ discussing the results of the review		12 (100)	
Provided a satisfactory explanation for any heterogeneity		12 (100)	
Reported a conflict of interest	11 (8)	1 (92)	

2.10 Review Findings

Thematic analysis revealed four main themes that describe the experiences and needs of carers of patients with cancer: (i) informational needs of carers; (ii) positive aspects of caregiving; (iii) caregiving burden and impact on carers' health; and (iv) coping in caregiving. These themes are described in the following sections. The steps taken to identify these themes are described in Table 4.

Table 4: Steps taken to synthesise the data.

Steps	**Step Description**	**Example**
Familiarisation of data	The results, discussion and conclusions sections were read line-by-line and key phrases were underlined.	"*... they had only received the information they required because they had been proactive in requesting it …*". "*International evidence frequently highlights a lack of practical guidance for carers, including poor information provision …*".
Initial coding	A list of codes was generated to best summarise the key phrases identified.	The code 'seeking information themselves' was used to summarise the key phrase "*... they had only received the information they required because they had been proactive in requesting it …*". The code 'lacking adequate information' was used to summarise the key phrase "*International evidence frequently highlights a lack of practical guidance for carers, including poor information provision …*".
Generating themes	Similar codes were grouped together to form the preliminary themes.	The codes 'seeking information themselves' and 'lacking adequate information' were grouped together with other codes to form the preliminary theme 'facing informational problems'.
Reviewing themes	Constant comparison was made between codes and themes for similarities and relationships between themes.	The preliminary theme 'facing informational problems' was compared with another preliminary theme 'requiring different facets of information'.

Table 4 (cont.): Steps taken to synthesise the data.

Steps	**Step Description**	**Example**
Defining and naming themes	The characteristics and name of each theme were defined.	The preliminary themes 'facing informational problems' and 'requiring different facets of information' led to the formulation of one of the main themes: 'informational needs of carers'.
Producing the report	Data analysis revealed four main themes. These themes are reported in this doctoral research.	"*Thematic analysis revealed four main themes that describe the experiences and needs of carers of patients with cancer: (i) informational needs of carers; (ii) positive aspects of caregiving; (iii) caregiving burden and impact on carers' health; and (iv) coping in caregiving.*".

2.10.1 Informational Needs of Carers

Two reviews (Bee *et al.*, 2009; McCarthy, 2011) focussed on the informational needs of carers. Bee *et al.* (2009) examined the practical informational needs of carers providing home-based palliative and end-of-life care to patients with advanced cancer. In this review, practical aspects such as physical care, patient nutrition, medication administration, and symptom control were included. The findings of this review suggest that carers face several informational problems, including a lack of practical information and guidance from health care professionals. As a result, carers request that health care professionals provide practical information in greater quantity and of better quality (Bee *et al.*, 2009).

McCarthy (2011) examined the type of information that carers generally seek, how they seek this information from health care professionals, and carers' experiences of communicating with health care professionals. McCarthy (2011) included studies of carers of patients diagnosed with a variety of cancers and at different points in the cancer trajectory. The findings of this review suggest that carers require different facets of information. Carers require information regarding cancer prognosis, cancer treatments, including information about treatment options, medications and their side effects, issues relating to sexuality, and cancer pain management (McCarthy, 2011). Furthermore, McCarthy (2011) found that carers experience negative communication encounters with health care professionals. These experiences include feeling ignored and not being respected by health care professionals, as well as encountering some health care professionals who lack empathy, sensitivity, and compassion (McCarthy, 2011). Moreover, carers must often actively seek information from health care professionals instead of having health care professionals actively providing information themselves (McCarthy, 2011; Petrie, Logan and DeGrasse, 2001).

However, caution is needed in interpreting the findings of these two reviews (Bee *et al.*, 2009; McCarthy, 2011). Firstly, Bee *et al.* (2009) only included studies of carers providing home-based palliative and end-of-life care to people with advanced cancer. Therefore, the findings of this review cannot be applied to all situations. It could be that carers of patients receiving active treatment might not experience such informational needs due to more contact with health care professionals during hospital admissions and outpatient appointments. Nevertheless, the findings of McCarthy (2011) seem to suggest that carers lack information at every point of the cancer trajectory. However, McCarthy (2011) included studies of carers of patients with a variety of cancer diagnoses, with most diagnoses being of breast and prostate cancers. Therefore, certain informational needs of carers that were found in this review might not apply to other types of cancers which were not represented in the data, such as haematological cancers and other less common cancers.

2.10.2 Positive Aspects of Caregiving

Two reviews (Li and Loke, 2013; Young and Snowden, 2017) suggest that carers also find positivity in caring for the patient with cancer. Positive aspects of caregiving include finding meaning, the discovery of personal strength, personal growth, and greater family closeness and developing a stronger relationship with the patient (Li and Loke, 2013; Young and Snowden, 2017). Other positive aspects of caregiving include feeling rewarded, perceiving personal satisfaction, and feeling respected and appreciated by the patient (Li and Loke, 2013). However, the findings of these two reviews (Li and Loke, 2013; Young and Snowden, 2017) have to be interpreted with caution. These reviews included studies with a variety of cancer diagnoses and hence, the findings may not apply to certain types of cancers which could have been underrepresented in the data.

Li and Loke (2013) also looked into the factors which determine whether carers perceive the caregiving role positively or not. Such factors include daily enrichment events and self-efficacy on the part of the carer. Daily enrichment events include taking time out for oneself, such as going for a walk and resting. Additionally, social support, religion and hope were also found to be related to the positive aspects of cancer caregiving (Li and Loke, 2013). However, the review by Li and Loke (2013) only included studies in which the carers were spouses of the patients with cancer. Hence, the findings of this review (Li and Loke, 2013) have to be interpreted with caution as such findings may not apply to other types of carers, such as adult children and friends, who may not be living with the patient.

2.10.3 Caregiving Burden and Impact on Carers' Health

Several reviews found that some carers struggle with the challenges imposed by the cancer caregiving role. Consequently, they experience numerous problems at diagnosis, during and after a patient's treatment for cancer. Emotional problems include anxiety and depression, fear of losing the patient, fear of recurrence, and uncertainty about the future and what the treatment holds (Beattie and Lebel, 2011; Couper *et al.*, 2006; Kitrungroter and Cohen, 2006; Kotkamp-Mothes *et al.*, 2005; LeSeure and Chongkham-ang, 2015; Li, Mak and Loke, 2013; Longacre *et al.*, 2012; Mosher and Danoff-Burg, 2005; Neris and Yokoyama dos Anjos, 2014; Obaidi and Al-Atiyyat, 2013; Resendes and McCorkle, 2006; Romito *et al.*, 2013; Stenberg *et al.*, 2010; Stenberg *et al.*, 2014; Sterckx *et al.*, 2013; Wheelwright *et al.*, 2015). Physical problems include sleep disturbances, fatigue, pain, anorexia, loss of appetite, and weight loss (Kitrungroter and Cohen, 2006; Kotkamp-Mothes *et al.*, 2005; Li and Loke, 2013; Li *et al.*, 2013; Obaidi and Al-Atiyyat, 2013; Romito *et al.*, 2013; Sterckx *et al.*, 2013). Some carers also experience social problems, such as being unable to attend employment, school or social functions, due to time constraints associated with caregiving responsibilities (Kotkamp-Mothes *et al.*, 2005; Li *et al.*, 2013; Obaidi and Al-Atiyyat, 2013; Stenberg *et al.*, 2010; Stenberg *et al.*, 2014; Sterckx *et al.*, 2013). Some carers also experience financial problems and sexual problems, often related to a lack of sexual activity and sexual intimacy (Li and Loke, 2013; Neris and Yokoyama dos Anjos, 2014; Obaidi and Al-Atiyyat, 2013; Romito *et al.*, 2013; Stenberg *et al.*, 2014).

Several reviews also report that some carers experience significant burden as a result of the responsibilities associated with the caregiving role (Beattie and Lebel, 2011; LeSeure and Chongkham-ang, 2015; Stenberg *et al.*, 2010). This burden is associated with both direct tasks, such as washing and handling the patient with cancer, and indirect tasks, such shopping and food selection (Obaidi and Al-Atiyyat, 2013; Stenberg *et al.*, 2010). Additionally, some carers take on many responsibilities that they are not prepared to handle, thus impacting their daily routine, health, finances, and self-esteem (LeSeure and Chongkham-ang, 2015; Stenberg *et al.*, 2014). When carers are not prepared to handle the many responsibilities associated with the caregiving role, they often become overwhelmed. As a result, they often neglect themselves, leading to further physical and emotional health problems (Lopes *et al.*, 2018; Madsen and Poulsen, 2011; Schmid-Büchi *et al.*, 2008; Stenberg *et al.*, 2014). This stems from the fact that carers often prioritise the needs of the patient with cancer above their own needs (Obaidi and Al-Atiyyat, 2013).

Some carers also experience a change in their role and responsibilities within the family. The care of the patient with cancer is added to their usual work activities and responsibilities, such as taking care of the household chores or taking care of the children, leading to great weariness (Aamotsmo and Bugge, 2014; Beattie and Lebel, 2011; Kotkamp-Mothes *et al.*, 2005; Li *et al.*, 2013; Neris and Yokoyama dos Anjos, 2014; Obaidi and Al-Atiyyat, 2013; Stenberg *et al.*, 2014; Sterckx *et al.*, 2013).

However, the findings of the above reviews have to be considered with caution. Although many of the above reviews included studies involving patients with a variety of cancer diagnoses, most included common cancers such as breast, prostate, gastrointestinal, colon, and lung cancers. Therefore, one cannot apply the findings of the above reviews to all carers, especially to carers of patients with haematological malignancies, which seem to be underrepresented in the literature.

2.10.4 Coping in Caregiving

One review explored the process by which carers adapt to the caregiving role (Duggleby *et al.*, 2016). However, this review only included studies of carers of patients with advanced cancer who were at the end-of-life and living in the community. Hence, the findings may not apply to how for example, carers adapt to the caregiving role during curative treatment. This review found that carers have to first ‘come to terms’ with the situation before they can adapt to the caregiving role. This meant that the carers had to acknowledge that a significant change had occurred in their life, in this case, the imminent death of their loved one. By ‘coming to terms’ with the changes in their situation, carers were able to connect with information and others. Connecting with information, with trusted experts, resources, and support, and for some with a higher power, assisted them to cope. Factors that influenced the process of ‘coming to terms’ included: (i) communication/information; (ii) attitudes, values, and beliefs toward caregiving; (iii) support networks; and (iv) caregiver/care-recipient relationship. Outcomes of adapting to the caregiving role included: (i) maintaining a sense of personhood; (ii) reframing hope; (iii) maintaining self-efficacy; and (iv) finding meaning (Duggleby *et al.*, 2016). Social support and support from health care professionals and the family is also important for carers to cope with the caregiving role (Aamotsmo and Bugge, 2014; Kotkamp-Mothes *et al.*, 2005; Lopes *et al.*, 2018; Petricone-Westwood and Lebel, 2016; Sterckx *et al.*, 2013).

One review provided a list of the different coping strategies adopted by carers (Neris and Yokoyama dos Anjos, 2014). These include maintaining both hope and positivity in the face of this difficult situation, spirituality, and faith in God when dealing with moments of great suffering. However, this review (Neris and Yokoyama dos Anjos, 2014) only included studies of carers of patients with breast cancer and thus, the findings may not apply to the experiences of carers of patients with other cancer types, which may have different trajectories. Li *et al.* (2013) also found that planning ahead, self-care and caregiving behaviours, such as providing emotional support to the patient, help carers to cope with the stress associated with the caregiving role.

Additionally, two reviews (Aamotsmo and Bugge, 2014; Neris and Yokoyama dos Anjos, 2014) found that carers also conceal their real feelings as a way to protect the patient, other family members, and even themselves from suffering. However, both these reviews (Aamotsmo and Bugge, 2014; Neris and Yokoyama dos Anjos, 2014) included studies of carers who were partners or spouses of the patient with cancer and hence, these findings may not apply to other types of carers, such as adult children or friends.

2.11 Limitations of the Literature

The findings of this systematic review of reviews reveal that a large number of reviews have been conducted on the experiences of carers of patients with cancer. However, although the included reviews covered many aspects of the experience of carers, the knowledge retrieved from these reviews does not present a clear picture of the common factors that shape the experiences of these carers. Firstly, most of the existing literature is on the experiences of carers of patients diagnosed with common cancers, such as breast cancer, colon cancer, and prostate cancer. Therefore, the findings of the available literature may not apply to less common and rare cancers. Secondly, most of the studies included in the reviews were cross-sectional in design. In fact, several authors indicate that there is a lack of longitudinal studies on the experiences of carers (Li *et al.*, 2013; Petricone-Westwood and Lebel, 2016). It is difficult to achieve a full understanding of the impact of cancer on the carer across the cancer trajectory through cross-sectional information (Kim and Given, 2008). Thirdly, most of the existing literature on the experiences of carers is descriptive in nature and does not attempt to explain for example, why carers experience physical problems whilst caring for the patient. In fact, most of the studies included in the reviews lacked a theoretical framework which limits the generalisability of their findings (Kim and Given, 2008). Additionally, critical appraisal using the AMSTAR 2 tool and INSA tool revealed that most of the included reviews are of poor quality. These limitations demonstrate that, although there is a lot of literature on the experiences of carers, health care professionals have to carefully appraise the available literature before utilising such literature to provide supportive services or interventions to meet the needs and concerns of these carers. In addition, the findings of this review highlight the need to develop theoretical frameworks that can be utilised by health care professionals with different groups of carers and at different phases of the cancer trajectory.

Although the identified themes covered many aspects of the experiences of carers of people with cancer, a gap in the literature could be identified. The findings of this review reveal that there is a gap in the literature on how the problems and burdens associated with the cancer caregiving role affect aspects of the carer's life which are not related to patient care. Several reviews reported that, when carers are not prepared to handle the many responsibilities associated with the caregiving role, they become overwhelmed with the caregiving and as a result, they often neglect themselves, leading to physical and emotional health problems (Madsen and Poulsen, 2011; Stenberg *et al.*, 2014). Another review reported that carers often prioritise the care of the patient above their own and consequently, they might lose control of the management of their chronic conditions (Given *et al.*, 2012). However, the review presented in this chapter fails to describe for example, why carers prioritise the care of the patient above their own health and which aspects of the caregiving role cause carers to neglect themselves. Furthermore, the review fails to identify which factors determine whether carers will neglect themselves or not and what resources and support are needed to help carers to take care of themselves. These findings corroborate the conclusions drawn in Chapter One, that further research is needed on the experiences of carers of patients with cancer, especially those carers with pre-existing chronic conditions. Therefore, there is little evidence to inform health care professionals about the best way to support carers in taking care of their chronic conditions whilst caring for the patient with cancer. Understanding how carers live with their own chronic conditions can help health care professionals who work in the oncology setting to develop and implement interventions to support these carers and deliver personalised care. This should be considered in the context that, health appointments may be months apart and between that time, carers have to take care of their chronic conditions on their own and may lack the necessary support. This was made worse during the COVID-19 pandemic which decreased the carers' health care utilisation due to concerns about safely accessing health care (Hacker *et al.*, 2021). Therefore, using the context of these findings, it was decided that the research problem for this doctoral research would be: What is it like for carers to live with their own chronic conditions and at the same time, care for someone with cancer?

2.12 Updated Search

An update of the search was conducted to identify newly added literature on the topic of interest published whilst conducting this research. The search strategies were re-run to search for relevant articles published from 1 December 2017 until 24 January 2022. The findings of this search support the four themes, as well as the limitations described in the previous sections. In addition, this search revealed that some of the findings of the reviews published in the last five years further justify the decision to focus on cancer caregiving. Kim and Baek (2022) reported that carers do not regard their self-care as a priority and felt guilty for caring for themselves rather than the patient. Similarly, Collaço *et al.* (2018) found that spouses of patients with prostate cancer disregarded their own needs, as they felt they were less important in comparison to the patient's care and as a result, experienced physical health problems. On the other hand, Teixeira *et al.* (2019) found that the chronic stress experienced by carers during the cancer trajectory can lead to changes in the cardiovascular and immune functioning which can compromise their physical health. The reviews by Aung, White and Bloomfield (2021) and Kusi *et al.* (2020) further corroborate these findings. This decline in physical health resulted in a decreased quality of life for the carer, as well as a decline in the quality of care provided to the patient (Costa de Souza Abreu and Costa Júnior, 2018). Moreover, Cai *et al.* (2021) found that, after taking up the caregiving role, carers who had pre-existing chronic conditions experienced an exacerbation of the symptoms of their chronic conditions and tended to take non-prescription drugs to relieve symptoms. However, Cai *et al.* (2021) failed to identify why, for example, carers resorted to taking non-prescription drugs to relieve symptoms rather than seek medical help. Therefore, these findings further highlight the importance of conducting further research on the experiences of carers with pre-existing chronic conditions. This is more so important in the face of the fact that a number of reviews identified in this search revealed that there is a lack of standardised approaches to providing education and ongoing support to carers and that their needs are often overlooked by health care professionals (Adashek and Subbiah, 2020; Green *et al.*, 2021; North *et al.*, 2021; Wang *et al.*, 2018). The main characteristics of the reviews included in this systematic review of reviews are illustrated in Table 5.

Table 5: Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Aamotsmo and Bugge, 2013	CINAHL, MEDLINE, PsycINFO.	1889 – 2009	7 qualitative studies.	Carers of patients diagnosed with advanced cancer. Couples.	Qualitative content analysis.	Carers reported taking up new roles, attempting to maintain a normal life, feeling alone even within the family, and providing support to other family members.
Adashek and Subbiah, 2020	PubMed	Not reported.	Not reported.	Carers of older adults with advanced cancer.	Not reported.	Caregiving impacted carers' quality of life and physical well-being.
Aung, White and Bloomfield, 2021	CINAHL, MEDLINE, PsycINFO, Scopus.	2008 – 2018	7 quantitative studies. 12 qualitative studies. 1 mixed methods study.	Carers of patients with head and neck cancer. Any point in the cancer trajectory.	Thomas and Harden's thematic analysis.	Carers experienced physical, psychosocial, and financial problems. They identified the need for informational, financial, and educational support whilst caring for the patient with cancer.
Beattie and Lebel, 2011	CINAHL, MEDLINE, PsycINFO, Academic Search Complete.	Inception – 2010	16 quantitative studies. 3 qualitative studies.	Carers of patients with haematological cancers undergoing stem cell transplantation.	Not reported.	Carers reported uncertainty, fear of the future, juggling patients' needs with their own, and difficulties adapting to new roles. .

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Bee, Barnes and Luker, 2008	PubMed, CancerLit, MEDLINE, PsycInfo, EMBASE, CINAHL, AMED, British Nursing Index, Cochrane Library, National Research Register, Zetoc, hand-searches of journals, websites.	Inception – 2006	5 quantitative studies. 5 mixed studies. 16 qualitative studies.	Carers of home based palliative and end of life patients with advanced cancer.	Narrative synthesis.	Carers reported a lack of practical support. As a result, carers often adopted a ‘trial and error’ approach to palliative care. Carers requested a greater quantity of practically-focussed information, improvements in quality and increased methods of dissemination.
Cai *et al.*, 2021	Wanfang database, China National Knowledge Infrastructure (CNKI), CINAHL, MEDLINE, PubMed, Cochrane Library, PsycARTICLES, PsycINFO.	2009 – 2019	6 qualitative studies.	Carers of patients diagnosed with any type and stage of cancer. Any point in the cancer trajectory.	Thomas and Harden’s thematic analysis.	Caregiving impacted carers’ quality of life, including their physical, social, psychological, and spiritual well-being.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Collaço *et al.*, 2018	MEDLINE, CINAHL, PsycINFO, Web of Science, SSCI, AHCI, ProQuest IBSS.	2000 – 2016	37 qualitative studies.	Carers of patients with prostate cancer. Any point in the cancer trajectory.	Modified version of Noblit and Hare's meta-ethnographic approach.	Carers experienced difficulties in balancing the demands of caregiving, family roles, and providing emotional support to the patient. Consequently, carers experienced physical problems and feelings of being overstrained. Carers disregarded their own needs as less important. Carers also felt unsupported by the healthcare system.
Costa de Souza Abreu and Costa Júnior, 2018	Latin American and Caribbean Literature in Health Sciences (LILACS), MEDLINE, PsycINFO.	2012 – 2017	13 quantitative studies. 1 qualitative study.	Carers of patients with cancer in palliative care.	Not reported.	Carers experienced a low quality of life, time constraints, employment problems, financial problems, and emotional problems.
Couper *et al.,* 2006	MEDLINE, PsycINFO, Biological Abstracts, CINAHL.	1994 – 2005	44 studies.	Carers of patient with prostate cancer. Any point in the cancer trajectory.	Thematic analysis.	Carers reported more distress than patients.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Duggleby *et al*., 2017	MEDLINE, Embase, PsycINFO, CINAHL, Web of Science.	2004 – 2014	70 qualitative studies. 2 mixed-methods studies.	Carers of community-living persons with advanced cancer at the end-of-life.	Qualitative analysis.	Carers' lives were permanently altered. Carers described the process of redefining normal which consisted of coming to terms with their situation and connecting with others.
Green *et al*., 2021	MEDLINE, PsycINFO, EMBASE, AMED, CINAHL, Cochrane Database of Systematic Reviews, Sociological Abstracts for studies reporting original qualitative data.	Inception – 2020	14 qualitative studies.	Female partners of patients diagnosed with prostate cancer. Any point in the cancer trajectory.	Thomas and Harden's thematic analysis.	Carers reported psychological burden.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Kim and Baek, 2022	Ovid-MEDLINE, Ovid-Embase, PsycINFO, CINAHL, Cochrane library.	2000 – 2021	4 qualitative studies. 1 mixed study. 3 quantitative studies.	Carers of patients with pancreatic cancer. Any point in the cancer trajectory, except palliative and end-of-life care.	Thematic analysis.	Carers experienced different roles, a lack of information, and emotional problems. They adopted positive coping.
Kim and Given, 2008	MEDLINE, PsycINFO, PubMed, CINAHL.	1996 – 2007	Not reported.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Carers reported psychological problems.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Kitrungrote and Cohen, 2006	PubMed, CINAHL, PsycINFO, Web of Science, EBSCO electronic databases.	No date restriction.	28 quantitative studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Providing care for the patient with cancer impacted the quality of life of carers.
Kotkamp-Mothes *et al.*, 2005	Psyndex, PsycINFO, MEDLINE, PubMed, Psychology and Behavioral Sciences collection, GVK.	Not reported.	Not reported.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory. Patients above 60 years of age.	Not reported.	Distress among family members was at times during the disease trajectory very similar to the distress experienced by patients.
Kusi *et al.*, 2020	PubMed, CINAHL, Scopus, Web of Science, PsycINFO.	2000 – 2020	15 quantitative studies. 4 qualitative studies.	Carers of patients with breast cancer in low- and middle-income countries.	Narrative analysis.	Carers experienced physical, emotional, and financial problems.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
LeSeure and Chongkham-ang, 2015	CINAHL, MEDLINE, Academic Search, Science Direct, Thai Library Integrated System (ThaiLIS).	No date restriction.	18 qualitative studies.	Carers of patients diagnosed with a variety of cancers. Diagnosis and during treatment.	Porter's phenomenological data analysis method.	Carers reported balancing their emotions, keeping life as normal as possible and lifting life above the illness.
Li, Mak and Loke, 2013	MEDLINE, CINAHL, Science Citation Index Expanded, Scopus, PsycINFO, the CAJ (China Academic Journal) Full-text Database.	2000 – 2012	20 quantitative studies. 5 qualitative studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory. Couples.	Not reported.	Female carers reported lower mental health, lower physical health, poorer health-related quality of life, lower life satisfaction, and decreased marital satisfaction than male carers. However, female carers were more likely to experience personal growth than male carers.

Table 5 (cont.): Main characteristics of included reviews.

Citation	Databases Searched / Websites Searched	Years Searched	Number of Included Papers	Inclusion Criteria	Method of Analysis	Main Findings
Li and Loke, 2013	MEDLINE, CINAHL, Science Citation Index Expanded, Scopus, PsycINFO, the China Academic Journals Full-text Database.	1996 - 2012	15 qualitative studies. 18 quantitative studies. 2 mixed studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory. Spouses.	Not reported.	Carers experienced various positive aspects of caregiving, such as an enhanced relationship with the patient, the feeling of being rewarded, a sense of personal growth, and a perception of personal satisfaction. Daily enrichment events and self-efficacy were identified as determining factors in the positive aspects of caregiving.
Li and Loke, 2013	MEDLINE, CINAHL, Science Citation Index Expanded, Scopus, PsycINFO, the CAJ (China Academic Journal) Full-text Database.	2000 – 2012	19 quantitative studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory. Couples.	Not reported.	Female carers experienced more mental morbidity, physical morbidity, and social morbidity than male carers.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Longacre *et al.,* 2012	PubMed, MEDLINE, PsycINFO.	Inception - 2010	11 articles.	Carers of patients with head and neck During treatment.	Not reported.	Carers experienced poorer psychological health, including higher levels of anxious symptoms, compared to patients and to the general population. Fear of cancer recurrence was associated with poorer psychological health.
Lopes *et al.,* 2018	PubMed, SciELO, BIREME.	2005 – 2015	12 qualitative studies. 7 quantitative studies. 2 reviews. 1 case study. 1 study with undefined research design.	Husbands of women with breast cancer receiving treatment.	Phenomenology of ambiguity of Merleau-Ponty.	Carers reported financial difficulties, psychological distress, lack of coping skills, and the acquisition of new responsibilities and roles.
Madsen and Poulsen, 2011	MEDLINE, PubMed, CINAHL, PsycINFO, EMBASE, Google scholar.	Not reported.	2 quantitative studies. 1 mixed study. 11 qualitative studies.	Carers of patient with malignant cerebral glioma. Any point in the cancer trajectory.	Not reported.	Carers were overwhelmingly exhausted by the caregiving role. The ever-changing circumstances left carers fearful, anxious, and apprehensive. They lacked information about how to provide day-to-day care.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
McCarthy, 2011	MEDLINE, PubMed, PsycINFO, CINAHL.	2000 – 2010	22 quantitative studies. 11 qualitative studies. 1 mixed study.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Carers reported the need for information on prognosis, cancer treatments, issues relating to sexuality, and cancer pain management.
Mosher and Danoff-Burg, 2005	PsycINFO, MEDLINE.	Not reported.	Not reported.	Carers were adult children of patients with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Many carers experienced psychological distress in terms of anxiety, depression, and posttraumatic stress symptoms.
Neris and Anjos, 2014	PubMed, PsycINFO, CINAHL, VHL, SciELO.	No date restriction.	8 qualitative studies.	Carers of patients with breast cancer. Any point in the cancer trajectory.	Thematic analysis.	Carers experienced a change of routine and took up new roles within the family.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Nicholls, Hulbert-Williams and Bramwell, 2014	PsycINFO, CINAHL.	Inception – 2013	15 quantitative studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Narrative synthesis.	A more insecure attachment style in carers was associated with depression, higher caregiving stress, less autonomous motivations for caregiving and difficulties with caregiving.
North et al., 2021	MEDLINE and EMBASE.	Inception – 2020	8 qualitative studies.	Cares of patients with advanced incurable head and neck cancer.	Modified version of Noblit and Hare's meta-ethnographic approach.	Carers had multiple needs and suffered psychological distress and loss of social life. They often physically struggled to deliver care and meet the patient's complex needs.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Northfield and Nebauer, 2010	PubMed, PsycINFO, CINAHL, SocioFile, ProQuest Health, Wiley Interscience, Internurse, Science Direct, Health Science, SAGE Journals Online, Australian Public Affairs Full Text, Family and Society Plus, Academic Search Complete, Web of Science.	2000 – 2009	70 studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Carers experienced a myriad of emotions as they struggled to find meaning and hope in their relatives' diagnoses. Their ability to cope was enhanced by the presence of the nurse as a support person. However, coping was also dependent on many personal characteristics.
Obaidi and Al-Atiyyat, 2013	PubMed, MEDLINE, CINAHL, Google.	2007 – 2012	7 quantitative studies. 1 qualitative study.	Carers of patients with breast cancer. During treatment.	Not reported.	Carers experienced physical, emotional, social, and financial problems which impacted their quality of life.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Petricone-Westwood and Lebel, 2016	PsycINFO, CINAHL, PubMed, Web of Science.	1990 – 2014	9 quantitative studies. 4 qualitative studies. 3 mixed studies. 3 case studies.	Any point in the cancer trajectory. Carers of patients with ovarian cancer.	Thematic analysis.	The experience of being a carer to patients with ovarian cancer changed overtime. There was little compromise in carers' quality of life in the first year post-diagnosis. However, quality of life steadily declined throughout the rest of the disease trajectory.
Petrie, Logan and DeGrasse, 2001	CINAHL, CancerLit, PsycINFO, MEDLINE.	1976 – 2000	16 studies.	Carers of patients with breast cancer. Any point in the cancer trajectory. Couples.	Supportive care framework.	Carers received significantly less support from healthcare professionals than patients throughout the course of the illness.
Resendes and McCorkle, 2006	CINAHL, MEDLINE, Cochrane databases.	Not reported.	Not reported.	Carers of patients with prostate cancer. Spouses. After prostatectomy.	Not reported.	Carers were more distressed than patients. Sources of distress included lack of information, fear of the unknown, fear of what the treatment will hold, and treatment-related concerns.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Romito *et al.,* 2013	PubMed, Web of Knowledge.	Not reported.	Not reported.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Carers' tasks were multifaceted and changed along the disease trajectory in concordance with patients' medical and emotional needs. Carers experienced physical, emotional and social problems.
Schmid-Büchi *et al.,* 2008	MEDLINE, CINAHL.	1995 – 2007	8 studies	Couples. Carers of patients with breast cancer. Any point in the cancer trajectory.	Not reported.	Carers wanted information concerning the patient's condition, prognosis and ways to help the patient.
Stenberg, Ruland and Miaskowski, 2010	MEDLINE, CINAHL, EMBASE, PsycINFO, AMED, ISI, Cochrane Library.	Inception – 2008	112 quantitative studies. 35 qualitative studies. 17 mixed studies. 18 reviews. 10 expert opinions.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Carers experienced social, emotional, and health-related problems, as well as significant burdens related to caregiving responsibilities.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Stenberg *et al.*, 2014	MEDLINE, CINAHL, EMBASE, PsycINFO, Cochrane Library.	2008 – 2012	65 quantitative studies. 40 qualitative studies. 3 mixed studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	The everyday life of carers changed. Carers took on many responsibilities which they were not prepared to handle. Moreover, carers became so overwhelmed with the caregiving role, that they often neglected themselves leading to physical and emotional illnesses.
Sterckx *et al.*, 2013	MEDLINE, Cochrane Library, EMBASE, PsycINFO, Web of Science, CINAHL.	2000 – 2010	16 qualitative studies.	Carers of patients with high grade glioma only. Any point in the cancer trajectory.	Not reported.	The experience of being a cancer carer was described as both positive and negative. Carers described the need for hope, support, and information.
Teixeira *et al.* 2019	MEDLINE, CINAHL, ERIC, Psychology & Behavioral Sciences Collection, Google.	Inception – 2018	5 qualitative studies.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Not reported.	Carers presented with higher electrodermal and cardiovascular reactivity when compared to non-carers. Therefore, they were at a higher risk of experiencing cardiovascular disease and immune suppression.

Table 5 (cont.): Main characteristics of included reviews.

Citation	**Databases Searched / Websites Searched**	**Years Searched**	**Number of Included Papers**	**Inclusion Criteria**	**Method of Analysis**	**Main Findings**
Wang et al., 2018	PubMed, CINAHL, EMBASE, CENTRAL, PsycINFO, Web of Science, Wan Fang Data, CNKI, CQVIP, CBM.	Inception – 2016	43 quantitative studies. 7 qualitative studies.	Carers of patients with advanced cancer.	Content analysis.	Carers experienced several unmet needs, including a lack of information on the cancer and its treatments.
Wheelwright *et al.*, 2016	PubMed, ISI, Web of Knowledge, EMBASE, MEDLINE, CINAHL, PsycINFO, PsycARTICLES.	1980 – 2015	16 qualitative studies.	Carers of patients with cachexia. Any point in the cancer trajectory.	Thematic analysis.	Five themes were extracted which highlighted the impact on everyday life, the attempts of some carers to take charge, the need for healthcare professional's input, conflict with the patient and negative emotions.
Young and Snowden, 2017	Cochrane Library, CINAHL, PsycINFO, SocINDEX, MEDLINE.	1990 – 2015	30 quantitative studies. 9 qualitative studies. 4 mixed studies. 9 reviews.	Carers of patients diagnosed with a variety of cancers. Any point in the cancer trajectory.	Evolutionary concept analysis.	Personal resources, such as confidence and self-esteem, and the capacity to construct meaning from the experience were identified as determining factors in the positive aspects of caregiving.

2.13 Conclusion

This chapter highlights that there is a gap in the literature on how carers live with their chronic conditions and at the same time, care for the patient with cancer. In addition, most of the existing literature on carers is descriptive in nature, lacks theoretical frameworks, and does not provide a full understanding of the impact of cancer on the carers across the cancer trajectory. Consequently, this systematic review of reviews assisted the researcher to identify a research problem, formulate the research questions, and choose an appropriate methodological framework for this research. The next chapter will describe this methodological framework.

Chapter 3 The Methodology

3.1 Introduction

This chapter discusses the rationale for adopting constructivist grounded theory as the methodological framework for this doctoral research (Charmaz, 2014). This decision was based upon two key issues: the methodological limitations of existing literature on the experiences of carers of patients with cancer and the researcher's constructivist philosophical stance.

3.2 Grounded Theory

Birks and Mills (2011) indicate that grounded theory is appropriate when: (i) little is known about the phenomenon being studied; (ii) the generation of a theory which explains the phenomenon being studied is the desired outcome, and (iii) a process is embedded in the research situation. Therefore, the use of grounded theory was deemed appropriate in this research for the following reasons:

3.2.1 The systematic review of reviews revealed that there is a lack of literature on how carers live with their chronic conditions whilst caring for the patient with cancer. Glaser and Strauss (1967) claim that when little is known about the phenomenon being studied, it is more appropriate to generate a theory from the data rather than try to explain the data using other theories. Most probably these theories would have been developed in a context which is different from the context of this research and hence, may not apply to the gathered data (Glaser and Strauss, 1967).

3.2.2 The systematic review of reviews illustrated that there is a lack of existing empirical literature and theoretical frameworks on the phenomenon being studied. The review revealed that theories have been used to explain certain aspects of cancer caregiving, such as the Transactional Stress Theory (Lazarus and Folkman, 1984) to explain caregiving burden. However, there are no theoretical frameworks which explain how carers live with their chronic conditions and at the same time, care for the patient with cancer. The aim of this research was to build a theory that not only describes this phenomenon but also explains why carers with pre-existing chronic conditions take certain actions when faced with the cancer caregiving role, and the resulting outcomes. Additionally, this theory would also describe the factors which influence how carers live with their chronic conditions. Moreover, this research aimed to build a theory which is applicable to a variety of contexts related to the phenomenon being studied, whereas the existing literature on carers tends to focus on specific contexts, such as carers of patients with breast cancer, colon cancer, and prostate cancer, and specific groups of carers, such as spouses only, as revealed by the review.

3.2.3 The review revealed that most of the literature on cancer caregiving is cross-sectional in design and focuses on a specific phase of the cancer trajectory. On the other hand, although this research was also cross-sectional in design, it aimed to interview carers who are at different phases of the cancer trajectory, including at diagnosis, during active treatment, post-treatment, palliative phase, and end-of-life phase. Thus, it aimed to build a theory which is applicable to all these different phases.

3.2.4 It was particularly appropriate to adopt grounded theory in this research because of its focus upon social processes (Glaser, 1978; Glaser and Strauss, 1967; Strauss and Corbin, 1990). Strauss and Corbin (1990) indicate that a process is a set of actions taken in response to a situation/problem over time. This research investigated how carers live with their chronic conditions (action) whilst providing care to the patient with cancer (situation). In addition, it investigated whether these actions change over time, considering that cancer caregiving often occurs over a long period of time.

Before choosing to adopt grounded theory in this research, other qualitative approaches were considered, as described in the next section.

3.3 Grounded Theory Versus Other Approaches

This research aimed to explore carers’ experiences of living with a chronic condition while at the same time, caring for a patient with cancer. As such, it does not lend itself to the hypothesis-driven and deductive methodology of quantitative research because the collected data would not be rich enough to provide an in-depth understanding of the carers’ experiences. On the other hand, qualitative research is a process of naturalistic inquiry that seeks an in-depth understanding of social phenomena within their natural setting and hence, was deemed appropriate for this research (Parahoo, 2006). There are different approaches to qualitative research, as described in the following paragraphs.

Descriptive phenomenological approaches, such as those outlined by Giorgi (2009) and Moustakas (1994), are primarily concerned with developing a general description of the phenomenon being studied (Masoodi, 2017). However, the aim of this research was not to describe the phenomenon but to provide an explanation for it. Hermeneutic phenomenological approaches, such as those outlined by Van Manen (1990) and Smith, Flowers and Larkin (2009), were considered to be relevant to this research because, similarly to constructivist grounded theory (Charmaz, 2014), they are also located in the constructivist paradigm and acknowledge the researcher's perspective. However, hermeneutic phenomenological approaches are concerned with understanding how participants make sense of their experience, and hence, are mostly concerned with cognitive processes. On the other hand, this research aimed to investigate the underlying factors, actions and outcomes, rather than how carers make sense of their experience of living with their chronic conditions whilst caring for the patient with cancer. Furthermore, the aim of this research was to build a theory, whereas hermeneutic phenomenological approaches are not appropriate for theoretical development (Masoodi, 2017).

Ethnography was also not deemed appropriate for this research. Ethnography focuses on understanding the shared values and taken for granted meanings held by a group of individuals within a culture (Creswell and Poth, 2018). Whilst an understanding of how culture impacts carers living with their chronic conditions whilst caring for the patient may prove to be of interest, this was not the focus of this research which sought to define and provide a broader insight into the topic. The next sections describe the keys features and main approaches of grounded theory.

3.4 The Key Features of Grounded Theory

Grounded theory has a number of distinguishing procedural features compared to other qualitative approaches (Chun Tie, Birks and Francis, 2019). These include:

3.4.1 The use of theoretical sampling - Using an initial purposive sample of participants who have experienced the phenomenon being studied to start generating data. Data are analysed and coded to develop categories before further data collection is undertaken. Theoretical sampling is then used to seek people or events to generate further data to confirm or refute the categories developed from the first data set and to continue with theory development (Chun Tie *et al.*, 2019; Singh and Estefan, 2018).

3.4.2 Using the constant comparative method for coding and category development. This involves the constant comparison of codes to codes, codes to categories and categories to categories until a grounded theory is fully developed (Chun Tie *et al.*, 2019; Singh and Estefan, 2018). There is the simultaneous collection and analysis of the data (Singh and Estefan, 2018).

3.4.3 Using memos to elaborate on categories, to specify their properties, to compare categories and to identify gaps in the theory. Moreover, memos provide detailed records of the researchers' thoughts and feelings, and decisions made relating to sampling and other aspects of the research process (Chun Tie *et al.*, 2019; Singh and Estefan, 2018).

3.4.4 Creation of analytical codes and categories developed from the collected data rather than using pre-existing concepts (Chun Tie *et al.*, 2019; Singh and Estefan, 2018).

3.5 Main Approaches of Grounded Theory

Grounded theory approach was developed in the 1960s in response to the predominant quantitative approaches at that time (Birks and Mills, 2011). Over time there have been several modifications to the methodology resulting in three main approaches of grounded theory: classic grounded theory (Glaser, 1978), Straussian grounded theory (Strauss and Corbin, 1990) and constructivist grounded theory (Charmaz, 2014). Similarities exist between the three approaches with regards to their methodological processes. All three approaches use the constant comparative method, facilitate theoretical sampling, and integrate categories into a theoretical framework. However, the three approaches differ with regards to their philosophical orientation (Singh and Estefan, 2018).

Charmaz (2014) and Singh and Estefan (2018) argue that classic grounded theory (Glaser, 1978) has positivist leanings because it encourages the researcher to adopt a neutral position and use a set of procedures to identify one true reality of the phenomenon being studied. On the other hand, Glaser (2005) denies having any philosophical orientation associated with his grounded theory approach. He argues that grounded theory should be a purely inductive methodology, meaning that ontology and epistemology should not be used to justify the use of grounded theory, but rather it is the data which determine the philosophical stance to be taken by the researcher (Glaser, 2005). However, Thornberg (2012) actually rejects Glaser's (2005) claim and argues that since classic grounded theory (Glaser, 1978) encourages the researcher to adopt a neutral position by putting aside his or her personal biases in order to discover one true reality of the phenomenon being studied, then Glaser's (1978) approach to grounded theory is actually grounded in positivism. Similarly, Strauss and Corbin (1990) did not reveal an initial philosophical orientation in their original text however, later writings suggest that they follow an interpretivism ontological approach (Strauss and Corbin, 1994, 1998). This means that although Strauss and Corbin (1994, 1998) do not contradict Glaser's (2005) claim of discovering one true reality of the phenomenon being studied however, they do acknowledge the inevitable influence of the researcher's subjectivity in the research process and hence, the difficulty of describing a phenomenon as it 'really' is. As a result, Strauss and Corbin (1990) propose a prescribed number of steps to minimise personal biases and maximise objectivity as much as possible in the research process. On the other hand, the constructivist approach to grounded theory (Charmaz, 2014) is rooted in pragmatism and relativist epistemology and argues that there are multiple realities of the phenomenon being studied since both the researcher's perspective and the participants' accounts play an integral role in theory development (Thornberg, 2012). In fact, Charmaz's (2014) approach to grounded theory acknowledges the role that the researcher's previous personal and professional experiences and the extant literature play in understanding the phenomenon being studied (Singh and Estefan, 2018). Since, the three main approaches to grounded theory differ philosophically, a choice had to be made regarding which approach to adopt. The next section describes why constructivist grounded theory (Charmaz, 2014) was chosen as the methodological framework for this research.

3.6 Constructivist Grounded Theory

Classic grounded theory (Glaser, 1978) maintains that the researcher has to detach himself from the research process. Similarly, Strauss and Corbin (1990) emphasise the importance of minimising personal biases and maximising objectivity in the research process (Sebastian, 2019; Singh and Estefan, 2018). However, the researcher is an oncology nurse by profession and has worked with both patients with cancer and their carers and hence, it would have been very difficult for the researcher to completely remove himself from the research process. Therefore, the researcher was already grounded in experiences related to the phenomenon being studied. Hence, it was going to be difficult to achieve an objective description of the phenomenon being studied. Furthermore, the researcher was aware that multiple realities exist because different patients and carers experience the cancer trajectory differently. For these reasons, classic grounded theory (Glaser, 1978), as well as Straussian grounded theory (Strauss and Corbin, 1990) approaches were both deemed inappropriate for this research because both emphasise that the researcher distances himself or herself from the phenomenon being studied, which did not seem achievable. As a result, constructivist grounded theory (Charmaz, 2014) was considered as more appropriate. Charmaz (2014) acknowledges the researcher's perspective as being integral to the processes of data collection and analysis. Therefore, constructivist grounded theory (Charmaz, 2014) provided the analytical tools which allowed the researcher to use his personal and professional experiences when co-constructing the theory with the participants (Singh and Estefan, 2018).

Charmaz (2014) presents constructivist grounded theory as an emergent approach which allows for flexibility when adopting its methods. In fact, Charmaz (2014) states that the methods should be seen as 'flexible' rather than 'prescriptive' to facilitate the emergence of data. On the other hand, Strauss and Corbin (1990) advocate the use of the 'coding paradigm' for theory development. However, Glaser (1992) argues that the coding paradigm can be seen as a verification method because the researcher tries to fit the data into the coding paradigm and then, he or she tries to see whether the resulting framework is found in the data or not. Therefore, there is the possibility that the emergent data may not fit the coding paradigm (Glaser, 1992). Moreover, other researchers argue that there is the risk that, if the researcher uses the coding paradigm, then he or she would start focusing too much on the framework and distancing themselves from the data. This would mean going against one of the fundamental features of grounded theory, that the theory emerges from the data (Charmaz, 2000; Heath and Cowley, 2004). Therefore, although Straussian grounded theory (Strauss and Corbin, 1990) has been recommended for researchers who are novice in grounded theory and who wish to have some form of structure to guide their research (de Beer and Brysiewicz, 2016), on the other hand, adopting this approach could have hindered theory development (Charmaz, 2000; Heath and Cowley, 2004). Additionally, in constructivist grounded theory (Charmaz, 2014), interaction is regarded to be dynamic and subject to change. In fact, Charmaz (2014) states that it is important to code for ‘actions’ rather than ‘themes’ so that the researcher can identify the potential temporal processes emerging from the data. Therefore, constructivist grounded theory (Charmaz, 2014) is further relevant to this research because both chronic conditions and cancer caregiving may be considered as long lasting but changing phenomena.

Finally, the main aim of this research was to develop an in-depth understanding of how carers live with their chronic conditions and at the same time, care for the patient with cancer. Charmaz’s (2014) approach to grounded theory is exploratory and interpretive and hence, enables an understanding of the breadth and depth of the developing theory (Singh and Estefan, 2018). On the other hand, Glaser (2006) argues that researchers should try and generalise across substantive areas of interest to identify a broader theory. However, applying this perspective to this research would have meant including carers of patients with different types of chronic conditions or functional limitations and not just cancer. This could have complicated the research process and introduced possible time constraints (Singh and Estefan, 2018). On the other hand, Charmaz (2014) encourages researchers to focus on building a theory in a particular substantial area of interest (Singh and Estefan, 2018) and hence, this methodological framework was deemed appropriate for this research since this research solely focused on cancer caregiving. Chapter One highlighted how cancer and chronic conditions potentially represent two separate substantial areas of interest.

3.7 Conducting a Literature Review in Grounded Theory

There is considerable debate regarding the timing and the role of the literature review in a grounded theory study (Deering and Williams, 2020; Dunne, 2011; Giles, King and De Lacey, 2013; Thornberg, 2012). Glaser (1992) advocates that neither an exploratory nor a detailed literature review should be conducted before the research has commenced in order to allow the theory to emerge from the data and prevent the researcher from importing preconceived ideas and imposing them on the theory (Deering and Williams, 2020; Dunne, 2011; Giles *et al.*, 2013). In addition, Glaser (1992) argues that the literature most relevant to the research may not actually be known at the outset since the researchers may lack the necessary knowledge to make an adequate literature search. Hence, conducting a time-consuming literature review at the outset may be wasteful (Dunne, 2011). However, Deering and Williams (2020) argue that researchers will often need to conduct a literature review before the start of their research to demonstrate that there is a gap in literature and to formulate research questions, so as to justify that their research will generate new knowledge. Furthermore, Ethics Committees often require researchers to provide a brief overview of the topic when submitting their ethics proposal and hence, all researchers will come to the research situation with some background of the pre-existing literature (Deering and Williams, 2020; Dunne, 2011). These notions are also acknowledged by Charmaz (2014) in her writings on the place of the literature review in constructivist grounded theory. In fact, constructivist grounded theory (Charmaz, 2014) does allow a preliminary literature review to be conducted before the research commences (Giles *et al.*, 2013). However, Charmaz (2014, p. 307) recommends "*to let this material lie fallow*" until the researcher has developed some categories. This will allow the developed theory to be grounded in the data and not in the existing literature (Deering and Williams, 2020; Giles *et al.*, 2013). Nevertheless, Charmaz (2014) acknowledges that the acquired knowledge from an early literature review can provide a sense of direction for the researcher. It can help the researcher identify concepts that could represent an initial idea from where to start engaging analytically with the collected data (Dunne, 2011). This view is also supported by Strauss and Corbin (1990) who argue that undertaking an early literature review can help researchers gain theoretical sensitivity, ask questions and think about theoretical sampling (Giles *et al.*, 2013). Therefore, these arguments justify the decision to carry out a systematic review of reviews before conducting the actual research. In fact, this review provided a general sense of direction for this research and assisted the researcher in preparing his Ethics proposal. It was central to the formulation and justification of the research questions and, importantly, enabled the researcher to identify an area of focus which previously had been largely overlooked.

Charmaz (2014) argues that, in addition to the preliminary literature review, a more detailed literature review should be conducted when potential categories start to emerge. This review would allow the researcher to start engaging with the research which is relevant to the developing categories. The extant literature is compared with the developing categories to further enhance theory development. The constant comparative method and reflexivity are used to further develop the theory, whilst ensuring that theory development is primarily rooted in the empirical data (Giles *et al.*, 2013; Thornberg and Dunne, 2019). Therefore, researchers should allow their developing theory to guide this review (Charmaz, 2014). With this debate in mind, a detailed literature review was conducted once some categories had been developed from the data, as suggested by Charmaz (2014). Literature for the detailed literature review was searched for in the SCOPUS and PubMed databases. The search terms that were utilised included ‘theory’, ‘caregiving' and ‘chronic conditions’, as well as other search terms mirroring concepts which were emerging from the developing theory, such as ‘disruption’ and ‘motivation’. This detailed literature review is described in Chapter Ten.

3.8 Conclusion

In summary, this chapter provided the rationale for choosing constructivist grounded theory (Charmaz, 2014) as the methodological framework for this doctoral research. This methodological framework was deemed appropriate because the aim of this research was to build a theory of how carers live with their chronic conditions whilst caring for the patient with cancer. Moreover, this methodological framework acknowledges the researcher’s personal and professional experiences as being integral to the research process. Additionally, this chapter provided the rationale for conducting a literature review prior to commencing this research and a more detailed literature review later on in the research process. The next chapter will describe the methods employed.

Chapter 4 The Methods

4.1 Introduction

This chapter describes how this research was conducted in accordance with Charmaz's (2014) constructivist grounded theory described in the previous chapter. Constructivist grounded theory takes into account the need for the researcher to be flexible since it is difficult to develop a set of detailed steps and procedures before the research has commenced (Charmaz, 2014). It was not clear then, when this research was started, exactly what direction the research process would take. This chapter presents the research question, eligibility criteria, recruitment strategy, and process of data collection. The ethical considerations which were applied to this research are also described.

4.2 Three Stages of Research

This research involved three stages. The first stage involved conducting and analysing the first seven interviews. The second stage involved conducting and analysing the next seven interviews. The third stage involved conducting and analysing the final thirteen interviews. Dividing this research into three stages allowed for an in-depth analysis of the data collected at each stage and hence, to consider the direction of theoretical sampling for the next stage. This was important for theory development as will be discussed in the next chapter. The next two sections describe how the research question was formulated after identifying the research problem.

4.3 Formulating the Research Question

In grounded theory, research questions serve to identify but not make assumptions about the phenomenon being studied since the concepts pertaining to that phenomenon have not yet been identified, at least in the population being studied (Strauss and Corbin, 1990). Therefore, although the initial intention was to use the word 'manage' instead of the words 'live with', it was then decided to refrain from using this word as then one would be assuming that all carers manage their chronic conditions whilst caring for the patient with cancer. Therefore, the initial research question of this research was: How do carers live with their chronic conditions whilst providing care to the patient with cancer?

4.4 Refining the Research Question

Charmaz (2014) encourages researchers to be willing to alter the research question as the research progresses. Therefore, after reading further into the tenets of constructivist grounded theory and considering the importance of identifying temporal sequences in this approach (Charmaz, 2014), the research question was refined to reflect ‘process’. Whilst the initial research question reflected the ‘action’ of how carers live with their chronic conditions whilst providing care to the patient, on the other hand, the refined question reflected how this action changes over time. Therefore, this research aimed to understand how carers live with their chronic conditions through different points along the cancer trajectory, including at diagnosis, during active treatment, post-treatment, palliative phase, and end-of-life phase. In addition, the second research question was about which factors affect how carers live with their chronic conditions whilst providing care to the patient throughout the cancer trajectory. Therefore, this research aimed to understand:

i. How do carers live with their chronic conditions whilst caring for the patient with cancer and does this change over time?
ii. Who or what influences how carers live with their chronic conditions?

At this stage, the term ‘live with’ in the research questions meant how carers deal with their chronic conditions whilst providing care to the patient. However, it is important to note that ‘living with a chronic condition’ is actually a concept, which emerged in 1975 from the works of Strauss and Corbin (Ambrosio *et al.*, 2015). Since then, several researchers have analysed and provided an understanding of this concept (Ambrosio et al., 2015; de Freitas and Mendes, 2007). However, such literature was not explored as part of the preliminary literature review, even though Parahoo (2006) states that if a researcher wants to conduct research on a particular concept, then he or she needs to explore and understand the main characteristics of that particular concept before commencing data collection and analysis. However, such literature was not explored in order to prevent importing preconceived ideas, emerging from reading such literature, and imposing them on the developing theory. Imposing such ideas goes against the tenets of constructivist grounded theory (Charmaz, 2014). Instead, such literature was read later as part of the detailed literature review (see Chapter Ten).

4.5 The Research Setting

This research was conducted in Malta. Patient care in Malta occurs in a number of different settings, both in institutions of various kinds, such as the local oncology centre, and in the community, such as community health centres. Furthermore, there are both public and private health services. Therefore, carers who were caring for patients with cancer both in the hospital setting and in the community setting, as well as from both public and private services, were recruited. Charmaz (2014) argues that, in constructivist grounded theory, variations within a category or a process usually become apparent when the researcher is conducting theoretical sampling and hence, later on in the research process. Therefore, utilising both the hospital setting and community setting, as well as both public and private services, allowed the recruitment of a diverse group of carers. This variation in population was key to developing a theory which is applicable to a variety of contexts related to the phenomenon being studied (Charmaz, 2014), as will be described in the next chapter. Examples of the variation which were sought in this research included:

i. Different groups of carers, such as parents, adult children, siblings, or friends of the patient with cancer.
ii. Carers with different chronic conditions.
iii. Carers caring for patients with different types of cancer.
iv. Carers who were caring for the patient either whilst the patient was in hospital or at home.
v. Carers who were either living with the patient or living in a different household.
vi. Carers who were either living alone with the patient or sharing the household with other members of the family.
vii. Carers who were either retired, unemployed or working.
viii. Carers who were caring for the patient at different phases of the cancer trajectory.

Additionally, participants were recruited from both the public and private health settings because, as discussed in Chapter One, research is needed in both settings (Ministry for Energy and Health, 2014). The research settings were the local oncology centre, two local acute hospitals, as well as the community setting, including community health centres and community-based carer organisations. The next sections describe the eligibility criteria and recruitment strategy.

4.6 Eligibility Criteria

The previous chapter described how constructivist grounded theory (Charmaz, 2014) is characterised by theoretical sampling. Theoretical sampling is a type of sampling in which the researcher aims to develop the properties of his or her developing categories. Hence, theoretical sampling is sampling carried out on the basis of categories that emerge from the data and not sampling a representative distribution of a particular population. For example, in the first phase of this research, one of the properties of the emerging categories suggested that being diagnosed with a complex chronic condition seems to impact the process of how carers live with their chronic conditions whilst caring for the patient with cancer. Therefore, in the second and third stages of this research, the researcher sought to recruit carers with complex chronic conditions to further develop the emerging categories. Therefore, to engage in theoretical sampling, the researcher must have already developed categories from the data. Hence, it is suggested that the initial sample should be a fairly random group of people who have experienced the phenomenon being studied, to begin to develop categories. Then, theoretical sampling is used to seek people or events to generate further data to confirm or refute these categories and to continue developing the theory (Charmaz, 2014; Chun Tie *et al.*, 2019). The next chapter will provide further examples of how certain categories helped with identifying the sample that needed to be recruited to further develop the theory. In the first stage of this research, the seven participants were recruited according to the eligibility criteria described in Table 6.

Table 6: Eligibility criteria.

Carers were eligible for this research if they:

- Were >18 years. No upper age limit.
- Have been diagnosed with at least one chronic condition.
- Cared for a patient with cancer, irrespective of cancer type.
- Were able to give informed consent. Carers who were not judged to be able to give informed consent by the intermediaries, who were unable to express their views due to communication difficulties, who were involved in other intensive research studies, or were unwilling to participate, were excluded from this research.

In the initial stage of this research, what was important was not the carer’s chronic condition, or the patient’s cancer or any other demographic characteristics, but that the participant could tell the researcher about his or her experience of living with a chronic condition whilst caring for the patient. In fact, the eligibility criteria did not include any sociodemographic characteristics or the number of hours of care provided by the carer as then one would be assuming that only these factors are theoretically relevant (Charmaz, 2014). Once the first stage was complete, it was possible to move onto theoretical sampling to develop the emerging categories. During theoretical sampling, that is during the second and third stages of this research, the above eligibility criteria were still used however, specific groups of carers were sought, as will be described in the next chapter.

As will be described in Chapter Five, in grounded theory studies, data collection stops when theoretical saturation is achieved. Theoretical saturation refers to the point at which no additional data are found which can further develop the properties of the categories (Charmaz, 2014). Nevertheless, a sample size of around 30 informal carers was expected to be enough to achieve theoretical saturation, based on Thomson's (2011) and Creswell and Poth's (2018) recommendations for achievement of saturation.

4.7 Recruitment Strategy

The original recruitment technique was that carers would only be recruited through intermediary Practice Nurses, Charge Nurses and Hospital Consultants. However, this technique could have led to mainly / only spouses being involved in this research, as spouses most often accompany patients to medical visits (Wolff and Roter, 2011). Moreover, recruitment by health care professionals acting as intermediaries has been shown to have a low success rate (Sygna, Johansen and Ruland, 2015). Additionally, carers often experience time constraints as they juggle between work, family and caregiving responsibilities and hence, may find it difficult to find time to participate in research studies, especially if they need to find someone to look after the patient with cancer (Leslie, Khayatzadeh-Mahani and Mackean, 2019). Therefore, there was the possibility of a high decline rate. Hence, considering these challenges and keeping in line with the tenets of constructivist grounded theory (Charmaz, 2014), it was important that the recruitment strategy employed was as flexible as possible in order to improve the chances of recruiting enough carers. In addition, it was also important that the recruitment strategy facilitated the recruitment of a heterogeneous sample of carers to allow for the development of a theory which is applicable to a variety of contexts related to the phenomenon being studied (Charmaz, 2014). As a result, different recruitment techniques were used to allow access to a heterogeneous sample of carers. Recruitment techniques included:

i. Partnering with intermediary Practice Nurses, Charge Nurses and Hospital Consultants.
ii. Partnering with intermediary organisations working in the field of cancer.
iii. Using print media advertisement.
iv. Distributing leaflets and posters in the two local acute hospitals, the local oncology centre and community health centres.
v. Employing snowball sampling.
vi. Using social media advertisement.

These recruitment techniques have been implemented elsewhere (Leslie *et al.*, 2019; Sygna *et al.*, 2015). Although certain techniques, such as partnering with intermediaries at the hospital and intermediary organisations, were more successful than others, recruitment rates were still low in these studies and hence, all the techniques were used to increase the chances of recruiting enough carers for this research. Furthermore, the above recruitment techniques are referred to as ‘opt-in techniques’ and these techniques were used because, according to Treweek *et al.* (2013), these techniques are ethically sound because the participants explicitly agree to be contacted by the researcher. Conversely, ‘opt-out techniques’, such as on-site recruitment by the researcher, may lead to ethical concerns because the participants may feel coerced to participate in the research (Treweek *et al.*, 2013). The next sections will describe the recruitment techniques used in this research. However, before moving on to the next sections, it is appropriate to state that the information sheet, leaflet and poster were reviewed by two carers of patients with cancer to determine whether they were easy to understand, and clearly explained what the study entailed and how potential participants could make contact with the researcher.

4.7.1 Partnering with Intermediary Practice Nurses, Charge Nurses and Hospital Consultants

In accordance with approved procedures, intermediaries approached potential participants and gave them information about the study. Intermediaries included Practice Nurses, Charge Nurses and Hospital Consultants, who were responsible for the care of the patient with cancer. The intermediary provided an information sheet to any family members or friends accompanying the patient. The intermediary did not ask family members or friends directly whether they have a chronic condition or not. Instead, people self-identified as having a chronic condition. Potential participants were given some time to read the information sheet and consider taking part. Those participants who expressed willingness to participate were asked to provide their contact details to the intermediary who passed on their contact details to the researcher. A meeting was then set up with interested participants to further discuss the objectives of the research, the possible risks associated with their participation, time requirements, as well as to answer any queries. During this meeting, arrangements were made for the time and place of the interview. When possible, the researcher also attended the clinics himself. When this happened, the intermediary at the clinic identified potential participants and introduced them to the researcher. The researcher then discussed the research with the participants and, if they were interested, provided them with an information sheet.

During the first stage of this research, only two out of seven participants interviewed, were recruited using this recruitment technique. This prompted the researcher to ask the intermediaries to document the reasons why potential participants declined participation. Reasons for non-participation included:

i. Lack of interest in participating in this research.

ii. Lack of time to participate in an interview.
iii. Length of the interview specified in the participant information sheet was too long.
iv. Not satisfying the eligibility criteria.

Other challenges reported by the intermediaries included:

i. Lack of time to mention the research to potential participants during consultations.
ii. Forgetting to mention the research to potential participants.
iii. Not prioritising recruitment.

Moreover, whilst attending the clinics, the researcher identified three issues with this recruitment technique:

i. Intermediaries were only approaching participants who they already knew were living with a chronic condition. As a result, it is possible that several potential participants were being missed.
ii. Intermediaries did not spend enough time introducing the research to potential participants before providing them with the information sheet.
iii. A number of participants were not reading the information sheet at that point in time but rather were informing the intermediary that they will read it at home and get back to them if they were willing to participate in this research.

According to constructivist grounded theory, the processes of data collection and analysis are directed by the emergent data rather than by ‘external prescriptions’ (Charmaz, 2014). However, considering the above pragmatic issues when recruiting carers, then it seems that ‘external prescriptions’ do exist and do play a key role in directing the data collection and analysis processes. Therefore, in order to limit these ‘external prescriptions’ and since constructivist grounded theory emphasises flexibility in the method (Charmaz, 2014), a guide for approaching potential participants was developed and introduced. This guide is illustrated in Appendix B. After distributing this guide to all the intermediary Practice Nurses, Charge Nurses, Hospital Consultants, another six participants were recruited through this recruitment technique.

4.7.2 Partnering with Intermediary Organisations Working in the Field of Cancer

Three community-based carer organisations, who have the outreach to, and are used by carers of patients with cancer, were approached. The main aim in approaching these organisations was to connect and form partnerships with those who had access to a heterogeneous population of carers that was needed in this research. These groups were asked to approach potential participants who attended their seminars. Furthermore, nurses at one of the organisations involved in providing hospice care in the community, were asked to act as intermediaries and provide an information sheet to any family members or friends who were present during their patient home visits. One participant was recruited through this recruitment technique.

4.7.3 Other Recruitment Techniques

Other recruitment techniques that were used included:

i. **Distributing leaflets and posters in the local acute hospital, local oncology centre and community health centres.** Posters and leaflets were distributed in the wards and waiting areas of the two local acute hospitals, local oncology centre and community health centres. These posters and leaflets provided information about the research, as well as how one can participate in it. Two participants were recruited through this recruitment technique.

ii. **Using print media advertisement.** The poster of the research was advertised twice on a local newspaper. One participant was recruited through this recruitment technique.

iii. **Snowball sampling.** After the interview, research participants were invited to identify other family members or friends who were also caring for the patient. Those participants who identified other family members or friends were provided with an information sheet to pass on to these individuals. One participant was recruited through this recruitment technique.

iv. **Using social media advertisement.** The poster of the research was advertised on social media, including Facebook, Twitter and Instagram. This recruitment technique was the most successful, with fourteen participants being recruited through this recruitment technique.

The next section describes the impact of the COVID-19 pandemic on the recruitment of participants. In this research, thirteen participants were recruited before the COVID-19 pandemic, whilst fourteen participants were recruited during the pandemic.

4.8 Recruitment During COVID-19 Pandemic

More than half of the participants were recruited through social media advertisement and this high successful rate of recruitment was a direct result of the COVID-19 pandemic. From April 2020 till March 2021, following directives issued by the Superintendent of Public Health in Malta, carers were not allowed to accompany patients for medical visits or to visit patients at the local oncology centre and local acute hospitals. As a result, it was impossible to recruit carers through intermediaries at the hospital or through leaflets and posters. Additionally, during this time period, intermediary organisations working in the field of cancer stopped holding seminars for carers. Therefore, from April 2020 till March 2021 and hence, during the third stage of this research, emphasis was put on recruiting carers through social media advertisement and snowball sampling, which explains the high success rate of recruitment through social media.

It is possible that relying solely on social media advertisement and snowball sampling could have influenced the age group of the participants recruited in the third stage of this research. Most of the participants recruited in the third stage were younger when compared to the participants recruited in the first two stages. This could have been due to the fact that the younger generation are more computer literate and spend more time on social media. Nevertheless, the researcher did not seek to recruit other elderly participants because the analysis of the data did not indicate that age was an important factor in this theory. The next sections describe the ethical considerations which were applied to this research.

4.9 Ethical Approval

This research received ethics approval from the Faculty Research Ethics Committee (FREC) at the University of Malta (Approval code: FRECFHS_1819_016) and the Research Integrity and Governance Team at the University of Southampton (Approval number: 46776).

4.10 Ethical Considerations and Management of Risk

To reduce the risk of coercion, potential participants were approached by either Practice Nurses or Charge Nurses or Hospital Consultants and not by the researcher. Although the intermediaries were encouraged to invite all eligible carers to participate in this research, to minimise risk of causing unnecessary emotional distress, the intermediaries were instructed to first consider possible impacts of research involvement and assess potential participants’ emotional capacity for participation before inviting them to participate.

Potential participants were provided with an information sheet. The information sheet included a description of the research, what was being requested of the participants, a description of any potential risks or harm involved in participating in this research and a description of the participant’s rights if they chose to participate. It was made clear to the participants that participation in this research was entirely voluntary and declining to take part would not affect their participant rights nor the clinical care of the patient with cancer. Similarly, the participants were free to withdraw from this research at any time without giving reasons and without prejudice. Furthermore, the consent form was only signed after the researcher addressed any queries that the participant had. Moreover, as suggested by Sivell *et al.* (2019), the researcher went through the consent form again immediately before the interview to check that the participant was still willing to participate in this research.

This research involved potentially vulnerable people since they were dealing with a cancer diagnosis and the burden associated with the cancer caregiving role. Therefore, there was the possibility of the participants experiencing psychological distress during the interviews. Hence, the researcher was always prepared to stop the interview if the participant requested this. A psychologist at the oncology hospital was available free of charge if the participant did experience psychological distress during or after the interview. Additionally, if during the interview, the participant indicated that they were no longer managing their chronic conditions, which was detrimental to their health, the researcher encouraged the participant to speak to his / her family doctor or to a health centre doctor or to the Practice Nurse.

Furthermore, all data was kept confidential at all times:

i. Audio recorders were password protected.
ii. Audio files were downloaded to the University of Southampton network in password protected folders as soon as possible after completion of the interview, and the file was deleted from the recorder.
iii. Audio files were only transcribed by the researcher.
iv. All participants who took part in this research were given a code and that code, rather than their name, was used to identify their recorded interview and the typed version.
v. The recording of the interview and the typed version were kept separately from the participant’s name and other identifiable information.
vi. The recording of the interview and the typed version, as well as the participant’s personal data and consent form were stored in separate locked filing cabinets in secure entry offices at the University of Malta.
vii. Written and digitally recorded data were stored in password protected folders.
viii. When the participant mentioned a person or organisation by name, these were removed and a descriptor (e.g. ‘participant’s husband’; ‘name of hospital’) added instead.
ix. With the participant’s permission, direct quotations from the interview were used in this report written about this research. Their names were not used. Instead, the term ‘Participant’ was used throughout the research to ensure that they cannot be personally identified in any way.

x. Research data will be kept for 10 years from the end of the research, in accordance with University of Southampton policy.

This research involved visiting people in their homes or another place of their choosing. This signalled a safety risk for the researcher and hence, appropriate steps were taken to ensure his safety whilst working alone, but also at the same time preserving confidentiality. The University of Southampton's guidance about risk assessment and lone worker policies and procedures were followed. Since the researcher was conducting interviews in a different country, before each interview, he informed a confidant at the University of Malta about when the interview will take place and for how long. A sealed envelope containing details of where the interview will be held was also given to the confidant. This envelope was kept in a locked cabinet at the same university and only the confidant had access to it. If the researcher did not make contact with the confidant after the interview had finished, the confidant had the permission to open the envelope. In addition, when the researcher found an interview to be challenging, any concerns were discussed with his research supervisors. Furthermore, a psychologist at his place of work was available to provide her services free of charge. The next sections will describe the process of data collection.

4.11 Data Collection

Data were collected by in-depth interviews at one point in time. This allowed the researcher to collect data from different carers who were at different stages of the cancer trajectory and hence, develop a theory which is applicable to a variety of contexts related to the phenomenon being studied (Charmaz, 2014). Due to time constraints, longitudinal interviewing was rejected as an approach as it would have resulted in the researcher recruiting less participants and hence, limiting the researcher's ability to recruit a diverse group of carers. Moreover, the aim of this research was to understand how carers live with their chronic conditions along different points of the cancer trajectory, including at diagnosis, during active treatment, post-treatment, palliative phase, and end-of-life phase. If the researcher had decided to follow participants along the cancer trajectory as with longitudinal interviewing, it is possible that the participants recruited would have experienced similar cancer trajectories, hence limiting the researcher's ability to recruit a diverse group of carers. Additionally, there is always the problem of sample attrition with longitudinal interviewing (Calman, Brunton and Molassiotis, 2013). Carers often experience time constraints and considering that they are also suffering from a chronic condition, they may become too burdened to commit to serial interviews with the researcher.

The interviews were conducted either in Maltese or English, according to the participants' preferences. Field notes were written after interviews to record details of the physical environment, record the researcher's reflections of the interview, and capture the participant's non-verbal behaviour as this cannot be revealed through transcription. In addition, memos were written about the researcher's thoughts, feelings, insights, and ideas in relation to this research. Field notes and memos will be described further in the next chapter. The carer's age and gender, employment status, chronic conditions, relationship to the patient, and phase of the cancer trajectory were also collected.

4.12 Interview Guide

Preparing an interview guide provided the researcher with the opportunity to think about what the interview would cover and to tackle any difficulties that could arise during the interview, such as question wording or sensitive areas (Smith *et al.*, 2009). The questions in the interview guide were developed using Charmaz's (2014) guidelines to constructing grounded theory interview questions. Charmaz (2014) suggests using an initial open-ended question, such as "*Tell me about what happened …?*". Intermediate questions are more focused, such as "*Tell me how you go about …? What do you do?*", or "*Could you describe a typical day for you when you are …?*". Ending questions are again open to allow the participant to talk about topics which have not been covered in the interview or which might have been missed out, for example, "*Is there something else you think I should know to understand … better?*". This type of format made it easier for the researcher to get the participant to speak about his or her experience. The interview guide is illustrated in Appendix C.

The first question of the interview schedule was "*Can you tell me more about yourself and the person you are caring for?*". As recommended by Smith *et al.* (2009), the aim of this question was to put the participants at ease and feel comfortable. The responses given by the participants during the interviews were used to guide the data collection, by probing the participants to obtain more in-depth information. The use of probes such as "*Can you say more about this?*" or "*How did you feel about that?*" amongst others were used to ensure clearer and more elaborate answers from the participants. This enabled an exhaustive exploration of the experiences and at the same time, ensuring that probes were not leading (Smith *et al.*, 2009). In addition, Smith *et al.* (2009) argue that sometimes the questions in the interview schedule are insufficient to elicit a useful response from the participants to answer the research question. Hence, prompts were developed for some of the questions to encourage the participants to keep talking and reveal more about their experiences. Therefore, the interview guide was developed in order to elicit information about the carer's experiences of living with a chronic condition and at the same time, caring for a patient with cancer. However, the interview guide was not considered a strict document to be adhered to and it was used as a guide rather than a fixed interview schedule. Using the interview guide as a fixed interview schedule would introduce 'external prescriptions' to the data collection process, possible inhibiting the emergence of data and hence, inhibiting theory development (Charmaz, 2014). The next section describes the role of researcher in the interview process.

4.13 The Role of the Researcher

The previous chapter described how, in constructivist grounded theory, the researcher influences the theory that emerges (Charmaz, 2014). However, in addition to the researcher's perspective which influences both the data collection and analysis processes, another factor which influences the developing theory is the researcher's role in collecting high quality data. Two criteria impact the researcher's role in collecting high quality data: nurse-researcher dilemma and building rapport. These two criteria are described in the next sections.

4.13.1 Nurse-Researcher Dilemma

Whilst conducting this research, the researcher had a dual role. In addition to being a researcher, he was also a nurse by profession. As a result, he experienced role conflict when deciding on how to introduce himself to the participants. Jack (2008) argues that the way nurse-researchers introduce themselves to the participants will influence the participants' perception of them. For example, if the researcher identifies himself or herself as a nurse-researcher, then those participants who had positive past experiences with nurses may feel more comfortable sharing certain information with him or her. On the other hand, those participants who had negative past experiences with nurses may omit certain information, especially if they fear that the nurse-researcher will act on information disclosed during the interview. Additionally, if the researcher introduces himself or herself as a nurse-researcher, the participants may view the researcher in the more familiar role of 'nurse' and attempt to ask questions about their clinical condition (Jack, 2008). Therefore, the way the researcher introduces himself or herself to the participants will impact the quality of the data collected and hence, theory development.

The researcher's original intention was to introduce himself as a researcher only and conceal his role as a clinician. He was concerned that if he identified himself as a nurse working in the oncology setting, the participants would start asking questions about their chronic condition or the patient's cancer. However, the researcher worked at the local oncology centre, which was one of the four recruitment sites. Hence, there was the possibility that the participants might see him in his nursing uniform. This could have created trust issues and hence, hinder his ability to establish a rapport with the participants which would have impacted data collection and theory development, as described in the next section. Furthermore, concealing his role as a clinician when introducing himself to the participants would have introduced the problem of deception (Colbourne and Sque, 2005). This would have resulted in increased scrutiny of this research by the Ethics Committees and hence, delays in gaining ethical approval. Therefore, with this debate in mind, the researcher introduced himself to the participants as a nurse-researcher.

Since the researcher introduced himself to the participants as a nurse-researcher, it is possible that this could have influenced how the participants recounted their experiences during the interviews (Colbourne and Sque, 2005). Several participants resorted to telling the researcher the story of the patient's cancer regardless of the explicit aim of the interview. It is possible that these participants considered the interview as an opportunity to talk to someone with a nursing background and hence, with an experience in cancer and who is ready to listen. Moreover, it is possible that they thought that the researcher, being a nurse, was more interested in hearing about the patient's cancer rather than their own experience (Sivell *et al.*, 2019). The researcher dealt with such situations by allowing the participants to recount their stories and then directing them back to the topic of interest by using prompts, such as "*This is all very interesting. I would like to know how, if at all, this impacted your chronic conditions*". Additionally, some of the participants also made attempts to ask clinical queries about the patient with cancer during the interview. This was dealt with by postponing the discussion of these issues until the end of the interview (Sivell *et al.*, 2019). At the end of the interview, the participants were then directed to speak to the Practice Nurse or Hospital Consultant.

4.13.2 Building Rapport

Building a good rapport with the research participants is important in order to collect high quality data which allows the researcher to build a theory of sufficient depth (Dey, 1999). In fact, Charmaz (2014) states that the ability of the researcher to build a rapport with the participants shapes the content of his or her data. This contradicts what Glaser and Strauss (1967, p. 75) state about establishing rapport in grounded theory, that it "*is often not necessary*" since the researcher plays a neutral role in the research process. In line with constructivist grounded theory (Charmaz, 2014), the researcher tried to establish a rapport with the participants. In addition, building rapport had to be performed quickly since there was a singular encounter with the participants (DiCicco-Bloom and Crabtree, 2006).

Rapport building also depends on the balance of power between the researcher and the participants. An imbalance in power may exist during different stages of the research process, especially since the researcher is often perceived as the 'expert in the field'. This often happens when the researcher introduces himself or herself as a nurse-researcher to the participants (Sivell *et al.*, 2019). Power imbalance between the researcher and the participants may also exist due to gender and interview location (Anyan, 2013). An imbalance in power relations makes it difficult for the researcher to establish a rapport with the participants (Sivell *et al.*, 2019). Therefore, steps were taken to minimise these power imbalances and hence, to try and establish rapport with the participants, as described in the following paragraphs.

The interviews were conducted in a setting selected by the participants to minimise inconvenience to them. This also ensured that they would feel more at ease to talk about their experiences. Participants were offered a face-to-face interview in their home or another place of their choosing or via telephone or Skype. Sivell *et al.* (2019) argues that conducting the interview in the home setting may help to balance the power between the researcher and the participants. When the interview is conducted in the home setting, participants tend to assume a host / hostess role. Consequently, they tend to feel less restricted and more in control of the situation. However, this role may lead the participants to undertake preparation for their researcher, such as housework, which places undue pressure on the participants which can be detrimental to their physical well-being, causing them to be tired during the interview and hence, impacting data collection (Sivell *et al.*, 2019). The systematic review of reviews revealed that carers experience time constraints when caring for a patient with cancer and hence, may lack the time to prepare their house for the researcher. This is why participants were offered the possibility of choosing where the interview would be conducted. On the other hand, conducting the interview in the clinical setting may increase the imbalance of power. Since the researcher introduced himself as a nurse-researcher, he might have been seen in his 'clinician's role', whilst the participant considered himself or herself as 'a client' (Sivell *et al.*, 2019). To tackle this problem, the interviews were conducted in a room which can be found in a different section of the hospital and not in the patient's ward. Furthermore, the researcher did not wear a hospital identification badge or a lab coat or his nursing uniform when conducting these interviews because these are symbols associated with the clinician's role. Selecting the time when the interview would be conducted was also decided by the participants, as this ensured that data was collected at a convenient time for them. Moreover, since the researcher chose to introduce himself to the participants as a nurse-researcher, he paid great attention to the way he introduced himself, in order to clearly communicate responsibilities and not create a power imbalance. Therefore, at the beginning of the interview, he introduced himself as "*I'm Daren Chircop, a researcher and a nurse*" rather than "*I'm Daren Chircop, an oncology nurse, who is conducting a research study on …*". This emphasised that, during the interview process, he was a researcher first and foremost rather than a clinician. The next section describes the pilot interview.

4.14 Conducting a Pilot Interview

Conducting a pilot interview provided the researcher with an opportunity to refine the interview guide and improve his interview technique. Additionally, it allowed the researcher to ask for feedback from the participants to determine whether the appropriate questions, prompts, and probes were being asked during the interview (Hunt, Chan and Mehta, 2011).

A pilot interview was conducted before the start of this research with a carer living with a chronic condition and at the same time, caring for a patient with cancer. This pilot interview lasted for about one hour. No changes were made to the questions of the interview guide after the pilot interview and hence, the findings of the pilot interview were included with the main findings. However, whilst listening to the recording of this pilot interview, the researcher noticed that, often times, he was using prompts such as "*I agree*" and "*I understand*". Thorne (2008) argues that such prompts should be avoided because they imply to the participant that, first and foremost, the researcher already fully understands the experience that the respondent is describing and secondly, that certain answers will be received positively, whilst others may not. Therefore, the researcher made sure to avoid using such prompts in the following interviews. Furthermore, the researcher noticed that he tended to ask questions immediately after the participant stopped talking, at times even intruding as the participant was about to speak. However, pauses and silence can be an important part of the interview. Participants often use silences to collect their thoughts and reflect on the question asked (Hunt *et al.*, 2011). Therefore, the researcher made sure to avoid rushing to fill pauses and silences by asking further questions in the following interviews. The next section describes why singular interviews were conducted.

4.15 Conducting Dyad Versus Singular Interviews

During the first stage of this research, one interview was conducted with the carer in the presence of the patient. A limitation of conducting dyad interviews is that, one person could dominate the interview by constantly talking and not giving the other person an opportunity to recount their experiences. If this happens, then it is possible that the other person would not actively participate in the interview (Wilson, Onwuegbuzie and Manning, 2016). In fact, during this particular interview, the patient interfered on several occasions, at times even intruding whilst the carer was speaking. As suggested by Sivell *et al.* (2019), the researcher tried to deal with this situation by, first and foremost, turning slightly to face the carer when asking questions and secondly, by explaining politely to the patient that it is best to let the carer answer the questions. However, this strategy was unsuccessful. Therefore, since the patient actively participated in the interview, he became a producer of research data which shaped the processes of data collection and analysis. From this perspective, the decision to allow the patient to be present during the interview might be seen as inappropriate because he was not a ‘neutral observer’ in the research process. Therefore, conducting the interview in the presence of the patient may have an impact on the type and quality of data collected. With this debate in mind and considering that this research aimed to understand carers’ perspectives rather than patients’ perspectives, in the second and third stages of this research, carers were interviewed alone and not in the presence of the patient or other family members. Another advantage of singular interviews was that they allowed the participants to share information which they might have withheld from the patient or other family members (Morgan *et al.*, 2013).

4.16 Audio Recording

There are two ways of recording data in an interview. A researcher can use an audio recorder to record the interview and then, transcribe verbatim the audio recording. Otherwise, a researcher can decide not to use an audio recorder and instead opt to write a script about the interview made from notes taken during the interview (Rutakumwa *et al.*, 2020). However, Rutakumwa *et al.* (2020) argue that using an audio recorder is often the preferred choice amongst researchers because it ensures the comprehensive recording of the data which enhances the validity and credibility of the data. Moreover, the use of an audio recorder ensures that the participants’ responses could be recalled after. On the other hand, if a researcher attempts to write everything that the participant is saying during the interview, there is the risk of missing out on important aspects of the participant’s experience, especially if the researcher lacks training in data capture without the use of audio recorders (Rutakumwa *et al.*, 2020). Nevertheless, the use of an audio recorder can influence what the participant states about a particular experience. It is possible that due to the participant’s circumspection, certain important details about the experience might not get said. Hence, the use of an audio recorder can influence the quality of the data and hence, theory development. Nonetheless, taking into consideration the fact that the researcher had never undergone training in capturing data without the use of an audio recorder and was a novice in qualitative research, it was decided to audio record the interviews with the consent of the participants (Rutakumwa *et al.*, 2020). The researcher tried to put the participants at ease, by firstly reminding them before the interview that the interview was strictly confidential. Secondly, after seeking the participant’s permission, he made sure that anything that was said at the end of interview after the audio recorder was switched off, was recorded on field notes.

4.17 Transcribing

In grounded theory, there is some debate about whether it is necessary for the researcher to transcribe all of his or her audio recordings. Glaser (1992) himself is against using recording and transcription in a grounded theory study. This view is dismissed by McMullin (2021) who argues that if the researcher does not audio record and transcribe his or her interviews, this limits their ability to truly ground the developing theory in the data because they cannot use the participants' quotations. Charmaz (2014) also agrees with the full recording and transcription of interviews and field notes, as this allows the researcher to better immerse himself or herself in the data and thus, conduct an in-depth analysis rather than a superficial analysis, which is imperative to build a theory of sufficient depth. On the other hand, Strauss and Corbin (1990) suggest that the first few interviews should be entirely transcribed and analysed before the researcher continues with the next set of interviews. Early in the research, the concepts pertaining to the phenomenon being studied have not yet been identified and hence, it is important to transcribe everything, otherwise important data may be missed. Later, as the theory develops, the researcher may wish to listen to the audio recordings and transcribe only those excerpts which relate to the developing theory. Therefore, later in the study, it is the developing theory which guides the researchers to which excerpts should be transcribed or not (Strauss and Corbin, 1990). However, Strauss and Corbin (1990) do suggest that it is the researcher who should decide how much of his or her interviews and field notes to transcribe. Nevertheless, they also recommend that "*more is better than less*" (Strauss and Corbin, 1990, p. 31) and that inexperienced researchers are "*wiser to transcribe all*" (1990, p. 30) of the interviews and field notes. With this debate in mind and taking into consideration that the researcher was a novice in grounded theory, it was decided that all the interviews would be fully recorded and transcribed.

Transcription is a time consuming process (McMullin, 2021). Therefore, hiring a professional transcriber may allow the researcher to focus on other aspects of his or her research. However, Charmaz (2014) argues that by transcribing the recordings himself or herself, the researcher immediately becomes immersed in the data which is imperative for an in-depth analysis of the data and hence, theory development. Moreover, Tilley and Powick (2002) argue that hiring a transcriber may actually decrease the trustworthiness of the transcripts. If the transcriber is not familiar with the discourse, they may find it difficult to decipher the conversation and may decide to omit or guess words, especially if the audio recording is not clear. Hence, the transcriber has to decide whether to include or not certain words, whether to correct mistakes, and edit grammar and repetitions (Davidson, 2009; Tilley and Powick, 2002). With this debate in mind, the interviews were transcribed by the researcher himself.

The aim of grounded theory is to develop a theory from the participant's accounts and hence, researchers are not required to transcribe all the prosodic aspects of the audio recordings (Charmaz, 2014). This means that the researcher is not required to record certain aspects of the conversation, such as the exact length of pauses and other nonverbal utterances, as is conducted in conversation analysis. However, whilst transcribing the interview word by word, the researcher also wrote down notes of any pauses or emotions expressed by the participants since these were considered very important when interpreting the data.

All interviews were transcribed by the researcher and as much of the transcribing of one interview as possible was completed before the next interview was undertaken. By transcribing the interview as soon as possible, the researcher became familiar with the interview content. Memos of any ideas that emerged during transcription of the interview were written down hence, starting the analysis as soon as possible, as is advocated in constructivist grounded theory (Charmaz, 2014).

Excerpts from the interview transcripts will be used in the next chapters to illustrate how the theory developed from the data. Each excerpt will be accompanied by a caption stating whom participant said it. These captions will be presented as either 'Participant 1', 'Participant 2' and so on. It was decided to use the term 'Participant' rather than use pseudonyms because, since the aim of constructivist grounded theory (Charmaz, 2014) is to develop a theory, it was not deemed appropriate to use pseudonyms since what is important is the developing theory, whilst who the participant were is less important. In addition, some excerpts will be used twice to illustrate how the different concepts pertaining to the phenomenon being studied are interrelated.

4.18 Using Computer Software for Data Management

A coding approach combining the computer software NVIVO Version 12 with the traditional material method was used. Such approach has already been utilised successfully elsewhere (Maher *et al.*, 2018). NVIVO was chosen because it has an additional benefit of allowing the user to write memos and link them with excerpts or with particular codes. The following steps were followed:

i. The interviews were transcribed on Word Processing documents.
ii. These documents were uploaded into NVIVO.
iii. NVIVO was used to create codes for the interview.
iv. All the codes developed were printed out and cut into strips and glued onto sticky notes.

v. These sticky notes were then arranged, compared with each other, compared with earlier interview codes and transcripts, and rearranged in order to identify emergent categories.
vi. The emergent categories were then imported into NVIVO.
vii. Memos describing the properties of the emergent categories were written down in NVIVO.

4.19 Translation

This research was conducted in Malta and hence, it was anticipated that most of the participants would want to conduct their interview in Maltese, even though the language of this research was English. Choi *et al.* (2012) describe that there are two ways to conduct interviews with participants who do not speak the same language of the research. The first way involves conducting the interview in the participant's language, transcribe the data into the participant's language and then, either translating whole or parts of the interview transcript. The second way involves conducting the research with the assistance of an interpreter (Choi e*t al.*, 2012). Being proficient in both Maltese and English languages, the researcher did not require the assistance of an interpreter however, he still had to face the methodological issues in relation to translation. If these issues had not been addressed, then they could have impacted the rigour of the research process (Choi *et al.*, 2012; Hennink, 2008).

Language is used to express meaning. However, language also influences how the meaning is constructed. In other words, through the use of concepts in language, meaning is constructed. Hence, when translating from one language to another, if a concept is translated differently, then there is a chance that the meaning constructed would be different from how the participant actually intended to explain. Often times, it is a complicated process to try and capture meaning with words. In fact, participants often use metaphors to capture the richness of meaning in an experience. The challenge with using metaphors is that metaphors vary from one culture to another and are specific to a particular culture (van Nes *et al.*, 2010). Therefore, translation can influence the accuracy of the data and hence, theory development.

A concern with translation is that the quality of the translation can affect the accuracy of the data (van Nes *et al.*, 2010). Therefore, in the initial phases of this research, the possibility of hiring a professional translator was considered. However, further reading into the recommended procedures for conducting translation in qualitative research revealed that, the way the translator interprets and translates the data may influence the data analysis process and hence, theory development. It is possible that the translator may not convey the precision or subtle nuances of the original intent described in the interview transcript, especially since the translator would not be listening to the tape recordings whilst translating the transcripts (Temple and Young, 2004). As a result, if the translator happens to convey a different meaning to a participant's statement than the participant originally intended, then this would have important implications in the data analysis process since the translator would have become involved in the construction of the theory. This goes against the epistemological foundations of constructivist grounded theory (Charmaz, 2014) since the theory would no longer be a co-construction between the researcher and the participant. Therefore, with this debate in mind, a professional translator was not hired in this research. Instead, the interview transcripts were translated by the researcher himself having had previous experience with translating interview transcripts from Maltese to English.

Initially, the researcher fully translated two interviews from Maltese to English. However, when discussing the translated interviews with his research supervisors, it soon became apparent that some of the codes identified when coding the Maltese transcripts were different from the codes identified when coding the English transcripts. This resulted from certain words having similar literal meanings but bearing different subtle nuances and cultural connotations between Maltese and English. For example, a literal translation of the Maltese phrase "*jien inbati minn kundizzjoni*" is "*I suffer from a condition*". The contextual connotation of the concept 'suffer' is different between the English and Maltese languages. According to the English language, if you suffer from an 'illness' or from some other disease, you are badly affected by it (2022). On the other hand, this connection is very weak when the concept is used in the Maltese cultural context. Although, it may also imply that a person is badly affected by an illness, sometimes, such concept is used instead of the Maltese term 'għandi' which in English means 'to have'. In fact, the first participant that actually used this term did not seem to imply in the rest of the interview that he was badly affected by his chronic condition. Therefore, with this debate in mind, the researcher did not translate the whole interview transcripts. Instead, he analysed the interview transcripts in the Maltese language and then translated the chosen excerpts for this report.

Another reason for translating short excerpts was that, as soon as the researcher began translating the aforementioned two interviews, concepts began to be identified, even prior to creating the full translation of the interview transcripts. Hence, it was difficult for the researcher to adopt what several researchers proposed, that translation should be performed after all the data has been collected but before data analysis (Lopez *et al.*, 2008; Regmi, Naidoo and Pilkington, 2010). It was difficult for the researcher to perform the two functions of translation and analysis in sequence because by translating the interview transcripts the researcher inevitably started to engage in conceptualizing the ideas that emerged from the interview transcripts. Therefore, the acts of translating and analysing literally become intertwined because analysis, coding, and memoing could not be delayed until the full translation is completed.

The translation process was as follows. All the interviews were fully transcribed by the researcher. The transcripts were analysed in the Maltese language but codes were written down in the English language. During the initial line by line coding, the codes were written down in English in order to use gerunds. Examples of gerunds include the words ‘Taking’ and ‘Forgetting’. Gerunds are verb forms which function as a noun and assist the researcher to detect the processes and stick to the data (Charmaz, 2014). Therefore, although interview transcripts were analysed in Maltese, the codes were written in English in order to be able to use gerunds, since there is no equivalent of ‘gerund’ in Maltese. Memos were written down about the properties of emerging categories and subcategories and about what further information is needed to further explicate these properties. Memos were written in English. Whilst writing memos, excerpts in the interview transcripts were sought which supported the emerging categories and subcategories. These excerpts were translated from Maltese to English whilst writing the memos. The excerpts were translated by the researcher himself and it was decided that there would be no back translation since verification by back translation goes against the epistemological foundations of constructivist grounded theory (Charmaz, 2014), as described below.

The above process is called the intertwining translation process and has been used successfully in another grounded theory study (Shklarov, 2009). However, according to the researcher’s knowledge, this is the first constructivist grounded theory research using this process. It was deemed appropriate because it is based on five concepts which reflect the classical features of constructivist grounded theory (Charmaz, 2014) and which are described below:

i. Allowing flexibility
ii. Preserving meaning
iii. Enhancing theoretical sensitivity
iv. Revealing influences
v. Preventing verification

4.19.1 Allowing Flexibility

According to constructivist grounded theory (Charmaz, 2014), the processes of data collection and analysis are directed by the emergent data rather than by ‘external prescriptions’. Therefore, if the researcher delays the process of data analysis in order to finish the full translation of the interview transcript, then such an act would be acting as an external prescription to the process of data analysis. There is a risk that if the researcher continues with the full translation of the interview transcript before commencing the data analysis process, any ideas that may emerge whilst translating the interview transcript may not be written down as the researcher focuses solely on finishing the full translation. Hence, in order to limit these ‘external prescriptions’ and since constructivist grounded theory (Charmaz, 2014) emphasises flexibility in the method, by employing the intertwining translation process, it allowed the researcher to continue with the data analysis process whilst translating the interview excerpts.

4.19.2 Preserving Meaning

According to Shklarov (2009), the simultaneous undertaking of translation and analysis leads to the simultaneous work with excerpts in both languages since the researcher is constantly identifying excerpts which support the data analysis process and translating such excerpts. The constant comparison across the languages helps ensure the link between the translated excerpts and the emerging concepts. Therefore, by translating the short excerpts during the data analysis process, the researcher is constantly ensuring that the translated excerpts reflect the participants’ meanings (Shklarov, 2009). On the other hand, if the interview transcripts are translated prior to commencing data analysis, there is the risk that the meaning of the participants’ words could be lost when translating from the source language to the target language, influencing the consequent coding procedures and hence, the findings of the research.

4.19.3 Enhancing Theoretical Sensitivity

Constructivist grounded theory acknowledges that the researcher’s theoretical sensitivity will influence the data analysis process (Charmaz, 2014). The intertwining translation process allows the researcher to capture the differences between linguistic meanings which enhance the researcher’s theoretical sensitivity. Important ideas can originate from capturing the differences between meanings or language structures. For example, the difference in contextual connotation of the concept ‘suffer’ between the English and Maltese languages described above, prompted the researcher to ask participants in the subsequent interviews to explain what they meant when they used the phrase “*jien inbati minn kundizzjoni*”.

4.19.4 Revealing Influences

By enhancing the researcher’s theoretical sensitivity and allowing the researchers to identify differences between meanings or language structure between the source and target languages, the intertwining translation process also allows the researcher to reflect on how the translation process may impact the results of the research. Taking the above example, if the researcher had translated the phrase “*jien inbati minn kundizzjoni*” to “*I suffer from a condition*”, there is a possibility that the translated excerpt would not have supported the emerging concepts.

Therefore, the intertwining translation process allowed the researcher to be constantly aware of his assumptions when translating the excerpts. This is imperative in order to allow the theory to emerge from the data and prevent the researcher from importing his own assumptions on the emerging theory (Charmaz, 2014).

4.19.5 Preventing Verification

Back translation is often employed to ensure the validity of a translation (Chen and Boore, 2010). The simultaneous undertaking of translation and data analysis and the constant comparison across the languages, helps ensure that the translated excerpts reflect the participants' meanings. Therefore, the intertwining translation process ensures that the translated excerpts are already grounded in the source text. Hence, there is no need for verification by back translation. Furthermore, in grounded theory analysis, the most important aspect is conceptual meaning. When researchers write memos, grammar and correctness of the text are irrelevant, because the priority is given to writing down ideas (Glaser, 1978). Similarly, when the researcher translates from the source language to the target language, there is no need for an accurate technical translation, but rather the researcher should focus on the conceptual meaning of the message. Su and Parham (2002) argue that back translation does not guarantee conceptual equivalence.

4.20 Evaluating the Research

Qualitative research has been criticised for being overly subjective and not open to scrutiny. Debates exist within the field of qualitative research about which criteria to adopt when evaluating qualitative studies (Lincoln and Guba, 2000; Morse *et al.*, 2002). Considering the fact that the methodological framework of this research is constructivist grounded theory, Charmaz's (2014) criteria for evaluating grounded theory research were used to assess the value of this doctoral research. These criteria include credibility, originality, resonance, and usefulness (Charmaz, 2014). These criteria as they apply to this research are set out in further detail in Chapter 11 and Appendix D.

4.21 Conclusion

In this chapter, the methods being employed in this research have been set out. It described the research design, recruitment strategies, and data collection methods. Additionally, it also presented the principles of ethics applied to this research. This chapter also contributes to existing knowledge by proposing an intertwining translation process in constructivist grounded theory studies. This translation process involves: (i) the researcher translating interview excerpts himself or herself; (ii) performing translation during data analysis; and (iii) not performing any back translation. This translation process seems to be appropriate for studies adopting constructivist grounded theory (Charmaz, 2014), where the researcher is fluent in both the source language and target language. It is ideal in keeping in line with the epistemological foundations of constructivist grounded theory, that theory is a co-construction of the researcher and the participants and that the methods should allow for flexibility (Charmaz, 2014). Additionally, it ensures that the participant's meanings as written in the original transcripts are preserved when performing translation and hence, ensuring the rigour of constructivist grounded theory studies. The next chapter describes the data analysis process.

Chapter 5 Data Analysis Process

5.1 Introduction

This chapter discusses the data analysis process. It describes the different components of the data analysis process including memos and field notes, theoretical sensitivity, as well as the two types of coding involved in constructivist grounded theory (Charmaz, 2014). Furthermore, this chapter provides an example of how the categories were developed from the data to eventually form the theoretical framework.

5.2 Preliminary Data Collection and Analysis

In the first stage of this research, seven participants were interviewed. The interviews lasted from 35 to 75 minutes with the average interview lasting for 50 minutes. Six of these interviews were conducted in the participant's homes. One interview was conducted in an interview room in the local oncology centre which ensured that there was quiet and privacy for the interview. Table 7 provides an overview of characteristics of the first seven participants. The characteristics described below were important factors when deciding on the direction of theoretical sampling. To safeguard the participants' confidentiality, it was decided not to present the patient's cancer type. Some of the participants in this research were caring for patients with rare forms of cancer and hence, considering the small population of Malta, they could be easily identified by providing such information.

Table 7: Characteristics of the first seven participants.

Participant	Age	Sex	Employment	Carer's condition	The patient's cancer phase	Relationship to patient with cancer
Participant 1	56	M	Employed	Heart disease	Inpatient treatment	Husband
Participant 2	71	F	Retired	Hypertension	Outpatient treatment	Wife
Participant 3	41	F	Employed	Arthritis and Addison's disease	Inpatient treatment	Wife
Participant 4	45	F	Unemployed	Hypertension	Outpatient treatment	Wife

Table 7 (cont.): Characteristics of the first seven participants.

Participant	**Age**	**Sex**	**Employment**	**Carer's condition**	**The patient's cancer phase**	**Relationship to patient with cancer**
Participant 5	64	F	Retired	High blood cholesterol and heart disease	Outpatient treatment	Wife
Participant 6	58	F	Unemployed	Hypertension, diabetes, high blood cholesterol and depression	Outpatient treatment	Wife
Participant 7	73	F	Retired	Heart disease	Survivorship	Wife

After seven interviews, a substantial amount of data had been generated. As a result, data collection was suspended to allow for more in-depth analysis writing and some time to think. It also allowed a review of methodological procedures and consideration of the direction of theoretical sampling. The next sections describe the different components of the data analysis process of this research.

5.3 Memo Writing

Memo writing is one of the essential components of grounded theory. Researchers write down memos to record their reflections, as well as to record any questions that come to mind whilst analysing the data in order to build upon and explore different ideas (Charmaz, 2014). Therefore, in this research, memos were written down by the researcher to record his thoughts about important issues that were emerging whilst analysing the data. Memos were written down about the properties of emerging categories and about what further information was needed to further explicate these properties. These memos were then used to direct theoretical sampling and to assist the researcher to identify which issues he needed to focus on in the subsequent set of interviews.

5.4 Field Notes

Field notes were written down by the researcher to record his observations before, during and after the interview (Charmaz, 2014). Field notes included details about the physical setting, carer's physical condition, patient's physical condition, non-verbal communication, and the carer's emotional responses. In addition, field notes included thoughts about any observations that were made during the interview process. Such observations could not be recorded on the audio recorder. The field notes were also used when analysing the data.

5.5 Theoretical Sensitivity

Theoretical sensitivity is the ability of the researcher to identify and separate data which is pertinent to the research question from data which is not. This allows the researcher to build a theory which is grounded, dense, and well integrated (Glaser, 1978). The researcher develops theoretical sensitivity from previous readings, or professional or personal experience. The researcher also develops their theoretical sensitivity during the research process (Strauss and Corbin, 1990). Therefore, theoretical sensitivity helps the researcher to extract the theory from the data. However, since theoretical sensitivity develops from previous readings, or professional or personal experience, it creates a problem in the research process: how can the researcher remain free from bias and not end up forcing theories and previous knowledge into the data?

As discussed in the previous chapters, the researcher was an oncology nurse by profession and had worked with both patients with cancer and their carers and hence, it would have been very difficult for the researcher to completely remove himself from the research process. A key tenet of constructivist grounded theory is that researchers must adopt a reflexive approach and consider how their preconceptions and assumptions influence the research process (Charmaz, 2014). By using a constructivist approach, the researcher was able to reflect upon and consider his role in the process of gathering the data in terms of coding, asking interview questions, and analysing the data. This practice of reflexivity has already been illustrated in the previous chapter when discussing topics such as nurse-researcher dilemma, building rapport, and interviewing skills.

5.6 Coding

The first step that Charmaz (2014, p. 116) recommends is ‘initial coding’ which allows the researcher to “*remain open to exploring*” the data. Initial coding enables the researcher to remain open to what the participants perceive to be important in their experience. In this research, line by line coding was used because this type of coding allows the researcher to stay grounded in the data and does not let any preconceived ideas define the emerging categories (Charmaz, 2014). Furthermore, in order to remain free from bias, when coding the transcripts, the researcher adopted Charmaz’s (2014) strategy of coding ‘actions’ rather than ‘themes’ and hence, coded the transcript using gerunds, as described in the previous chapter.

The next step was to conduct what is termed ‘focused coding’. Charmaz (2014, p. 138) defines this process as: “*using the most significant and/or frequent earlier codes to sift through and analyse large amounts of data*”. This involves a process of extracting the key and ‘frequently used’ codes and grouping them together to form categories. Focused coding then develops the categories conceptually. The researcher then begins to define the category’s properties, such as specifying the conditions under which it exists and showing how this category relates to other categories. The next section will provide an example of how these different components were incorporated into the data analysis process.

5.7 Example of Data Analysis Process

This section provides an example of how data analysis was conducted. It demonstrates initial and focused coding, how memo writing and field notes were used to explicate the properties of emerging categories, as well as how the researcher’s theoretical sensitivity influenced the data analysis process and directed theoretical sampling. This example was taken from the second interview, conducted with the wife of a patient with bladder cancer. Table 8 illustrates the initial coding of a short excerpt from this interview.

Table 8: Example of initial coding in the first stage of this research.

Initial Coding	**Interview Excerpt**
Taking medications. Taking medications – Comparing pre and post cancer diagnosis. Facing difficulties to keep up with daily routine. Neglecting oneself. Changing daily routine – Prioritising patient’s care. Changing daily routine. Stopping healthy behaviours – Comparing pre and post cancer diagnosis. Changing daily routine - Blaming treatment regimen.	**I:** Can you please tell me what conditions are you living with? **P:** I have high blood pressure. I take one pill in the morning and one pill in the evening. Nothing has changed in that regard. However, I found it difficult to cope with everyday life. You have to forget yourself. You forget your routine because the patient’s care takes priority, especially if the patient is a close relative, such as your husband or son. You forget your routine. For example, we have a gym at home and every morning I used to do the treadmill. I used to do some exercises and then, I used to have breakfast. I have not done any exercises or used the treadmill since my husband has been going in and out of hospital to have chemotherapy.

Table 9 illustrates a field note written down after conducting the interview from which the above excerpt was taken. Table 10 illustrates two memos that the researcher wrote down regarding the codes identified in the above excerpt.

Table 9: Field note written on the second interview.

Participant 2 (15 May 2019)

I have just interviewed the wife of a patient diagnosed with bladder cancer. The patient has just finished his chemotherapy treatment and is waiting to undergo surgery to resect part of his bladder. The wife has hypertension. Before the interview she revealed that she had been living with hypertension for more than 20 years. She is independent in her ADLs. She is a retired. Neither she nor her husband drive. They live in a large household, which also includes a gym. They have one son which does not live in the same household and does not help around the house. They used to have another son who died as a teenager. The patient received his chemotherapy on an outpatient basis. However, since the patient was not staying in hospital, he had to go to hospital twice a week to have his bloods taken. The patient is independent in his ADLs and is also a pensioner. In fact, he was walking around the house at the time of interview. However, he did not interfere with the interview and stayed in another room.

Table 10: Memos written whilst analysis the short excerpt from the second interview.

Taking medications (18 May 2019)

After cancer diagnosis, carers seem to continue living with their chronic conditions by taking their medications as they used to before cancer diagnosis. Therefore, caregiving does not seem to impact adherence to medication (Code: *Taking medications*). However, this participant had already experienced caregiving since she had cared for her son who was diagnosed with brain tumour. Therefore, this raises the following question:

- Does previous experience of caregiving impact how carers live with their chronic conditions and whether they will adhere to their medication regime?

Furthermore, this participant is suffering from hypertension. From my experience as a professional nurse, the management of hypertension involves other tasks, such as routine monitoring of blood pressure and healthy behaviours. Therefore:

- Does caregiving impact routine monitoring of chronic conditions and healthy behaviours and why?

Moreover, these tasks are considered basic when compared to the management of other chronic conditions, such as diabetes. The management of diabetes involves more complex tasks, such as routine monitoring of blood sugar, diet planning, potential administration of insulin. For example, patients with diabetes have to monitor their blood sugar regularly or they risk developing hyperglycaemia which leads to potential complications in the body or hypoglycaemia and potential risk of dying. Therefore, this raises the following question:

- How does caregiving impact those carers who are living with chronic conditions which require more complex tasks?

The participant was taking care of her husband who was independent in his ADLs and received his chemotherapy on an outpatient basis. From my professional experience as well as from the literature read whilst conducting the systematic review of reviews, carers seem to experience more burden when the patient is dependent on them for his or her ADLs and when the patient is receiving treatment as an inpatient. Therefore, this raises the following questions:

- Does the patient's level of independence impact carers' treatment adherence, healthy behaviours and routine monitoring of chronic conditions?
- Does receiving treatment as an inpatient or outpatient impact carers' treatment adherence, healthy behaviours and routine monitoring of chronic conditions?

Table 10 (cont.): Memos written whilst analysis the short excerpt from the second interview.

Changing daily routine (18 May 2019)

It seems that one of the reasons why carers find it difficult to cope after cancer diagnosis is because they lose their everyday routine (Code: *Facing difficulties to keep up with everyday routine*). After cancer diagnosis, carers cannot follow their everyday routine (Code: *Changing daily routine*) and cannot take care of themselves (Code: *Neglecting oneself*). They cannot perform healthy behaviours (Code: *Stopping healthy behaviours – comparing before and after cancer diagnosis*). This is because they prioritise the care of the person with cancer above their own (Code: *Changing daily routine – Prioritising patient's care*). It seems that the treatment regimen that the patient is receiving may be a contributing factor related to why healthy behaviours are abandoned (Code: *Changing daily routine - Blaming treatment regimen*). Therefore, this provides an answer to one of the questions raised in the memo **Taking medications (18 May 2019)** - does receiving treatment as an inpatient or outpatient impact carers' treatment adherence, healthy behaviours and routine monitoring? Carers seem to deviate from their normal routine but not treatment adherence. This raises the following questions:

- Why do carers abandon healthy behaviours but not treatment adherence?
- Is it possible that carers do not understand the importance of healthy behaviours?
- Is it possible that carers do not find time to perform healthy behaviours?

However, in this case, the patient was receiving the treatment on an outpatient basis and hence, he was staying at home rather than in hospital. From my professional experience, carers seem to find it more difficult to find time when the patient is receiving treatment in hospital. They end up spending more time in hospital with the patient and hence, when they go home they do not find time to do healthy behaviours because they have to finish the housework etc. However, it seems that receiving treatment on an outpatient basis also impacts carers. Therefore:

- Why do carers still find it difficult to follow their everyday routine and perform healthy behaviours when the patient is at home?
- Do carers of patients who are receiving treatment in hospital actually find it more difficult to find time to follow their everyday routine and perform healthy behaviours?
- Does the patient's level of independence impact whether carers find time to follow their everyday routine and perform healthy behaviours? From my experience, when a patient is fully dependent on the carer, the carer will find it more difficult to find time to perform healthy behaviours. However, this was not the case with Participant 2.
- Could it be because she is alone at home?
- What about the fact that the carer does not work and still found it difficult to follow her everyday routine? What about those that do work?

The above example illustrates how the researcher developed his own theoretical sensitivity not only from previous readings, or professional or personal experience, but also during the data analysis process, as illustrated by the questions asked about the data in the above memos. Moreover, the above memos illustrate an example of the constant comparative method by comparing the code 'Taking medications' with the code 'Changing daily routine'. Additionally, these memos directed theoretical sampling by identifying the need to interview: (i) carers with more complex chronic conditions, such as diabetes; (ii) carers of patients who are receiving cancer treatment in hospital; and (iii) carers who are providing care to patients who are dependent in their ADLs. Moreover, these memos assisted the researcher to identify which issues he needed to focus on in the subsequent set of interviews. Table 11 illustrates how the questions raised in the above memos directed the questions asked in the ninth interview, which was conducted in the second stage of this research.

Table 11: Example of questions asked in the second stage of this research.

Initial Coding	**Interview Excerpt**
	I: How is your condition affected?
Neglecting routine monitoring. Neglecting routine monitoring. Neglecting routine monitoring. Neglecting routine monitoring – Comparing pre and post cancer diagnosis.	**P**: I’m supposed to have my blood pressure checked every two months, but I don’t go. Not even here when I am next to him. I don’t ask the nurses to check my blood pressure. Not even at home. I don’t check it even though I have a blood pressure machine. A couple of weeks before he was diagnosed with cancer, I went to the doctor and he increased my medications. He prescribed Amlodipine and within one week the blood pressure was normal. These days, I don’t check it.
	I: Why don’t you check your blood pressure even though you have a blood pressure machine at home?
Being able to identify worsening of chronic condition. Associating symptom with worsening of chronic condition. Hiding symptoms from patient.	**P**: Because I can tell when my blood pressure is high or not. When it is high I feel this particular headache which runs down the back of my neck. I can tell when it is high because I can feel this pain. I also don’t want to show to my husband that it is high so as not to worry him. I don’t want to make him feel guilty that it’s his fault.
	I: What do you do when you feel this pain?
Taking medications when chronic conditions worsens.	**P**: When I feel this pain, I just follow the doctor’s order. I take one Amlodipine in addition to my regular medication. I go and buy it and I take it and the pain goes away. This is the only way to control the pain. By taking the Amlodipine.
	I: What do you mean by “it is the only way”?
Taking medications.	**P**: That it can only be controlled by taking the Amlodipine. There is no other way.
	I: What do you think about exercise?
Comparing taking medications with performing healthy behaviours.	**P**: Well, you read about the importance of going for a walk. But when I have these headaches, one does not feel like going for a walk. But just rest. So there is only one way. To take the Amlodipine and rest.

The above example illustrates how the researcher specifically asked the participant about her thoughts on healthy behaviours in order to try and explicate some of the questions raised in the memos presented in Table 10: (i) why do carers abandon healthy behaviours but not treatment adherence? and (ii) does receiving treatment as an inpatient or outpatient impact treatment adherence, healthy behaviours, and routine monitoring? Table 12 illustrates a memo that was written down regarding the above interview excerpt.

Table 12: Memos written whilst analysis the short excerpt from the ninth interview.

Changing daily routine

Addendum (17 August 2020)

Carers not only seem to abandon their healthy behaviours but also the routine monitoring of their chronic condition, even when the patient is receiving treatment as an inpatient (Code: *Neglecting routine monitoring*). It seems that this is because they seem to know how to live with their chronic condition. Some carers can tell from their experience when their chronic condition is under control or not (Code: *Being able to identify worsening of chronic condition*) and how to live with it when not under control. As a result, this may lead them to think that there is no need to go for a medical visit. So here, we may be talking about another important concept, that is temporality. It seems that how long has the carer been diagnosed with his or her chronic condition will impact how they live with their chronic condition. This raises the following questions:

- Does the length of diagnosis and hence their experience of the condition impact whether they undergo routine monitoring or not and perform healthy behaviours?
- What about those carers who have recently been diagnosed with their chronic condition?
- What about those carers who suffer from multiple conditions and hence, face complex management of their conditions?

This is an important point to look into. Being a nurse by profession, I always thought that individuals who have been diagnosed with a chronic condition for a long time must be aware of the severe consequences of not having one’s chronic condition under control. These individuals should be ‘experts’ in their chronic condition and hence, I expect them to seek medical help when their chronic condition is not under control. However, the data seems to be suggesting otherwise. Hence, it is important that I do not continue making these assumptions but actually probe into why and how temporality affects the carers’ chronic conditions.

It seems that carers may also rely on the presence of symptoms to determine whether their condition is under control or not (Code: *Associating symptom with worsening of chronic condition*):

- What about those carers who suffer from conditions which are asymptomatic, such as hypercholesterolemia?

Carers may perform treatment adherence but not healthy behaviours because they think that only medications actually control their condition (Code: *Comparing taking medications with performing healthy behaviours*). Although healthy behaviours may have some benefits, when their chronic condition is not controlled, only medications can help.

- Why is this so?

Table 12 (cont.): Memos written whilst analysis the short excerpt from the ninth interview.

Changing daily routine

Addendum (17 August 2020) cont.

- Do carers do the bare minimum in relation to the management of their chronic condition, that is, doing the most important thing – taking medications? After all, from my professional experience, the most important thing in the management of any chronic condition is treatment adherence. If an individual skips his exercise routine, the chronic condition will not be affected. On the other hand, if the individual skips his medications, then the chronic condition will be affected.
- Could it be that carers do not consider healthy behaviours as a priority in the management of their chronic conditions?

The above memo provides an example of how theoretical sensitivity and reflexivity were involved in the data analysis process. The data revealed that the concept of 'temporality' seems to play an important role in how carers live with their chronic conditions whilst caring for the patient with cancer. This concept did not stem from the researcher's personal or professional experience, nor did it stem from reading the extant literature. Since 'temporality' emerged as an important concept in the developing theory, the researcher sought to ask questions about this concept in the following interviews. Furthermore, the emergence of this concept made the researcher engage in the process of reflexivity to consider his preconceptions and assumptions with regards to how temporality impacts how individuals live with their chronic conditions, as illustrated in the above memo.

The memos presented so far assisted the researcher to start identifying and explicating the properties of developing categories. In fact, in the later stages of this research, the researcher wrote the following short memos, illustrated in Table 13.

Table 13: Memo writing in the later stages of the research.

Potential category – Changing daily routine (24 August 2020)

I am considering using the code 'Changing daily routine' as a potential category for the theory. The participants interviewed so far have all described how they have experienced a change in their daily routine when they started caring for the patient with cancer. This is because they prioritise the care of the patient and hence, they experience time constraints. Further information on this category can be found in the memo **Changing daily routine**.

Table 13 (cont.): Memo writing in the later stages of the research.

Potential category – Doing the bare minimum (19 December 2020)
In the memo **Changing daily routine Addendum (17 August 2020)** I had mentioned the concept 'doing the bare minimum' when referring to fact that carers tend to rely solely on medications when living with their chronic conditions whilst caring for the patient with cancer. After discussions with my supervisors, I concluded that this concept might also be a potential category in the theory. The participants seem to rely on taking medications because other health behaviours, such as exercise and cooking healthy diets, take time to perform. The carer may not find the time to perform health behaviours especially if the patient is fully dependent on him or her. Therefore, carers seem to do the bare minimum when living with their chronic conditions so that they have enough time to care for the patient with cancer.

Therefore, the above example illustrates how, through memo writing, the researcher was able to start developing the categories of the theory presented in this research. In fact, these memos assisted the researcher to identify some of the properties of these categories. For example, these memos revealed that the category 'Changing daily routine' depends on the patient's treatment regimen, the patient's level of independence, the complexity of the carer's condition, the presence of other family members in the household, and experiencing time constraints. The potential categories identified in memo writing aided in the formulation of focused codes. Table 14 illustrates how focus codes were used to code the interview excerpt which was presented in Table 8.

Table 14: Example of focused coding.

Initial Coding	**Focused Coding**	**Interview Excerpt**
Taking medications. Taking medications – Comparing pre and post cancer diagnosis. Facing difficulties to keep up with daily routine. Neglecting oneself. Changing daily routine – Prioritising patient's care. Changing daily routine. Stopping healthy behaviours – Comparing pre and post cancer diagnosis.	Doing the bare minimum. Changing daily routine. Changing daily routine. Changing daily routine. Changing daily routine.	**I:** Can you please tell me what conditions are you living with? **P:** I have high blood pressure. I take one pill in the morning and one pill in the evening. Nothing has changed in that regard. However, I found it difficult to cope with everyday life. You have to forget yourself. You forget your routine because the patient's needs take priority, especially if the patient is a close relative, such as your husband or son. You forget your routine. For example, we have a gym at home and every morning I used to do the treadmill. I used to do some exercise and then I used to have breakfast. I haven't done any exercise or

Table 14 (cont.): Example of focused coding.

Initial Coding	**Focused Coding**	**Interview Excerpt**
Changing daily routine - Blaming treatment regimen.	Changing daily routine.	used the treadmill since my husband has been going in and out of hospital to have chemotherapy.

The next step involved comparing categories together to form higher order categories. The following are examples of two short memos which illustrate this step in the data analysis process (Table 15).

Table 15: Memo about higher order categories.

Biographical disruption (6 September 2020)
Since the participants are talking about how their daily routine changed when taking up the caregiving role, I decided to conduct further reading on this issue and I came across the theory of biographical disruption (Bury, 1982). In this theory, Bury (1982) refers to the effect of chronic illness and how it disrupts everyday life. This notion actually reflects the accounts of the carers in this research. Cancer diagnosis and caregiving have a disruptive effect on the day-to-day routines of carers. In fact, carers seem to make a clear distinction between life before and after cancer diagnosis. However, in this theory, Bury (1982) does not only refer to disruption of daily routine but also refers to disruption of social relationships and self-identity. Therefore, this raises the following question: • Does caregiving affect the carers' social relationships and self-identity and are these related to each other?
Biographical disruption addendum (11 September 2020)
After analysing the data, it seems that participants do not only experience a change in their daily routine, but also experience a change in their social relationships, as well as their self-identity. Therefore, I think these are all subcategories of a higher order category. The names 'Changing biography' or Biographical change' come to mind.

The above memo exemplifies how the research data guided the researcher to read literature related to the concepts which were emerging from the data. This theoretical sampling of the literature (Thornberg, 2012) will be discussed in further detail in Chapter Ten. In return, this information helped to enhance the researcher's theoretical sensitivity. For example, by reading literature on the Theory of Biographical Disruption (Bury, 1982), the researcher identified two other potential concepts: changes in social relationships and self-identity. Consequently, the researcher re-analysed the data to determine whether or not the participants also experienced changes in their social relationships and self-identities whilst caring for the patient with cancer.

As described in the previous sections, the researcher's theoretical sensitivity directs theoretical sampling. The next sections will describe how the data analysis in the first stage of this study directed recruitment in the second stage of this research.

5.8 Theoretical Sampling

As described in the previous sections, grounded theory studies are characterised by theoretical sampling. Charmaz (2014) suggests that theoretical sampling is best used when some categories have already been developed. Therefore, initial data collection is commenced with a fairly random group of people who have experienced the phenomenon under study, to begin to develop categories and then theoretical sampling is utilised to confirm or refute these categories and to focus on theoretical development (Charmaz, 2014). This highlights one of the central features of grounded theory: concurrent data collection and analysis. The new data emerging from theoretical sampling is utilised to confirm and refute original categories. This means that subsequent data collection is carried out in light of initial data analysis. Theoretical sampling was used to develop the categories identified by the participants as being relevant to the research problem. These categories were raised by the participants and hence, noted for inclusion in subsequent interviews to facilitate their development and 'saturation' (Charmaz, 2014).

5.9 Theoretical Sampling in Action

Although a large amount of rich data was collected from the first seven interviews, it was clear that there was a lack of variation in the sample of carers interviewed. For example, as described above, one of the memos written after the first set of interviews was 'Changing daily routine', which describes how cancer caregiving has a disruptive effect on the day-to-day routine of carers. One property which seems to impact the extent of how much cancer caregiving has a disruptive effect on the day-to-day routine of carers is the patient's level of independence. In fact, one participant described the importance of the patient with cancer continuing to live a normal life:

> "*He continued to live a normal life. He went out with his friends. He went shopping. He continued to take care of the car and papers. He continued to live a normal life. He continued to do the work he used to do before. That helped a lot … because I could continue with my normal life.*" (Participant 4; Wife; Outpatient treatment; Hypertension)

This excerpt raised the following question: What happens when the patient with cancer is fully dependent in their ADLs? All the carers interviewed in the first stage of this research were taking care of patients who were fully independent in their ADLs. Hence, it was imperative that, in the second and third stages of this research, the researcher interviewed carers who were providing care to patients who were fully dependent in their ADLs. Interviewing this group of carers would further develop this property of the category.

Another property which seems to impact the extent of how much cancer caregiving has a disruptive effect on the day-to-day routine of carers is whether the carer works or not. During the first stage of this research, only two participants were working whilst taking care of the patient. However, it was clear that these two participants did not find it difficult to get off work in order to take care of the patient or to accompany the patient during one of his or her hospital appointments:

> "*I also considered stopping work. I can retire if I wish to do so … I was ready to stop working and retire.*" (Participant 1; Husband; Inpatient treatment; Heart disease)
>
> "*My boss lets me take time off from work when I want to especially since my husband's appointments are usually at the end of the day … Sometimes, he does not even write down my vacation leave …*" (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

These excerpts raised the following question: What happens when the carer works a full-time job and has difficulty taking time off work? Therefore, it was decided that this group of carers would also be interviewed to further develop this property.

Another memo which was written after the first set of interviews was 'Taking medications' (Table 10). Six of the participants interviewed in the first stage of this research described how they controlled their chronic conditions by just taking prescription medications. However, one participant with multiple chronic conditions described the difference between living with high blood pressure and diabetes. She only needed to take the prescription medication for her high blood pressure. On the other hand, for her diabetes, not only did she have to take her prescription medication, but she also needed to be aware of her diet:

> "*My blood pressure is fine. All I have to do is just take one pill every day. The problem is my high blood sugar. I really get frustrated with my blood sugar because, as soon as I eat something, it increases. It increases even though I would have taken my medication.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

This excerpt made the researcher question the difference between those carers who only need to take prescription medications and those carers who need to undertake more complex tasks on a daily basis when living with their chronic condition. Therefore, in the second and third stages of this research, the researcher focused on recruiting carers with chronic conditions which involve close monitoring or cause functional disability. The focus was especially on those carers with diabetes or arthritis or multiple chronic conditions. These groups of carers were chosen because firstly, patients with diabetes have to adhere to a complex dietary regimen and perform complex tasks, such as checking their blood sugar regularly and administering medication either in tablet or injection form, on a daily basis to manage their chronic condition. Secondly, patients with arthritis have to deal with pain, disfigurement, loss of functional ability, and periods of remission. On the other hand, patients with multiple chronic conditions have to adhere to complex combinations of treatment, and may also experience aggravation of one chronic condition with the treatment of another (Nolte and McKee, 2008).

Finally, one of the participants also revealed off the record that she had depression. She did state that her depression had not deteriorated since her husband's cancer diagnosis. However, the researcher could not probe further in this topic because their conversation was interrupted by the patient with cancer who had requested the help of the carer. Therefore, in the second and third stages of this research, the researcher also focused on recruiting carers with mental health problems. The characteristics of the participants interviewed in the second and third stages of the research are illustrated in Tables 16 and 17 respectively.

Table 16: Characteristics of the seven participants interviewed in the second stage.

Participant	**Age**	**Sex**	**Employment**	**Carer's condition**	**Cancer phase**	**Relationship to the patient with cancer**
Participant 8	55	F	Unemployed	Arthritis and fibromyalgia	Inpatient treatment	Wife
Participant 9	69	M	Retired	Chronic migraines	Inpatient treatment	Husband
Participant 10	58	F	Employed	Arthritis	Outpatient treatment	Sister-in-law
Participant 11	54	F	Unemployed	Breast cancer and arthritis	Outpatient treatment	Wife
Participant 12	60	F	Employed	Diabetes	Inpatient treatment	Sister
Participant 13	44	F	Unemployed	Hypertension	Inpatient treatment	Wife
Participant 14	39	F	Unemployed	Heart disease	Survivorship	Wife

Table 17: Characteristics of the thirteen participants interviewed in the third stage.

Participant	Age	Sex	Employment	Carer’s condition	Cancer phase	Relationship to the patient with cancer
Participant 15	67	F	Retired	High blood pressure, lung disease and arthritis	End-of-life	Friend
Participant 16	69	M	Retired	High blood cholesterol	End-of-life	Husband
Participant 17	45	M	Employed	Hypertension	Survivorship	Husband
Participant 18	63	F	Retired	Thyroid disease	Survivorship	Parent
Participant 19	64	M	Retired	Hypertension	Survivorship	Parent
Participant 20	44	M	Employed	Lung Disease	End-of-life	Child
Participant 21	68	F	Retired	Arthritis	Outpatient treatment	Wife
Participant 22	33	F	Unemployed	Thyroid disease	Survivorship	Parent
Participant 23	37	F	Unemployed	Hypertension	Inpatient treatment	Parent
Participant 24	47	M	Employed	Diabetes	Outpatient treatment	Husband
Participant 25	41	M	Employed	Hypertension	Inpatient treatment	Child
Participant 26	59	F	Unemployed	Depression	Survivorship	Wife
Participant 27	46	F	Unemployed	Fibromyalgia	Outpatient treatment	Sister

As illustrated in the tables above, the recruitment techniques employed were successful in recruiting a variety of carers which was imperative for the development of the theory (Charmaz, 2014). In the second stage of the study, three participants were interviewed at the hospital, whilst four participants were interviewed in their homes. In the third stage, ten participants were interviewed via Skype, whilst three participants were interviewed in their homes. The next section will describe theoretical saturation and how this was achieved.

5.10 Theoretical Saturation

Dey (1999) suggests that grounded theory is an approach which indicates both how to initiate research and how to conclude research. In fact, in grounded theory studies, data collection stops when theoretical saturation is achieved. Theoretical saturation refers to the point at which no additional data are found which can further develop the properties of the categories (Glaser and Strauss, 1967).

Dey (1999) argues that researchers may easily misunderstand the term ‘saturation’ as indicating that the categories have been exhausted. However, Dey (1999) argues that the categories are never exhausted because they do not undergo the process of verification and hence, should be considered incomplete. As a result, Dey (1999) suggests using the term ‘sufficiency’ rather than the term ‘saturation’. This would mean that at this stage the categories would cope well with new data from further interviews without requiring continual extensions or modifications. Nevertheless, there is always the possibility that new data from further interviews or a re-examination of current data may lead to new ideas emerging which may refine current categories or add new ones to the theoretical framework (Dey, 1999). So how would the researcher know when to stop if there is always the uncertainty that a fresh look at the data may lead to further refinement of categories or development of new ones?

Since constructivist grounded theory (Charmaz, 2014) is rooted in pragmatism and relativist epistemology, it seemed appropriate to consider Low’s (2019) pragmatic definition of the concept of theoretical saturation. Low (2019) argues that researchers should determine whether they have reached theoretical saturation or not by answering the following questions:

i. Does the theory address process?
ii. Does it address the exploratory questions of how and why?
iii. Does it account for variations in the sample?
iv. Is it informed by the theoretical sampling of relevant literature?
v. Is the analysis based on the unit of analysis, that is the phenomenon being studied and not the person, the group, or the case?
vi. Does it include categories which are connected together to form a theoretical framework that is generalizable because it is contextualised in the broader social context?

In this research, the researcher determined that theoretical saturation was reached firstly because, the theory does explain the process of biographical compromise and also describes the contextual factors which impact this process. In addition, the theory seeks to explain why and how carers decide to engage in this process, as discussed in further detail in Chapter Eleven. Secondly, the theory is made up of a number of categories connected together. These categories will be described in detail in Chapters Six to Nine. Thirdly, a variety of carers were recruited, as already illustrated in Tables 7, 16 and 17. Fourthly, the theory was informed by the theoretical sampling of relevant literature, as illustrated in Table 15 and as will be discussed in Chapter Ten. Finally, the data analysis was based on the unit of analysis, that is the phenomenon being studied and not on specific individuals or cases. This is illustrated by the fact that the researcher does not make reference to specific individuals when describing the theory. In fact, interview excerpts were only provided to illustrate that the researcher's claims were backed up by the research data.

5.11 Developing the Core Category

A key part of the research process in a grounded theory study is the identification of a core category. The core category conceptualises the social process addressed by the theory, as well as ensures the relevancy and workability of the emerging categories. In fact, those categories which are related to the core category are examined in more depth, whilst the remaining categories which are not related, are excluded from the theory (Dey, 1999). Dey (1999) suggests that the core category should have certain features:

i. Relates and explains the other categories.
ii. Can be seen as a recurrent pattern in the data.
iii. Explains the underlying social process.
iv. Is sensitive to variations in the factors influencing the underlying social process.

A core category was discovered in this research: 'Making Concessions'. The properties of this core category are presented in Chapter Nine to explain how the major categories of 'Feeling Obliged', 'Changing Biography' and 'Minimising Interference' are related to explain how carers live with their chronic conditions whilst caring for the patient with cancer.

5.12 Conclusion

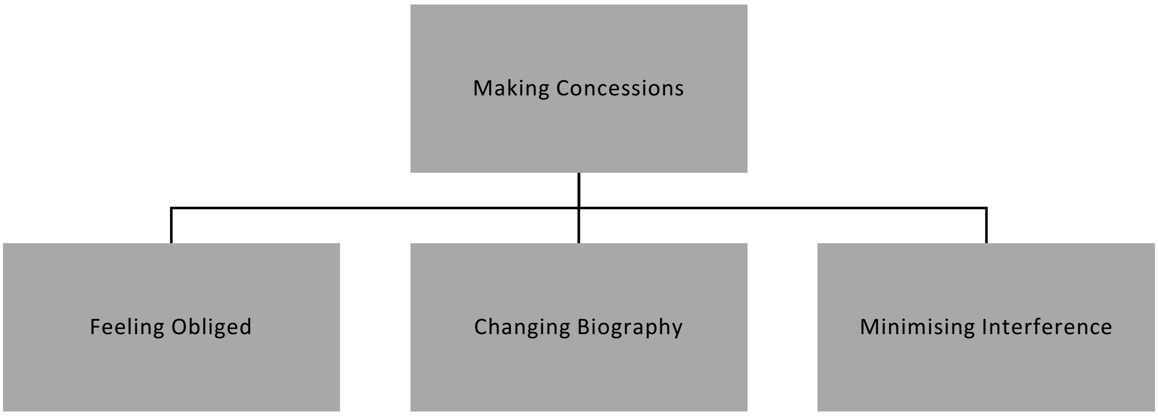
This chapter described how data analysis was carried out. It also described how theoretical saturation was deemed to have been reached. The next chapter will present the findings from the research data.

Chapter 6 Feeling Obliged

6.1 Introduction

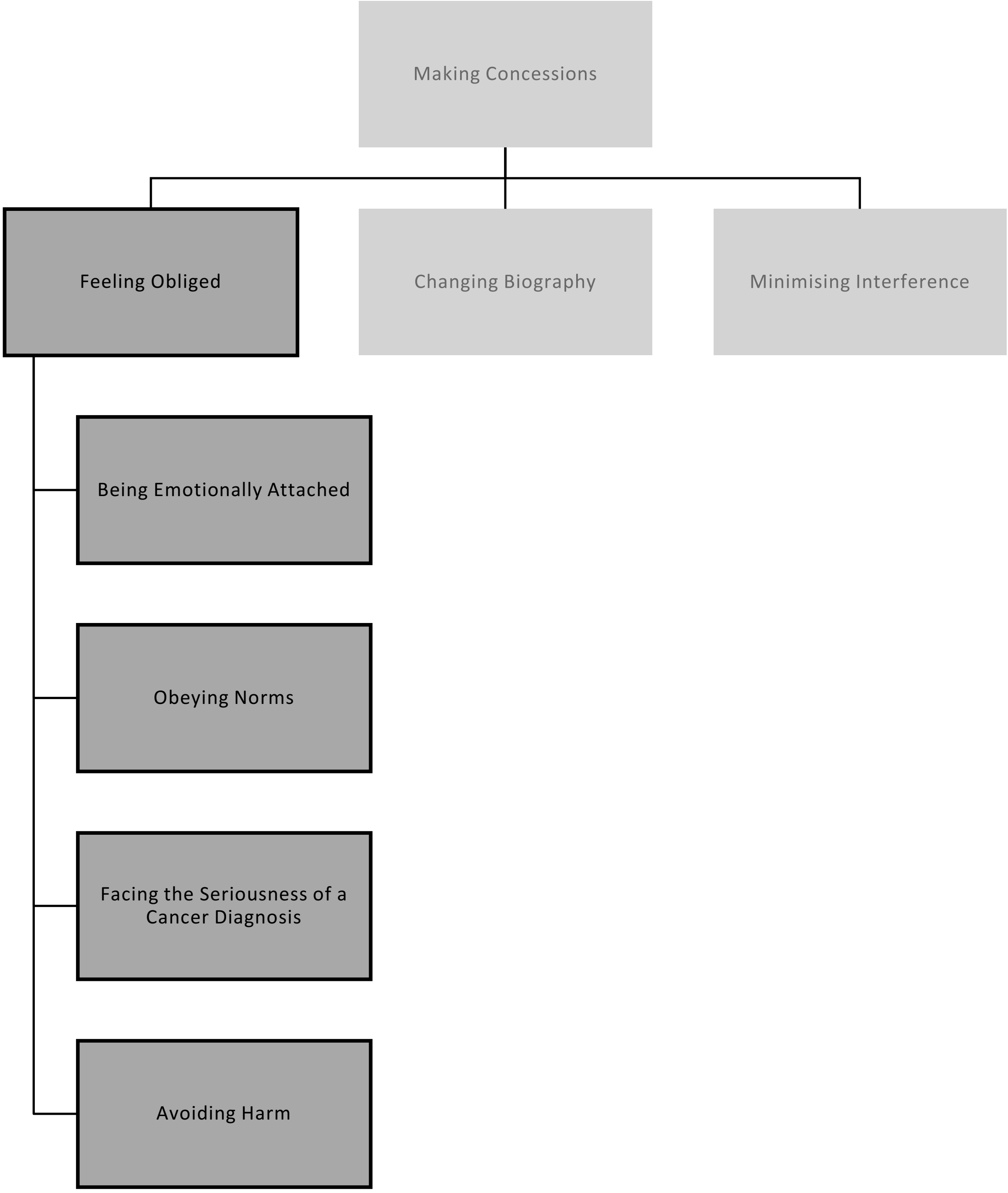
The next four chapters present the findings from the research data by describing the conceptual framework illustrated in Figure 2. The data were derived from twenty-seven interviews conducted with carers of patients with cancer and having at least one chronic condition. Following the principles of constructivist grounded theory (Charmaz, 2014), the major categories identified were drawn from the participants' responses. Each quotation will be labelled with the participant's unique research number.

Figure 2: Conceptual framework illustrating how carers live with their own chronic conditions whilst caring for the patient with cancer.



As illustrated in Figure 2, the core category of the process of living with a chronic condition whilst caring for the patient with cancer is 'Making Concessions', which will be described in further detail in Chapter Nine. This core category describes how, throughout the cancer trajectory, carers make concessions in their daily life to maintain a balance between caring for the patient and at the same time, living with their chronic conditions. This core category relates to three major categories: 'Feeling Obliged', 'Changing Biography', and 'Minimising Interference'. This chapter will describe the first major category 'Feeling Obliged' and its subcategories, as illustrated in Figure 3.

Figure 3: The major category ‘Feeling Obliged’ and its subcategories.



6.2 Feeling Obliged

This category describes why the participants decide to make concessions in their daily life to maintain a balance between the caregiving role and living with their chronic conditions. Analysis of the interview data revealed that the participants cared for the patient with cancer out of a sense of obligation. Both positive and negative emotions, as well as social norms were involved in the creation of this sense of obligation, as described in the next sections.

6.3 Being Emotionally Attached

All the participants emphasised that their primary motivation for taking up the caregiving role was love and respect for the patient with cancer:

> "*Love dictates whether you will take care of the patient or not. If there is love, then you are going to take care of him. Sometimes, I hear other carers saying that they are fed up of taking care of their husband or wife, but they have no choice but to do it. I think there is something wrong in that. There is no love.*" (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*I try my best to take care of her. We have been together for all these years. I love her. I love her so much. I would do anything for her.*" (Participant 16; Husband; End-of-life; High blood cholesterol)

The word "*dictates*" in the first excerpt clearly illustrates how love made it necessary for the participants to care for the patient. Therefore, they felt a sense of obligation to take up the caregiving role. In addition, the first excerpt suggests that although love may not always be present, the carer will still feel a sense of obligation to care for the patient, as emphasised by the phrase "*they have no choice but to do it*". In fact, analysis of the interview data revealed that, although all the participants cited love and respect as their primary motivation for taking up the caregiving role, there were other factors which influenced the participants to take up this role, as will be described in the following sections.

This section described how the emotional connection between the participants and the patients emphasised by love and respect made it necessary for the participants to take up the caregiving role. Therefore, it was decided to name this subcategory 'Being Emotionally Attached' to illustrate how the feelings created in being close to the patient obliged the participants to assume caregiving responsibilities. The next section will describe how norms are involved in the creation of the participants' sense of obligation to care for the patient.

6.4 Obeying Norms

Those participants who were spouses of patients with cancer felt a sense of duty and obligation to take up the cancer caregiving role because they were married to the patient:

> "*I am married to him and so I have to take care of him. That is what I have signed up for when I married him. To remain by his side in both good and bad.*" (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> “*I married him to be with him on both his good and bad days*.” (Participant 26; Wife; Survivorship; Depression)

The phrase “*signed up for*” continues to emphasise how this participant felt a sense of obligation to care for her husband. Another participant described how she would never consider asking another person to care for her husband because she is the one married to him and hence, it is her responsibility to take care of him:

> “*I know that there are some things which are my responsibility and I have to do them myself. I am not expecting someone to come and take it off my hands. He is my husband and I have to take care of him. If something happens to me, I expect him to take care of me.*” (Participant 2; Wife; Outpatient treatment; Hypertension)

Therefore, the commitment of marriage vows made spouses feel obliged to provide the necessary care to the patient. This illustrates how the participants felt it was necessary to fulfil the obligations and duties that are inherent in certain relationship dynamics, in this case, the husband-wife relationship. However, this need to fulfil such obligations and duties was also seen in one of the interviews with the parent of a patient:

> “*This is my son we are talking about. So, I am going to take care of him because no one wants to see their children suffering. It is not like we are talking about a distant cousin or a friend.*” (Participant 18; Parent; Survivorship; Thyroid disease)

Although the above excerpt suggests that such obligations and duties do not exist in other relationship dynamics, such as friendship, an interview with a participant who happened to be the patient’s friend revealed how she still felt it necessary to care for the patient with cancer especially since the patient had no one else to care for her:

> “*I have to take care of her. She has no one. She is not married and does not have any children. Both her parents are dead and her other family members live in Australia. So she has no one. I have to take care of her.*” (Participant 15; Friend; End-of-life; Multiple chronic conditions)

In one of the above excerpts, the participant stated how she expected the patient to take care of her if she ever falls ill. This excerpt suggests that reciprocity may have also been a motivation factor for this participant to take up the cancer caregiving role. This can also be seen in another excerpt:

> “*I also expect her to do the same if something happens to me.*” (Participant 1; Husband; Inpatient treatment; Heart disease)

These participants expect the patient to repay the favour if the carer-patient roles are reversed. Nevertheless, reciprocity was not the critical motivation for these participants because they still took care of the patient even though there is no guarantee of reciprocity from the patient due to the uncertainties of cancer and its treatment. On the other hand, other participants felt obliged to take care of the patient in order to repay what the patient had done for them and thus, as a form of reciprocation:

> "*Furthermore, I have to give my time to her. After all, she had a lot of patience with me when I was always out with work*." (Participant 9; Husband; Inpatient treatment; Chronic migraines)

> "*She did a lot when I was in hospital. So now it is my turn to take care of her.*" (Participant 24; Husband; Outpatient treatment; Diabetes)

> "*When I fell into a depression, he did everything for me. He used to do everything around the house. He used to cook, clean, do the laundry. Sometimes, he also assisted me in the shower … So I did my best to take care of him.*" (Participant 26; Wife; Survivorship; Depression)

Another participant described how his father had sacrificed a lot to bring him up and now he wanted to pay him back:

> "*My dad did everything to take care of us when we were young. Now it is my time to take care of him.*" (Participant 25; Child; Inpatient treatment; Hypertension)

Analysis of the interview data also revealed how some of the female participants took up the cancer caregiving role because they were expected to do so by the rest of the family members. In fact, although occasionally there were several family members who were available to care for the patient with cancer, often times the workload fell on one sole person, usually a woman. One of the participants described how she considered herself as the main carer in the family and hence, had to take care of her husband even though their children still lived in the same household:

> "*First of all, I already take care of my mother. She is 81 years old. Our children still live with us but it is me who takes care of him. I have to do everything.*" (Participant 4; Wife; Outpatient treatment; Hypertension)

Another participant recounted how she was taking care of her sister-in-law even though her sister-in-law was married:

> "*I take care of my sister-in-law. She does not have any children. She has nephews and nieces but because I am close to her and I am a nurse, automatically I took over the role of taking care of her. She is married but I automatically took over and started taking care of her.*" (Participant 10; Sister-in-law; Outpatient treatment; Arthritis)

The above excerpt also illustrates how this participant felt obliged to take care of her sister-in-law because she was a professional carer. This was also revealed in another interview:

> "*As a nurse, when there is someone who needs your care, you are expected to take care of them. I took care of my mother. She died of a stroke. She lived here for over two months. Now, I am taking care of my husband.*" (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

Some of the female participants also identified themselves as caring people and therefore, they did not find it difficult to take up the caregiving role. They explained how they always prioritised the care of other people over their own:

> "*I always prioritise the needs of others over my own. That is just me. I do not think about myself. I care a lot about the others*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I do not think about myself. I just want to help the others. I just think about helping my sister.*" (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

This section described how due to social, reciprocity and gender norms, the participants felt it necessary to take care of the patient with cancer. The next sections will describe how negative emotions fuel the participants' sense of obligation to care for the patient.

6.5 Facing the Seriousness of a Cancer Diagnosis

All the participants described how cancer diagnosis and taking up the caregiving role brought them face to face with the pain and suffering of the patient, as well as the possibility of the patient dying from cancer. Hearing the diagnosis of cancer resulted in strong feelings of shock, disbelief, and fear. The participants were shocked at the cancer diagnosis because they never expected their loved one to be diagnosed with cancer, especially because the signs and symptoms experienced by the patient were not usually associated with cancer but with less severe illnesses:

> "*I remember when we went to hospital because she had a high calcium level. This was on a Thursday. She was feeling weak but she was not in pain. Then, on Monday, she called*

> *me and she told me that she had cancer. I was shocked when she told me so. I was shocked. She never felt any pain. So, I was shocked when she told me that she had cancer.*" (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*It was like a bolt out of the blue. We were shocked when the consultant told us that he had lymphoma … I was shocked that my son was at ITU. At that moment, I did not know whether I was living or not*." (Participant 19; Parent; Survivorship; Hypertension)

> "*He had been complaining of this sore throat for about two weeks even though he was taking antibiotics. Then, our GP decided to take some bloods … We were shocked when he informed us that he was referring my dad to the local oncology centre.*" (Participant 25; Child; Inpatient treatment; Hypertension)

Furthermore, some of the participants described that they were shocked at the cancer diagnosis because they never expected their loved one to experience what they had heard or seen on social media:

> "*We used to watch this local fundraising programme for patients with cancer. We never thought that our son would feature on this programme as a patient.*" (Participant 19; Parent; Survivorship; Hypertension)

> "*We used to watch these fundraising programmes for children and teenagers with cancer and we used to contribute to the cause by giving them some money. We never thought that our son would end up being diagnosed with cancer and benefit from these fundraising programmes.*" (Participant 22; Parent; Survivorship; Thyroid disease)

Such feelings of shock and disbelief all emphasise the fact that the participants considered cancer as a serious condition. As a result, this motivated them to take up the cancer caregiving role and prioritise the care of the patient:

> "*Since you are dealing with a serious disease, automatically your first priority will always be the patient and not yourself or other family members.*" (Participant 14; Wife; Survivorship; Heart disease)

> "*Cancer is a serious illness and I knew that the treatment period was going to be difficult. So I had to figure out what to do with regards to work and our children because I had to take care of her.*" (Participant 17, Husband; Survivorship; Hypertension)

> "*You love all your children the same. However, in such cases because you are talking about serious illnesses, without wanting to, your first priority is going to be the patient.*" (Participant 22; Parent; Survivorship; Thyroid disease)

Some of the participants also described how they considered cancer as being more serious than their chronic conditions, as highlighted by one of the participants:

> "*I do believe that the medications and chemotherapy that they are giving him will cause side effects. And I do believe that his symptoms are worse than the ones I feel because of my condition.*" (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

All the participants perceived a cancer diagnosis as an impending death, and they could not live their lives as they did before the cancer diagnosis without acknowledging the fear of death of the patient:

> "*You start worrying about whether she is going to survive or not. Whether the treatment will be successful or not … So, the only thing on your mind is to help her. You do not think about yourself.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

> "*There is always that fear about what is going to happen whilst he is having his chemotherapy and when he goes abroad for his bone marrow transplant. You do not know whether he is going to make it or not.*" (Participant 13; Wife; Inpatient treatment; Hypertension)

> "*The thought keeps running through your mind … whether he is going to make it or not.*" (Participant 23; Parent; Inpatient treatment; Hypertension)

The fear of death of the patient often stemmed from the uncertainty of cancer and its treatment. For the participants, this uncertainty started upon receiving the news of cancer diagnosis, as recounted by one of the participants:

> "*We did not know what was wrong with him. We did not know what was wrong with him until we got transferred from the surgical ward to the haematology ward. We did not know whether the cancer had spread or not. Whether he was going to make it or not.*" (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

The participants also acknowledged this feeling of uncertainty before the patient started treatment:

> "*You start worrying about whether the treatment will be successful or not.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

> "*This is not the same as when you come down with the flu. You are taking chemotherapy and so you are going to feel really unwell and sick. So, you do not know what is going to happen when he starts receiving treatment.*" (Participant 14; Wife; Survivorship; Heart Disease)

> "*Only God knows whether he will make it through treatment or not.*" (Participant 23; Parent; Inpatient treatment; Hypertension)

These feelings of uncertainty continued throughout cancer treatment:

> "*I was getting quite upset because he was getting better. Not that I did not want him to get better, but it is because you just think 'Is it really happening?' … I think he was so excited, and I am thinking 'Do not get excited because what if it is not right'. I mean I knew it was right but what if it does not work out that way.*" (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*You do not know what is going to happen. Every day you do not know what is going to happen, especially when he is receiving treatment. That makes you worry. You wake up every morning and you say to yourself 'What is going to happen today?' and then you get through that day, and you ask yourself the same thing the next day.*" (Participant 21; Wife; Outpatient treatment; Arthritis)

These feelings of fear and worry were exacerbated when the participants heard other carers of patients with cancer talking about their experiences of cancer, as illustrated in the following excerpt:

> "*When you hear other people talking about their experiences of cancer you start to worry. Some people say that chemotherapy can do this and it can do that. It can do this, this and this. You start to worry. It is difficult not to compare yourself to others. However, you have to try not to compare yourself to others.*" (Participant 13; Wife; Inpatient treatment; Hypertension)

Another participant described how these feelings of fear and worry were also exacerbated by past experiences of cancer. He described how he had lost his brother to cancer two years before and hence, he was afraid that his son would end up having the same fate as his brother:

> "*I lost my brother two years ago. I used to take care of him whilst he was receiving chemotherapy and I had actually travelled to England with him so that he could undergo his bone marrow transplant. When my son was diagnosed with cancer, I could not stop thinking about whether he will end up like my brother or not. I could not stop thinking*

> *about whether he will make it or not.*" (Participant 19; Parent; Survivorship, Hypertension)

Nevertheless, hope from receiving positive test results about cancer motivated the participants to continue caring for the patient with cancer:

> "*I felt good about it especially when we were told that the cancer had started to dissipate. That gives you hope.*" (Participant 9; Husband; Inpatient treatment; Chronic migraines)
>
> "*When I see positive results, it gives you hope. It gives you hope. It encourages me to push on and I feel better.*" (Participant 13; Wife; Inpatient treatment; Hypertension)
>
> "*The consultant informed us that the last CT scan was clear … there are no signs of cancer. That gives you hope*." (Participant 21, Wife; Outpatient treatment; Arthritis)

Another participant maintained hope by comparing her situation to others:

> "*I was speaking to someone the other day. I did not know her. She is 45 years old, and we were speaking in the corridor. She has three. Three cancers. One in the intestine, one in the liver and one in the lymph nodes. I was shocked when she told me so. I could not utter a single word. I started crying with her in the corridor. She has a 16-year-old daughter. She needs help. She needs a lot of help. It is very difficult to accept. I do not have that problem. I have hope. That gives you the power to plod on.*" (Participant 2; Wife; Outpatient treatment; Hypertension)

Therefore, hope was important to the daily lives of the participants. It gave the participants courage to support the patient. This was articulated by one of the participants who described the difference between someone who is caring for a patient receiving curative treatment and someone caring for a patient where the chances that the cancer would be cured were minimal:

> "*I have met people who do not have any hope of being cured. They tell you that they are waiting to die. It makes a difference if you are caring for someone like him or her. Poor people. If there is hope, then it makes a difference because it gives you the courage to continue caring for the individual.*" (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

The above excerpt seems to suggest that carers may find it difficult to care for the patient with cancer when there is no hope of recovery from the cancer. However, interviews with participants who were taking care of patients at the end-of-life revealed that these carers still continued to care for the patient even when there is no hope of recovering from the cancer. Besides the positive emotions and norms described in the previous sections, these participants felt that it was necessary to take care of the patient to avoid feelings of guilt for not doing something for the patient before he or she dies:

> “*Better than if I went home and kept thinking about the fact that she wanted to have a bath and I did not help her. Most probably she would have become upset. So, I would start feeling guilty that I did not help her have a bath.*” (Participant 15; Friend; End-of-life phase; Multiple chronic conditions)

> “*We are doing everything for him. Whatever he needed, we did it. So, we do not have any guilt feelings or anything.*” (Participant 20; Child; End-of-life; Lung disease)

In addition, caring for the patient gave a sense of satisfaction to the participants:

> “*A big satisfaction that she was happy. A big satisfaction. Because, as I was saying, you do not know when there is an end to this or not. You do not know when she is going to die. So, thank God that I did all those things for her.*” (Participant 15; Friend; End-of-life; Multiple chronic conditions)

> “*I really feel happy when I do something for someone else. I really feel happy when I help someone else … I get a feeling of satisfaction when I care for my father.*” (Participant 20; Child; End-of-life; Lung disease)

The feelings of uncertainty continued when the patient finished his or her cancer treatment due to the possibility of the cancer coming back:

> “*But you know, cancer is something that is dormant and then, suddenly it can explode.*” (Participant 17; Husband; Survivorship; Hypertension)

> “*Even now that he has finished his treatment, we still worry about the possibility of a relapse because as you know, cancer never goes away completely. At least he is undergoing regular blood tests.*” (Participant 18; Parent; Survivorship; Thyroid disease)

> “*Although he is feeling much better now, we do not know whether the cancer will come back or not. The consultant told us that we have to wait at least five years until we can be certain*.” (Participant 26; Wife; Survivorship; Depression)

Therefore, the participants experienced fear and worry about the possibility of the patient dying from cancer throughout the whole cancer trajectory. This motivated some of the participants to do their best to help the patient get through the cancer trajectory and hence, recover from the cancer, especially because they were afraid of ending up alone if the patient dies:

> "*What is the point of staying healthy but then, the people that you love, your husband and children, do not take care of themselves? I do not want to live until I am 90 years old, but my loved ones would have already died. So, I take care of my husband because I do not want to end up living all alone in this house.*" (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*I hope nothing happens to him but at the same time I have to accept it, I have to accept everything that comes our way. I am all the time praying so that he is not sick, and he does not die so that I can continue my life with him. But at the same time, I have to accept what is going to happen.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

On the contrary, one of the participants interviewed in this research stated that she was not afraid of ending up alone if the patient dies:

> "*Not self-pity. For me, it is not self-pity. I know that I can cope if he dies. I am a very strong person. I am not afraid if I end up alone. I will not burden my children. I can cope all alone. I do not mind. However, I pity him. That is all.*" (Participant 13; Wife; Inpatient treatment; Hypertension)

The phrase "*it is not self-pity*" in the above excerpt continues to suggest that reciprocity may in part be a motivation factor for those participants who did their best to help the patient recover from the cancer because they were afraid of ending up alone. On the other hand, this participant cared for the patient because of feelings of sadness and sympathy towards the patient.

This section described how due to the seriousness of a cancer diagnosis, the participants felt it necessary to care for the patient and support him or her throughout the cancer trajectory. The next section will describe how feelings of guilt also made it necessary for the participants to care for the patient.

6.6 Avoiding Harm

The emotional attachment and social norms, coupled with the seriousness of a cancer diagnosis meant that the participants had to avoid confrontations and hide their feelings to prevent causing physical harm and emotional distress to the patient with cancer. This created a problem when they tried to encourage the patient to get more involved in his or her care. The participants wanted to support the patient in being or keeping active, but this was accompanied by a difficulty in getting the balance right and knowing the appropriate amount of activity and rest. This was often a source of tension within dyads. The participants were confused about how much activity was too much or, conversely, how little was too little and whether they should be encouraging the patient to do more. Consequently, the participants often did everything themselves which meant changing their biographies to take on new roles and responsibilities, as will be described in the major category ‘Changing Biography’. They did so to avoid feeling guilty because of the possibility of causing physical harm to the patient. One of the participants described the emotional dilemma that she faced on a daily basis whilst caring for her husband. Although she felt angry when her husband did not do his best to get better, she was afraid that pushing him too hard to do something would physically harm him:

> “*One time, I was in a lot of pain. He spends all day sitting on the sofa and he does not come and help me in the kitchen. I was very angry because I consider myself a highly driven person. I am a positive person. However, I think that he is being too negative … So, I get angry, and I tell him to start doing something. But then afterwards, I start worrying that maybe he is too sick to do what I asked him to do, and that he stays sitting all day on the sofa not because he is lazy but because he is too tired to do anything. Therefore, I end up doing everything on my own.*” (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

This participant went on to describe this particular situation as “*abuse*”. Nevertheless, the strong feelings of guilt and fear prevented her from doing anything about this situation:

> “*I think he makes us feel that that is what is needed. That is how he makes us feel. Especially me. It is not only because he has cancer. Even his character. He manipulates me … I think there were moments where he should have done more. Where he should have helped more around the house. That I do not think it is fair. I feel it is abuse. But then I still question myself whether I am being a bitch or whether he is truly tired and not feeling well. I start feeling guilty that I might have pushed him too hard. I do not know what he is going through. You have to go through it yourself to understand.*” (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

This participant went on to describe how she avoided such confrontations with the patient because she did not want to emotionally upset him:

> “*He has four dogs and I love them. Not that I do not love them, but you have to think it through. In my opinion, we had to get rid of one or two dogs due to the increased*

> *workload, their dirt and needs … He cannot clean after them because of the risk of infection … However, he did not want to get rid of them. His in-laws stated that if we got rid of them it would kill him … So as not to upset him, I try to avoid arguments.*”
> (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

The above excerpt suggests that other family members may have also influenced this participant's sense of obligation to take up other roles and responsibilities so as to prevent causing physical harm and emotional distress to the patient. Another participant described how she had encouraged her husband to remain in hospital until he had gained more independence in his ADLs. However, her husband, being stubborn, decided to go against the participant's advice and asked the doctor to discharge him. This resulted in increased burden on the participant because the patient ended up being totally dependent on her in terms of his ADLs:

> “*He informed the doctor that he was feeling fine. That he was managing to go to the bathroom alone. When she left, I told him that he was lying because I knew that he was finding it difficult to walk on his own. Then the doctor came back in and asked him whether he was feeling ready to be discharged home. He said 'yes' and in fact, they discharged him that same afternoon. Now, it is not that I did not want him to come home, but I knew what was going to happen. And in fact, as soon as we arrived home, he said he was feeling too tired to walk and so, I had to lift him from the couch onto the wheelchair and then assist him in bed. I do not know why he does this. I do not know why he tells them that he can be discharged home. Now, he is totally dependent on me.*”
> (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

When this participant was asked about why she never informed the doctors herself about these issues, she responded by saying:

> “*Whenever I have tried to speak to a doctor, he always gets angry and tells me that I do not want him to go home, so that I can go out and play bingo with my friends or tell them to come over to our house. So, then I just shut up and say nothing because then I start feeling guilty. Guilty that I made him angry and that I am not doing enough to take care of him.*” (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

All of the participants described how they did their best to hide their feelings of fear and worry so as not to emotionally upset the patient with cancer:

> “*Not to show him that I am sad. That I am sad when I am with him. I encourage him all the time even though I myself would be feeling sad and upset.*” (Participant 4; Wife; Outpatient treatment; Hypertension)

> “*I always tried not to show him that I was sad and in pain.*” (Participant 7; Wife; Survivorship; Heart disease)

> “*It was a big problem staying all the time next to our child, trying to smile all the time even though we knew the seriousness of his condition. There were times when I emotionally collapsed in front of him. However, I always tried my best not to so as not to make him worry. Because it affects him whether he sees his mother crying or smiling. It will either help him or not. So, you show a different face in front of the patient. But it is difficult.*” (Participant 23; Parent; Inpatient treatment; Hypertension)

Some of the participants described how they tried to stop the patient from harming himself or herself. The participants described how caring for the patient was not always easy, especially when they were stubborn and dug in their heels. One of the participants recounted how his wife was a “*clean freak*” and this was a concern because it was not the first time that he found her cleaning the house even though this activity is bad for her health. As a result, he decided to take over this role himself:

> “*At the moment I have to stay with her all the time because my wife is a clean freak and so she will immediately start cleaning even though the doctor told us that she should not. So, at the moment, I am doing all the cleaning.*” (Participant 24; Husband; Outpatient treatment; Diabetes)

Another participant described how she had told her husband not to clean the house whilst she was in hospital because she was afraid that he might get an infection:

> “*When he was alone at home, I told him not to worry about the cleaning. I will do the cleaning myself. I was worried that he may start cleaning the house and get an infection or something.*” (Participant 4; Wife; Outpatient treatment; Hypertension)

All the participants also expressed feelings of frustration and guilt when they were unable to avoid harm to the patient, such as seeing the patient suffering from the side effects of the treatment but being unable to help alleviate them, or when witnessing the patient’s deterioration during the end-of-life phase:

> “*When he starts improving and then something happens, and he goes one step backwards. Like for example, when he has fever. I get frustrated and upset.*” (Participant 13; Wife; Inpatient treatment; Hypertension)

> “*I become frustrated when she is in pain, and I cannot help her. Or when she asks me certain questions and I cannot answer, and I have to lie to her. When she asks certain*

> *questions and I do not know how to answer them, and that frustrates me.*" (Participant 15, Friend; End-of-life; Multiple chronic conditions)

These strong feelings of guilt further motivated the participants to do everything to help the patient with cancer:

> "*I hope that she is telling me everything. I hope that she is telling me what she is feeling and if she needs help or not. I cannot do anything about her cancer but at least I can help her get through the chemotherapy.*" (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*Sharing first of all. I feel that I have to know so that I can encourage her when she is feeling down. Do you know what I mean? So, we are walking the journey together. Obviously, she is going through it more than I am. But we are in this together. We are sharing the experience. We are passing through this stage in our lives.*" (Participant 9; Husband; Inpatient treatment; Chronic migraines)

Therefore, the above excerpts suggest that since the participants had no control over the cancer and the side effects of its treatments, this motivated them to do their best when performing caring tasks, tasks which they had control of. This introduces the concept of 'exerting control', which will be discussed in further detail when describing the core category 'Making Concessions'.

It is important to note that the participants' sense of obligation to care for the patient with cancer continued throughout the cancer trajectory. Analysis of the interview data revealed that even when the participants were unable to care for the patient themselves, they all felt obliged to make arrangements to make sure the patient was cared for in their absence. One of the participants described how she had her son take care of his father whilst she visited her parents in a nursing home:

> "*In the evening, my son stays with his father. In the meantime, I go and visit my father and mother in the nursing home. Therefore, whilst I visit my parents, I know that there is someone taking care of my husband. If it was not for my son, I would not find the time to pay them a visit.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Another participant recounted how difficult it was for her to undergo a total knee replacement since this involved spending time in hospital and hence, being unable to take care of the patient. However, she had no other option but to undergo the procedure due to severe arthritis. Nevertheless, she decided to undergo the procedure only when she made sure that the patient was cared for. In fact, at the time of the interview, she was awaiting a reply from a respite care organisation about the possibility of getting her husband into a nursing home until she recovers from the procedure:

> "*The doctor recommended that I undergo a total knee replacement. At first, I was very reluctant to undergo such a procedure because I did not know who was going to take care of my husband whilst I am in hospital. In fact, I have the respite papers here. I am going to call them and see whether I can get him into a nursing home until I recover from the procedure. I will try and get him into a nursing home before I undergo the procedure.*" (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

In addition, the parents of a patient who was in the survivorship phase recounted how, although the patient was now able to care for himself, they still prioritised his care above everything else:

> "*If he asks for something and his sister asks for something else, I often tend to his needs first. He takes the priority. At least, his sister understands this.*" (Participant 18; Parent; Survivorship; Thyroid disease)

> "*If something happens and the cancer comes back, I will stop whatever I am doing and take care of him*." (Participant 19; Parent; Survivorship; Hypertension)

The above excerpts illustrate how all the participants felt it necessary to support the patient throughout the whole cancer trajectory. This meant that the participants had to change their biographies in order to take up other roles and responsibilities associated with caregiving role, as will be described in Chapter Seven:

> "*When I decided to take care of her, I knew that I was going to spend less time with my family, that I will have to stay up late to finish the housework, that I will not have time to continue going to the animal sanctuary.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

The next section will provide a summary of the major category 'Feeling Obliged' described in this chapter.

6.7 Summary of the Major Category 'Feeling Obliged'

The review presented in Chapter Two highlighted that there is a lack of literature on why carers prioritise the care of the patient and as a result, neglect themselves. Therefore, the major category 'Feeling Obliged' contributes to existing knowledge by illustrating how positive and negative emotions, as well as social norms influence carers to care for the patient. Carers seem to report little to no choice in assuming caregiving responsibilities for the patient and hence, the reason why this major category was named ‘Feeling Obliged’. This perceived lack of choice to taking up the cancer caregiving role may be due to several reasons including: (i) emotional attachment towards the patient; (ii) obeying social norms; (iii) facing the seriousness of a cancer diagnosis; and (iv) avoiding harm to the patient. It seems that carers are forced by these factors to take care of the patient and hence, they lack control over the decision to take up the caregiving role.

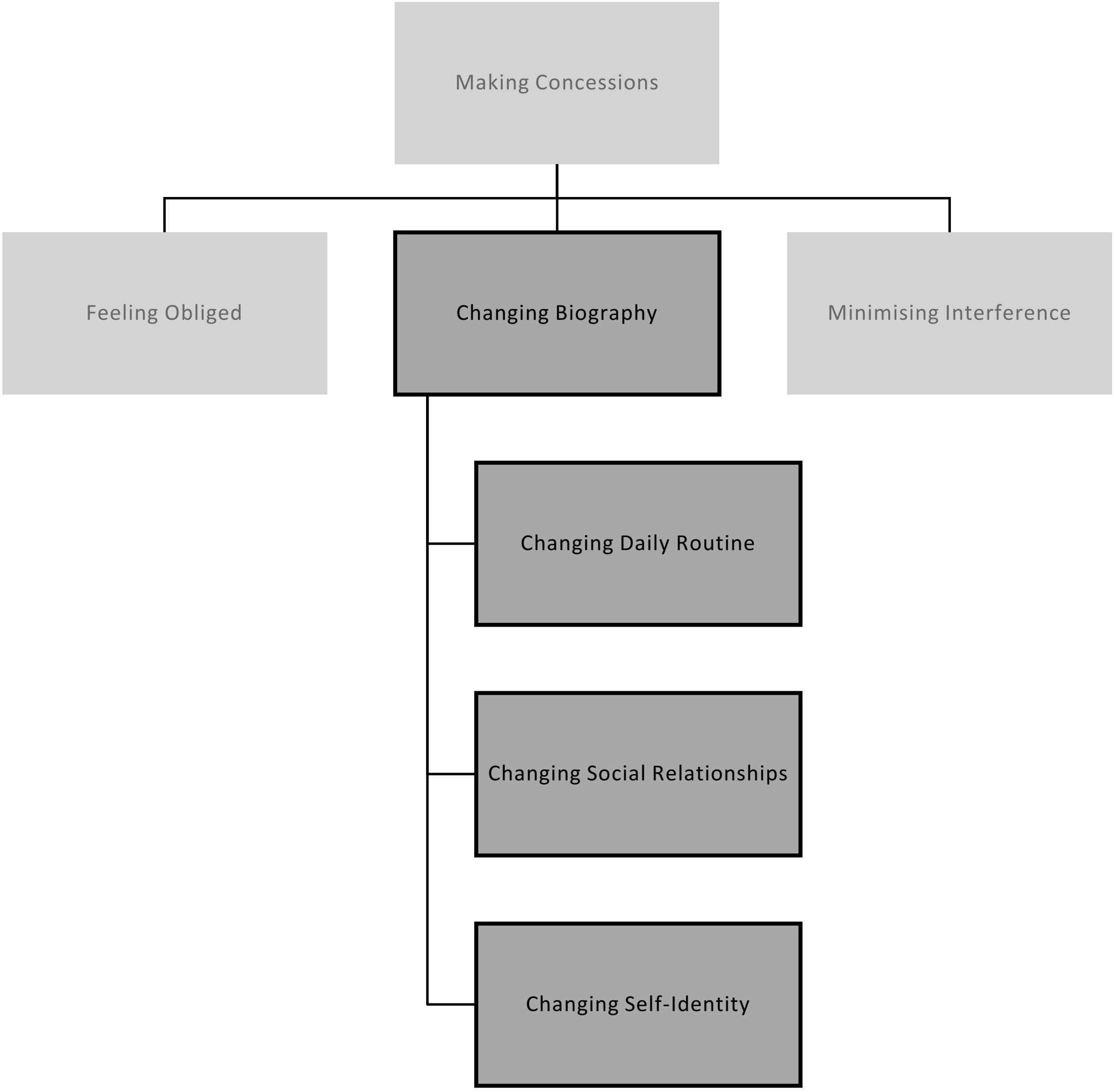
It is important to note here that this major category strongly resonates with the existing Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010). According to this model, the intention to perform a particular behaviour is based on emotional processes and thus, the emotional response associated with a behaviour. It is also based on cognitive processes and hence, whether the behaviour is worth doing or not (Fishbein and Ajzen, 2010). This corroborates the findings described in this chapter. As already described, the emotional connection between the carer and the patient as emphasised by love and respect, makes it necessary for the carer to take up the caregiving role. In addition, the fear of ending up alone if the patient dies and the need to abide by reciprocity norms, that is, the need to take care of the patient in order to repay for what the patient had done for the carer, made taking up the caregiving role worth doing. Therefore, it seems that carers’ decision to take up the caregiving role is also based on both emotional and cognitive processes. The connection between the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) and the grounded theory of this research will be explored in further detail in Chapter Ten.

Chapter 7 Changing Biography

7.1 Introduction

This chapter describes the major category ‘Changing Biography’ and its subcategories which are highlighted in Figure 4. This category describes how cancer diagnosis and taking up the caregiving role brought about a change in the participants’ biographies.

Figure 4: The major category ‘Changing Biography’ and its subcategories.



All the participants described how cancer diagnosis and taking up the caregiving role changed the life they were living before the cancer diagnosis. One of the participants articulated this distinction between the life before and after the cancer diagnosis:

> "*Your life changes completely. Like a flick of a switch.*" (Participant 1; Husband; Inpatient treatment; Heart disease)

One of the most interesting features of the conversations with the participants was that although they were asked to describe whether cancer diagnosis had impacted their health or not, the participants discussed the change in their daily routine rather than solely focussing on their health. Therefore, it seemed clear from early on that this change in daily routine had an important part to play in the developing theory. Hence, the next section describes how cancer diagnosis changed the participants' daily routines.

7.2 Changing Daily Routine

All the participants agreed that they experienced a change in their daily routine when they started caring for the patient with cancer. The participants often experienced discontinuity of their life because, as described in the major category 'Feeling Obliged', they felt obliged to prioritise the care of the patient and caring for the patient challenged taken for granted routines, such as exercise, sleep and work:

> "*You forget your routine because the patient's care takes priority, especially if the patient is a close relative, such as your husband or son. You forget your routine. For example, we have a gym at home and every morning I used to do the treadmill. I used to do some exercises and then, I used to have breakfast. I have not done any exercises or used the treadmill since my husband has been going in and out of hospital to have chemotherapy. Moreover, before we were told that he has cancer, I used to sleep all night. Now I barely sleep, especially since he started having his chemotherapy. Almost every night, at around midnight, I have to wake up to prepare him a snack. I also wake up every time he goes to the bathroom.*" (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*After the first cycle of chemotherapy, he was feeling very tired. He was feeling very tired all the time and he did not feel like getting out of bed. So, every morning, I had to help him wash, get dressed, feed himself and take his medications. I also had to help him whenever he wanted to use the bathroom. These things take up a lot of your time. I found it very difficult to find time to do the housework.*" (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

> "*When he started chemotherapy, he needed a lot of help … I used to take leave from work to come here and stay with him. At times two to three days a week.*" (Participant 25; Child; Inpatient treatment; Hypertension)

The above excerpts illustrate how, after cancer diagnosis, the participants had to take on the additional responsibility for doing a number of caring tasks. Caring tasks included preparing meals, helping the patient get to the bathroom, get washed and dressed, moving the patient from one place to another, as well as assisting the patient in health care related tasks, such as administering medications. As a result, the participants had to change their daily routine in order to incorporate these new responsibilities. The participants became extremely busy and found it difficult to continue with their daily routines. The participants felt that activities or pastimes they had previously enjoyed had to be forgotten about when they started caring for the patient:

> "*Three times a week I used to do voluntary work at the organisation. I am very happy there, helping other people. For me, it is like a medicine. It helps me to relax. However, nowadays, I rarely go there.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I used to enjoy going to the animal sanctuary two or three times a week. However, I have only gone once since my sister has been diagnosed with cancer*." (Participant 12; Sister; Inpatient treatment; Diabetes)

> "*I used to go to the bar and play darts with my friends. However, I have not done so since my father has been diagnosed with cancer*." (Participant 25; Child; Inpatient treatment; Hypertension)

As described in the major category 'Feeling Obliged', the participants felt guilty when they left the patient alone and hence, they needed to be constantly available for the patient and as a result, they did not have time for any leisure activities, as illustrated by the following excerpts:

> "*Not only do I have to take care of him, but I also have to spend time with him. Before, every Sunday, I used to go out. I used to go to mass and then, spend some time with my friend. Nowadays, staying at home takes priority. I do not want to leave him alone because he often tells me that he feels better when in my presence. He feels better when in my presence.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*Every morning, I used to go to the town square and hang out with my friends. Drinking tea and talking about this and that. Now I have to go to hospital to care for my wife … I cannot leave her alone.*" (Participant 16; Husband; End-of-life; High blood cholesterol)

> "*I do not have the heart to go and play darts and not visit my father in hospital.*" (Participant 25; Child; Inpatient treatment; Hypertension)

One of the participants described how, before cancer diagnosis, she used to plan when to take leave from work in order to catch up on her responsibilities at home. However, after cancer diagnosis, she was reluctant to take leave because she wanted to save her leave in case her husband required treatment abroad and she had to accompany him. As a result, she found it difficult to fulfil her responsibilities at home:

> "*Before cancer diagnosis, I used to plan my vacation leave so that I can rest and catch up on house chores and shopping. However, now, I am not taking any vacation leave. I am saving it because there is the possibility that my husband may have to travel to England for treatment. So, I find it difficult to find time to do house chores … I used to take vacation leave to catch up on the housework. So that I do not have to stay up late at night to do the housework. So that I can stop earlier and go to sleep early*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

In the above excerpt, the participant highlighted the unpredictable cancer trajectory faced by carers as already described in the major category 'Feeling Obliged'. As a result, the participants' everyday life was filled with the feeling of uncertainty about the future. Due to the unpredictable cancer trajectory, the participants described how they were reluctant to plan their week or even the next day because they did not know whether the patient's condition would deteriorate or not. Consequently, they refrained from deferring activities, such as laundry and cleaning:

> "*You have to take it day by day. You cannot plan for the next day. You have to take it day by day because you do not know what is going to happen tomorrow or the day after. You may wake up the next day and find him feeling unwell or feeling weak and hence, you have to spend more time with him. Then, who is going to do the laundry and cleaning? So, you have to take it day by day.*" (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*You have to start thinking about how you are going to adapt to living day by day.*" (Participant 19; Parent; Survivorship; Hypertension)

> "*Day by day. That is how I used to live. Day by Day. You do not know what is going to happen the day after. Whether he is going be unwell or not. Whether he will need your help or not.*" (Participant 26; Wife; Survivorship; Depression)

The phrase “*living day by day*” suggests that the participants harboured a sense of insecurity regarding their immediate future due to the unpredictable cancer trajectory. This led participants to change their time orientation towards the present as illustrated in the following excerpt:

> “*You have to take things on a daily basis. Try not to think too much in the future sometimes. Even if you want to think in the months ahead you have to take it on a daily basis. If you start thinking too much then something else might happen. Like when he was ok and then you start thinking we might go home next week, and then something happens. I try not to think about the future. I think on a daily basis.*” (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

On the other hand, before cancer diagnosis, the participants used to stop what they were doing when they started feeling tired and continued their activities on another day:

> “*Before, if I started feeling tired, I could stop and continue on another day. But now, whatever the workload, it has to be done. I have to do it … I cannot say that I can stop and do it on another day, as I used to do before.*” (Participant 2; Wife; Outpatient treatment; Hypertension)

> “*Because of my fibromyalgia, my body starts aching and I get tired very easily. Before, I used to stop and continue whatever I am doing on another day. Now, I cannot do so. I have to finish whatever I am doing so that I can take care of my sister*.” (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

Another participant described how her son often came down with a fever early in the morning and consequently, this ruined her plans for that day:

> “*He used to come down with a fever. So, we used to go to the emergency department. We used to go there and wait for hours. Sometimes five, six hours. So, our plan for the day was ruined. You cannot plan anything … I used to prepare everything in a bag just like a pregnant woman prepares a bag for when her water breaks. I used to prepare a bag so that as soon as my son tells us that he is feeling unwell, we rush to the emergency department. So, you cannot plan anything from beforehand*.” (Participant 22; Parent; Survivorship; Thyroid disease)

After taking up the caregiving role, the daily routines of the participants changed and became more restricted. Due to the unpredictable cancer trajectory, the participants had to plan their daily routine around the responsibilities involved in the care of the patient with cancer. They were aware of how important it was to being flexible to the shifting needs and circumstances of the patient's condition. Therefore, they devoted themselves completely to the task of caregiving. Then, they spent the rest of the time carrying out other responsibilities, such as work and household chores. As a result, they had limited opportunities to rest. If they became extremely busy and were unable to care for the patient because of other responsibilities, then they often decided to abandon these responsibilities. One of the participants perfectly articulated this by describing how, before cancer diagnosis, she used to plan her daily routine the way she wanted. However, when her husband was diagnosed with cancer, she started planning her daily routine according to his needs:

> "*I never had any rules. It did not matter at what time I woke up, or went to sleep, or at what time I prepared meals. I used to plan my day as I wanted. Now, I have to think about my husband. Now, I have to make rules. I have to cook for him at specific times during the day. I have to wake up early to do this and that before he wakes up, and I have to take care of him*." (Participant 2; Wife; Outpatient treatment; Hypertension)

The fact that this participant stated that now she has to make rules when planning her day further emphasises how the participants' lives became more restricted after cancer diagnosis and taking up the caregiving role. The participants' lives shrank as they cared for the patient with cancer. Moreover, the above excerpt also seems to introduce the concept of 'losing control', since the participants lost control over their daily routines, which are now controlled by the patient's condition and the caregiving role. This concept will be discussed in further detail when describing the core category 'Making Concessions'.

It seemed clear from early on that the change in daily routine had an important part to play in the emerging theory. In fact, in the early stages of data analysis, a category called 'Changing Daily Routine' was generated. However, in one of the above excerpts, the participant also highlighted the impact on social relationships:

> "*Before, every Sunday, I used to go out. I used to go to mass and then, spend some time with my friend. Nowadays, staying at home takes priority.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Furthermore, the notion of change in daily life before and after cancer diagnosis prompted the researcher to search for theories related to the phenomenon of 'disruption' which might shed further light on this. This led to the discovery of Bury's (1982) description of the concept of biographical disruption and how chronic illness disrupts the individual's daily routine and social relationships. This made the researcher question whether the participants also experienced a change in their social relationships after taking up the caregiving role. In fact, analysis of the study data revealed that the participants did experience this change, as described in the next section. The connection between the grounded theory of this research and the concept of biographical disruption (Bury, 1982) will be explored in further detail in Chapter Ten.

7.3 Changing Social Relationships

All the participants agreed that they experienced social isolation when they started caring for the patient with cancer, irrespective of whether they cared for the patient before or during the COVID-19 pandemic. The participants described how they found it difficult to find time to visit family members and friends because they had to juggle caring for the patient and at the same time, carrying out other responsibilities:

> "*You distance yourself from your family. I used to babysit my grandchildren, but I have not done so since my husband was diagnosed with cancer. Because I have to take care of my husband. And I cannot take care of him and at the same time, take care of the children*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*When he was in hospital, we lost one year of the upbringing of our niece because she could not come here due to COVID-19. We were afraid that she may catch it from school and then give it to us, and then we could give it to our son when we go and visit him in hospital.*" (Participant 18; Parent; Survivorship; Thyroid disease)

> "*I used to go for a walk with my friend. We used to go walk for an hour every day. However, I have not met her since my son has started treatment.*" (Participant 23, Parent, Inpatient treatment, Hypertension)

Therefore, the participants experienced changes in their relationships with others. Once the caring role was dominant, there was a sense of loss in relationships with others, including other caregiving roles. In fact, the participants had to reprioritise their caring responsibilities according to the most pressing need. They considered the patient as having greater needs than other family members due to the seriousness of a cancer diagnosis, as previously described in the major category 'Feeling Obliged'. In the following excerpt, one of the participants described how she could not be there for her son when his brother was diagnosed with cancer:

> "*His brother did not get angry, but he used to tell me 'Mummy when are we going to the beach?' At times, I used to take him to my husband's sister, who is a nun, and she used to take him to the beach with her. However, he wanted his parents. However, since we used to spend most of our time at the hospital, we did not have time to take him to the*

> *beach. We used to tell him that we needed to go to the hospital and stay with his brother. We could not do otherwise*." (Participant 22; Parent; Survivorship; Thyroid disease)

It was also necessary for the participants to force themselves into isolation in order to protect the patient from infections. Patients with cancer are at a higher risk of contracting infections due to cancer and its treatments:

> "*I try to avoid going to places where there are too many people because I do not want to catch an infection and then, put my husband at risk. Hence, I prefer to stay at home rather than go out.*" (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)
>
> "*I have recently been invited to a wedding. I am not going. I am not going out. I do not want to be a carrier of something that can affect my husband … This is why I am not going out*." (Participant 13; Wife; Inpatient treatment; Hypertension)
>
> "*At work, I have my own office and I try to stay away from people as much as possible. In fact, I try to hold all my meetings online.*" (Participant 24; Husband; Outpatient treatment; Diabetes)

The above excerpts continue to emphasise how the participants' motivation to avoid causing harm to the patient forced them into social isolation. In fact, social gatherings and meetings with others and the thought of leaving the patient alone invoked feelings of guilt which prevented the participants from going out and enjoying themselves:

> "*How can you leave a person alone? How can you leave him alone and instead go out and enjoy yourself? How can someone do that and not feel guilty? It never crosses my mind to do such a thing*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)
>
> "*I never considered leaving him alone to go out with my friend.*" (Participant 26; Wife; Survivorship; Depression)

As a result, the participants only exited the house to do the chores as illustrated in the following excerpt:

> "*You do not feel like going out. You will go out for a short walk or to the supermarket but that is all*." (Participant 4; Wife; Outpatient treatment; Hypertension)

In fact, those participants who were taking care of the patient with cancer during the COVID-19 pandemic, recounted how the pandemic helped them to protect the patient from infections as hospital consultations were held by phone, and family members and friends were not allowed to visit:

> "*COVID-19 stopped any contact that we had with other family members and friends. So, in a way, it helped to protect us from infections*." (Participant 18; Parent; Survivorship; Thyroid disease)
>
> "*We did not find it difficult to distance ourselves from the rest of family … you know … with COVID-19 and all. The pandemic made it easier for us to protect ourselves from infections which, after all, could have killed him.*" (Participant 26; Wife; Survivorship; Depression)
>
> "*Nowadays, she does not need to go to hospital for her appointments, but instead we speak to the doctor by phone. So, we do not have to worry about catching COVID-19*." (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

Furthermore, as described in the major category 'Feeling Obliged', the participants described how they were constantly worrying about the patient, and this impacted their social behaviour when in the presence of others. It seems that the participants were constantly thinking about the patient and as a result, this made it difficult for them to interact and maintain meaningful relationships with other people:

> "*My friends have noticed that I have changed. They always ask how I am and how is my husband. And sometimes I feel depressed, and I tell them that I am feeling sick and that I am going home. So, they have noticed that I have changed, and I am not interacting as much with them as I used to.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)
>
> "*At work, I used to enjoy spending time with my colleagues especially during lunch break. Nowadays, I spend most of my break talking to my wife on the phone to see how she is doing … I also remain in my office during lunch break because of COVID-19.*" (Participant 24; Husband; Outpatient treatment; Diabetes)

The participants described how family members and friends seemed to disappear once caring began. It seems that others may distance themselves from the situation because they cannot handle the emotions associated with cancer. However, it is also possible that there is some form of stigmatization involved, as recounted by two participants:

> "*It hurts when you start seeing family members and friends who disappear from your life as if you have the plague. I do understand that there are some people who do not know how to cope with the emotional impact of cancer. However, there are many, who as the proverb goes 'You laugh and the whole world laughs with you, you cry and you cry alone'. Then you start realising who the true friends are. There are many family members or friends who do not even pick up the phone and call you to ask how you are doing. That is very difficult to handle*." (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*He used to go to church every day. However, only one of his friends came to visit him in hospital. I do not know why. Maybe they are afraid of catching something if they come and visit him … I do not know why. So, it hurts when no one comes to visit him*." (Participant 13; Wife; Inpatient treatment; Hypertension)

Cancer diagnosis and taking up the caregiving role also changed the relationship dynamics between the carer and the patient with cancer. The participants described how, before cancer diagnosis, they used to rely on the patient to carry out certain responsibilities both inside and out of the house. However, after cancer diagnosis, the patient became reliant on them and as a result, the participants had to take over tasks that used to be done by the patients:

> "*He always said over the years that we have been together 'I will always look after you.'… He has always done everything. He did everything. Always has. He looked after me. But now, I am looking after him and I am doing everything myself.*" (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*He used to do everything around the house … Nowadays, I have to do everything myself. I cannot rely on him.*" (Participant 13; Wife; Inpatient treatment; Hypertension)

Furthermore, as already described in the category 'Feeling Obliged', the participants described how, after cancer diagnosis, they found it difficult to deal with the patient's behaviour. At times the patient's stubbornness led to the carer experiencing more burden. One of the excerpts already presented in the previous chapter clearly illustrates this:

> "*He informed the doctor that he was feeling fine. That he was managing to go to the bathroom alone. When she left, I told him that he was lying because I knew that he was finding it difficult to walk on his own … [however they still] discharged him that same afternoon … as soon as we arrived home, he said he was feeling too tired to walk and so, I had to lift him from the couch onto the wheelchair and then assist him into bed*." (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

Therefore, after cancer diagnosis and taking up the caregiving role, the participants also experienced a change in their social relationships. The participants became extremely busy and hence, did not find the time to attend social gatherings and meetings with family members and friends. Furthermore, feelings of fear, guilt, and worry also affected the participants' relationships with others. Moreover, cancer diagnosis also brought about a change in the relationship dynamics between the participants and the patient with cancer. After cancer diagnosis, relationship dynamics changed as the patient took up the 'sick role' and became reliant on the participants, who not only had to perform caring tasks, but also had to take up new responsibilities previously held by the patient. This often led to tension within dyads. This corroborates what is discussed in the previous chapter, when the participants talked about the emotional dilemma they faced when patients did not want to engage in their care. Therefore, it seems that the participants' social relationships were also impacted by the patient's cancer and the caregiving role. The next section will describe how cancer diagnosis and taking up the caregiving role also changed the participants' self-identities.

7.4 Changing Self-identity

Those carers who have been taking care of the patient with cancer for long periods of time acknowledged that caregiving had become part of their life and hence, part of their self-identity, as highlighted by one of the participants:

> "*Taking care of my sister … going in and out of hospital. This has all now become part of life. It has become part of me and there is nothing I can do about it*." (Participant 12; Sister; Inpatient treatment; Diabetes)

The phrase "*there is nothing I can do about it*" continues to emphasise the lack of choice and control in assuming caregiving responsibilities for the patient, as already described in the major category 'Feeling Obliged'. Another participant described how she had to replace her 'outlets' with activities related to the caregiving role. As a result, she had lost part of her self-identity. These outlets were described as largely routinized and taken for granted everyday activities which contributed to feelings of self-worth and self-esteem for the individual:

> "*I used to do crafts. Do this. Do that. Come up with different ideas. I like to create different stuff and that made me feel good. Now I have put that on the shelf. That has affected me deeply because everyone needs an outlet and I do not have an outlet to help me rest. It is as if I have lost part of myself*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

Other participants described how they adopted new habits after taking up the cancer caregiving role and they continued performing these habits even after the patient had recovered from cancer:

> "*I started eating healthier because I had to cook healthy food for her. Even nowadays I still try to eat healthy*." (Participant 17; Husband; Survivorship; Hypertension)

> "*There is always that possibility that the cancer may come back and also the fact that you have to take care of the individual. This remains inside of you. It becomes part of you. Before, I did not use to wash the floor before he came here. But now, I do so even though he has finished his treatment. I also tell him to wash his hands, and I tell my husband to wash his hands.*" (Participant 18; Parent; Survivorship; Thyroid disease)

This notion of caregiving responsibilities becoming part of life can be illustrated by the fact that some of the participants found it easier to cope with the COVID-19 pandemic because they already knew the 'art of infection prevention' having learnt it whilst taking care of the patient with cancer, as highlighted in the following excerpt:

> "*When the COVID-19 pandemic hit, I found it very easy to cope with the situation because I already knew how to effectively prevent infections. I had learnt how to do so whilst my husband was receiving chemotherapy. I used to wash my hands all the time, disinfect everything that I bought from the supermarket, clean the house every day. And I still continued to do so when my husband finished his treatment. Thanks God, COVID-19 hit after he had finished his treatment*." (Participant 14; Wife; Survivorship; Heart Disease)

7.5 Naming the Major Category 'Changing Biography'

Taking into consideration the above sections, the participants not only experienced a change in their daily routine, but also experienced a change in their social relationships, as well as their self-identity. These changes were all brought about by the patient's cancer, as well as a change in mind set as the participants started prioritising the care of the patient. As a result, they focused all their attention on caring for the patient and put their lives on the backburner. Therefore, the major category encompassing these changes was named 'Changing Biography'. This major category illustrates how the participants' worlds shrank as they took on the cancer caregiving role. Their daily routines and social relationships were taken away from them as the participants transferred their attention from the self to the patient with cancer.

This change in biography before and after cancer diagnosis strongly resonates with Bury's (1982) description of the concept of biographical disruption and Schlossberg's (1981) transition theory. Whilst Bury (1982) describes chronic illness as a major disruptive event which causes a disruption in an individual's daily life similarly, taking up the caregiving role caused a disruption in the participants' biography by impacting taken for granted everyday activities and routines, such as exercise, sleep, and work. Therefore, the impact of caregiving on the participants' biography can also be considered as a biographical disruption. As a result, the participants had to change their daily routine in order to incorporate the new roles and responsibilities associated with the caregiving role. This corroborates Schlossberg's (1981) definition of a transition as an adaptive process which is triggered by a critical event and results in changes in the individual's routines, roles, and relationships. Therefore, caregiving can also be conceptualised as a transition process. The connection between the grounded theory of this research and the concepts of biographical disruption and transition will be explored in further detail in Chapter Ten. The next sections will describe the temporality and degree of biographical change experienced by the carers.

7.6 Temporality of Biographical Change

The search for theories related to the phenomenon of disruption also led to the discovery of Selder's (1989) theory of transition. Selder (1989) claims that an individual needs to acknowledge the change in daily life in order to engage with it. This prompted the researcher to question how carers acknowledge the change in their biography brought about by cancer diagnosis and the caregiving role. Further analysis of the interview data revealed that those participants who were caring for the patient in the treatment phase considered this change in their biography as being temporary, which gave them the strength to hold on until the patient recovers from the cancer:

> "*Now when she finishes her chemotherapy cycles, we can return back to normal life … I just want my wife to get better so that we can continue with our lives. I only think about that. This gives me the strength to continue caring for her*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I suppose you want everything to be normal again. You want your life back. You want your life back to where it was*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*We want our old life back*." (Participant 21; Wife; Outpatient treatment; Arthritis)

These excerpts suggest that carers only experience a change in their biography when the patient is receiving treatment. However, the research data revealed that all the participants experienced this change in their biography, whether they were caring for the patient during the treatment phase, the survivorship phase, or at the end-of-life phase. One of the participants, who was caring for her friend who had finished her treatment and was in the end-of-life phase, described how she had not visited her parents, who reside in a nursing home, for weeks, whilst before cancer diagnosis, she used to visit them every week:

> "*Since she was diagnosed with cancer, I rarely visit my parents who are in a nursing home. I used to visit them every week. In fact, I have not seen them for weeks*."
> (Participant 15; Friend; End-of-life; Multiple chronic conditions)

Another participant, who had cared for her husband in both the treatment phase and now that he has finished his treatment and is recovering from the cancer, described how she continued experiencing changes in her life because, often, the patient was too tired to do what he used to do before cancer diagnosis:

> "*He still has not recovered completely from his cancer. There are days when he feels too tired to help around the house. So, I have to do everything myself … I also have to accompany him to hospital for his appointments every two weeks … This has become our new life routine*." (Participant 26; Wife; Survivorship; Depression)

The above excerpt illustrates that this participant did not consider the changes in her biography as being temporary but rather as becoming her new life routine. This continues to emphasise how cancer caregiving became part of the participants' lives as already described in the subcategory 'Changing Self-identity'.

Although all the participants experienced a change in their biography, they experienced different degrees of change. One of the participants, who was caring for her husband during the treatment phase, described how, since her husband continued living a normal life, she still found time to carry out other responsibilities at home:

> "*My husband continued living a normal life. He continued living a normal life. He went out shopping, took care of the children, took care of the car and the house. Therefore, he continued doing what he used to do before he was diagnosed with cancer. Therefore, although I take care of him, I do find time to carry out the housework and do groceries*."
> (Participant 4; Wife; Outpatient treatment; Hypertension)

This is interesting since later in the interview, this participant stated:

> "*In one year, my life changed upside down. In one year, my life has changed. In one year, our lives have changed*." (Participant 4; Wife; Outpatient treatment; Hypertension)

Therefore, although this participant experienced a change in her biography, she still found time to carry out other responsibilities at home, which contrasts with what other participants, who were also caring for patients in the treatment phase, stated in the subcategory ‘Changing Daily Routine’. Another participant stated:

> “*She is your priority. So, you have to give up other priorities in order to take care of her. For example, if before cancer diagnosis you used to wash the floor every day, now you cannot do so. You have to make her your priority during that time. You cannot do the housework and at the same time, take care of her. It is impossible. You have to give up something or you will not cope*.” (Participant 10; Sister-in-law; Outpatient treatment; Arthritis)

Therefore, this participant found it “*impossible*” to do the housework and at the same time, take care of the patient, whilst the other participant found time to do both. This made the researcher question whether there were mediating factors in play which influenced the degree of biographical change experienced by the participants.

7.7 Degree of Biographical Change

Analysis of the interview data also revealed that the degree of biographical change was influenced by a number of contextual factors which included:

i. Type of caregiving
ii. Having other priorities in life
iii. Having support from family and friends
iv. Willingness to find and accept support from family and friends

7.7.1 Type of Caregiving

The health of the patient with cancer and his or her degree of dependence for ADLs impacted the degree of biographical change. The participants experienced an increased degree of biographical change when the patient declined in his or her ability to take care of himself or herself. As the patient became more dependent on the participant for managing everyday activities, such as getting washed and dressed, and caregiving became more overwhelming, the participants found it more difficult to care for the patient and at the same time, carry out other responsibilities. On the other hand, if the patient remained independent in his or her ADLs then, the participants found it easier to carry out other roles and responsibilities:

> "*He continued living a normal life. He did not stay inside. He used to go out with friends. Go shopping and taking care of other stuff. So, I did not need to take over his roles and responsibilities and that helps a lot. So, I can do something else whilst he is doing something. Are you understanding? He still kept on helping me around the house. He goes to pay the cheque etc. I do not drive and hence, he kept on doing these things. If not, I would have needed to do them and would have taken me a long time to catch the bus*." (Participant 4; Wife; Outpatient treatment; Hypertension)

> "*Things changed when her condition started deteriorating and now, I find it more difficult to address her needs. At first, I only used to drive her to hospital so that she could have her chemotherapy. I used to stay with her whilst she was having her chemotherapy but that was it … Now she is a complete disaster. I go and stay with her until late. Then I go back home, I do not have time to do any of the housework or laundry. In fact, I do the laundry once of week*." (Participant 15; Friend; End-of-life; Multiple chronic conditions)

Furthermore, the degree of biographical change also seemed to depend on whether the carer and the patient with cancer lived in the same household or not. Those participants who lived in the same household as the patient experienced a decreased degree of biographical change than when the carer and the patient lived in different households:

> "*I waste a lot of time in traffic when I go to visit her at the hospital. Sometimes, it takes me about an hour to arrive there.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

> "*Since she lives up north, whenever she had an appointment, I had to drive all the way up there and vice versa. So, I used to spend a lot of time driving around the country*." (Participant 15; Friend; End-of-life; Multiple chronic conditions)

When the patient with cancer was living in the same household as the carer, then the carer could attend to the patient's needs and at the same time, carry out household responsibilities. On the other hand, when the patient was in hospital or living in a different household, then the participants had to find time to attend to the patient's needs at the hospital or at their house and then, go back home to carry out household chores. In fact, those participants who cared for patients receiving treatment as inpatients experienced an increased degree of biographical change when compared to those participants who cared for patients receiving treatment as an outpatient. These participants made a clear distinction between their life when the patient was in hospital and when the patient was at home:

> “*When it is time for him to be admitted to hospital for his treatment, I get really upset. I get really upset because I hate going to the hospital with him. When he is in hospital, I stay next to him. I spend all day staring at the wall or playing with the tablet. I hate doing nothing. I prefer when he is at home because I can carry on with the housework whilst at the same time, taking care of him*.” (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> “*Since she has been at home, it has been better than when she was in hospital because I find more time for myself. I do some exercise and I go to work … I used to go to hospital, go to work, drive here and there. It was exhausting. Especially when she was in hospital … Even now that she is at home, I have to drive her to her appointments and for bloodletting. So, it is still a hassle however, much less when compared to when she was in hospital*.” (Participant 24; Husband; Outpatient treatment; Diabetes)

When the patient was receiving treatment, it created the most stress for the participants because they had to ensure that everything was clean. The type of treatment that the patient was receiving also influenced the degree of biographical change experienced by the participants. Those participants who were caring for patients who were receiving treatment which weakens the body’s defence systems seemed to experience an increased biographical change. It seemed that these participants had to change their cooking recipes, as well as clean the house on a regular basis in order to prevent the patient from getting an infection:

> “*The house cleaning and dogs. Obviously, I have to clean all the time. I am cleaning all the time and this is something important to think about. I am cleaning more than I used to before the cancer diagnosis. This does not mean that I did not used to clean before the diagnosis, but now I am all the time cleaning certain places where he stays and where the dogs stay. I am cleaning the house all the time. Always running after the dogs with the mop. Because I am afraid that he might get an infection. I am tired. I am dead tired*.” (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

This participant continued to recount:

> “*When he was receiving his first six cycles of chemotherapy, we became obsessed about what we were going to give him to eat and I used to disinfect everything. All the time washing everything with bicarbonate of soda and yes, I did go out of my way a lot because they had told me that certain food was unhealthy and certain food was healthy, and that everything had to be fresh and genuine. And so, I used to go here and there to*

> *buy fresh food. It was very stressful*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

Another participant described how they used to wipe down all their grocery store purchases with disinfectant to decrease the risk of COVID-19 transmission when their son was still receiving treatment:

> "*During COVID-19, he was still receiving chemotherapy. We used to wipe down all the items bought from the supermarket and leave them in the garage for a day or two … we put on gloves and everything*." (Participant 19, Parent, Survivorship, Hypertension)

7.7.2 Having Other Priorities

The degree of biographical change was also impacted by whether the participants had other priorities in life. Having to take care of other family members who are sick and dependent on the participants resulted in an increased degree of biographical change because the participants found it difficult to integrate the different priorities. On the other hand, those participants who did not have other priorities in life whilst they were caring for the patient, seemed to experience a decreased degree of biographical change because they could focus on the care of the patient without having to sacrifice other responsibilities in their life. When there were no other priorities in life it made it easier for the participants to focus on the caregiving role:

> "*My children are all grownups, and my husband can take care of himself. So, she was my only priority. That helped because I could focus only on her*." (Participant 10; Sister-in-law; Outpatient treatment; Arthritis)

> "*I am retired now. But if I was still working, then that would have created a problem because you would need to juggle between taking care of him, going to work, and doing the housework*." (Participant 21, Wife; Outpatient treatment; Arthritis)

> "*The fact that I am a housewife and that I did not work, helped me a lot. Because I could just focus on caring for our son*." (Participant 22; Parent; Survivorship; Thyroid disease)

Another priority could be work. Those participants who were able to stop working or take extended leave from work experienced a decreased degree of biographical change than those participants who did not have the luxury to do so. For example, one of the participants described the importance of giving up work just before his wife was diagnosed with cancer:

> "*It would have been difficult if I did not give up work and handed everything to my daughter … Last week, I had to go to work twice because my daughter suffers from*

> *migraines as well. I found it difficult to go to work and then, find time to come here. It would have been a big stumbling block had I not given up work … It is a big relief to me. The work would have been a stumbling block*." (Participant 9; Husband; Inpatient treatment; Chronic migraines)

However, stopping work was not possible for all the participants. One of the participants described how he was the only bread winner in the family and hence, he could not stop working when his father was diagnosed with cancer due to financial reasons:

> "*I have to continue working by force. We still have the house loan to pay, and our son's school fees. So I have to continue working especially since my wife is a stay-at-home mum*." (Participant 20; Child; End-of-life; Lung disease)

In fact, another participant described how they had appreciated the fact that the patient's wife was allowed to take paid sick leave when she missed work to take care of her husband:

> "*The company where his wife works, allowed her to take paid sick leave when she had to accompany him to the hospital or when she had to stay at home to take care of him. That was very important considering that they had the house loan to pay*." (Participant 19; Parent; Survivorship; Hypertension)

Those participants who had to take on new roles and responsibilities which were previously held by the patient also experienced an increased degree of biographical change:

> "*I had to take care of the wife, but I also had to take care of the home. I did not know how to do anything. I had to take care of the house. Cleaning and what not. I had to do the ironing, wash clothes, cook. I am trying my hand at different things now. That is when I realised how important my wife is at home*." (Participant 9; Husband; Inpatient treatment; Chronic migraines)

> "*I also have to help her husband around the house and drive her kids to school. So, I find it very difficult to find time to go home and do my household chores, to cook, to do the laundry.*" (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

7.7.3 Having Support from Others

The participants reported that more social support meant that others could help in the care of the patient with cancer or other household responsibilities. With this support, the participants could continue with their normal activities, such as returning to work:

> "*I am supported by my brothers and sisters. I appreciate the fact that, when my wife is in hospital, they prepare food for both of us. They also wash our clothes. This way, I can continue working and do other stuff at home. Every little help helps*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> *"My friends who come here all the time. They have been absolutely brilliant. I really think I would not have coped as I did without them because they have been absolutely marvellous. They are there. They have been absolutely brilliant*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

Support was also important because other family members and friends could take over some of the roles and responsibilities previously held by the carer so that the carer could focus on the care of the patient:

> "*I have a younger sister who is physically handicapped. I take care of her. Even my wife used to help me to take care of her. But now my wife cannot. So, I have asked my other sister to help me, especially since my father is also in a nursing home and hence, everything depends on me. So, now I have asked her to take care of his needs, of his pills and what he has to buy and what not. At least, she goes to see him once a week*." (Participant 9; Husband; Inpatient treatment; Chronic migraines)

> "*Often times, my sister helped me with the groceries. That really helped especially during COVID-19 as I was scared going to places where there were a lot of people … This way, I could continue taking care of my husband*." (Participant 26; Wife; Survivorship; Depression)

If the carer and the patient were living with other family members in the same household, then responsibilities were often shared between them. One of the participants described how her son took care of his father whilst she visited her parents in a nursing home, as already described in the previous chapter:

> "*In the evening, my son stays with his father. In the meantime, I go and visit my father and mother in the nursing home. Therefore, whilst I visit my parents, I know that there is someone taking care of my husband. If it was not for my son, I would not find the time to pay them a visit.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Having support from others also allowed this participant to plan ahead for a particular day or week:

> "*Knowing that my children will be with him in the weekend helps me to plan ahead to decide what I will do during the weekend whilst they are taking care of him*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

The participants described the sympathy showed by their work colleagues and the fact that they could leave work whenever they wanted in order to attend to the patient's needs:

> "*At work, I do not have any problems because when I told them that my wife has cancer, they all gave me the go ahead to take time off whenever I wanted*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I am supported by my work colleagues. My boss allows me to work with flexible hours and hence, I can leave work whenever I want without any problems. He tells me that I can leave without asking for his permission. This way, it makes it easier to accompany my husband to his appointments and when he comes to hospital for treatment*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I am supported by my work colleagues. I receive a lot, a lot of support from them*." (Participant 12; Sister; Inpatient treatment; Diabetes)

Moreover, the participants also appreciated the support they receive from health care professionals:

> "*The practice nurse, she really takes care of us. She really takes good care of us*." (Participant 4; Wife; Outpatient treatment; Hypertension)

> "*We have nothing to complain about how they treated us at the hospital. Both the nurses and the doctors took good care of us*." (Participant 7; Wife; Survivorship; Heart disease)

> "*The doctors and nurses on the ward are brilliant. I really cannot complain about them. They all go out of their way to help us and our son.*" (Participant 23; Parent; Inpatient treatment; Hypertension)

In addition, the participants also talked about the importance of support groups since they would know what the carer is going through and thus, can offer insight into how the carer can cope with the caregiving situation:

> "*So, I suppose a support group is probably a good idea. Talking to people who would know what you are going through would help because they would tell you how to cope*

> *with the situation and be able to do this and that*." (Participant 15; Friend; End-of-life; Multiple chronic conditions)

> "*I would join a support group if there was one … I do follow one of these support groups on social media*." (Participant 22; Parent; Survivorship; Thyroid disease)

The participants described that they did not only appreciate physical help from others but also emotional help:

> "*It helps, not just the physical help. At times, the fact that the person tells you a word of encouragement helps as well. Because when the person calls you and tries to encourage you and offer their help, it helps a lot, and you appreciate it*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*If it was not for my family and friends, then I would have collapsed emotionally, especially when they told us that she has cancer. I would not have coped*." (Participant 12, Sister; Inpatient treatment; Diabetes)

On the other hand, the participants described how a lack of social support from others made it difficult for them to find time to carry out other responsibilities and roles and at the same time, care for the patient. The participants found the burden to be harder when there was no support:

> "*It makes a difference having other family members helping in the housework. It makes a big difference. My daughter lives in England and hence, I have no one here. I have to do everything on my own. I find it difficult to find time to do everything*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*My sister lives in Australia, whilst my brother works very long hours and finds it difficult to take leave from work. So, it is usually up to me to take care of my father and it is not easy. It is not easy, especially since I have a family of my own*." (Participant 25; Child; Inpatient treatment; Hypertension)

Although the participants highlighted the importance of having support from others nevertheless, analysis of the interview data revealed that some of the participants found it difficult to find and accept this support, as described in the next section.

7.7.4 Willingness to Find and Accept Support from Others

Some participants felt they could not be assisted by their family and friends because these had their own commitments, such as work and taking care of young children. Consequently, they were too busy to help the carer and the patient:

> "*One of my daughters is abroad studying, whilst the other is married and has two children and hence, finds it difficult to find time to come and visit. Similarly, my son is a teacher and works as a part-time football coach and hence, also finds it difficult to find time to come and visit*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*Our daughter is still at school. At the moment, she is doing her A levels. So, she already has a lot on her plate*." (Participant 24; Husband; Outpatient treatment; Diabetes)

Therefore, whilst the participants had to change their lives because the care of the patient became central in their lives on the other hand, this was not necessarily happening in the lives of other people, including family members and friends.

Furthermore, the participants described how they considered themselves independent and self-sufficient and as a result, were reluctant to ask for help:

> "*I am a nurse by profession and hence, I do know how to take care of my husband, how to administer his medications, how to assist him in his activities of daily living … When the community nurse came to change his dressing, I informed her that I am a nurse and asked her whether I could do it myself*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I just probably do not like people to think that I cannot do something. I just like to do things for myself. You know people would be saying 'Are you sure you can do that?' 'Do you need help?' and I will tell them 'Listen, I am ok, I am fine. Just leave me alone, I am ok.' I just do not like people asking me all the time whether I can do this or that. I always think that I am a nuisance to people. Or the fact that they have got to look after me and I do not want that. I do not want my friends to think that. I think that is why … I find it very difficult to ask for help. I like to do everything myself. I find it very difficult to ask other people for help. I like to do everything myself … I do not know why. I just do not like asking other people for help. I always feel as though I am inadequate of myself because I cannot do it even though I know people would help*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

The above excerpt also illustrates how the participants did not wish to overburden others with their own worries about the illness or current health problems, preventing the possibility of others helping:

> "*I do not want to ask them to come and help us because as long as we are coping on our own, I do not want to worry them. So, I used to tell them that I will ask them if I needed any help … I used to hide my emotions so as not to worry them. I used to hide my emotions. I tried to cope on my own. Do things alone*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I do not want to bother them … Our children like going out for dinner. I am not going to tell them not to go out in order to help me. I have never done that and will not do it now*." (Participant 13; Wife; Inpatient treatment; Hypertension)

Some of the participants also refused help from other family members because they did not want the patient to think that he was disrupting the life of his loved ones which would make him or her upset. This continues to emphasise how the participants were afraid of causing emotional distress to the patient, as already described in the major category 'Feeling Obliged'. One of the participants described how his daughter, the patient's sister, had decided to stop her doctoral studies to care for her brother. However, he told her to continue with her studies because he did not want her to upset the patient:

> "*His sister had gone to hospital to speak to him. The day after, she came up to me and told me that she was going to stop her doctoral studies so that she could take care of her brother. I told her 'You do not have to stop your studies. You have your own life and I do not want you to stop. If you stop, it would also upset your brother and we do not want that.*" (Participant 19; Parent; Survivorship; Hypertension)

Moreover, the participants wanted to do everything themselves because this way, they were sure that the patient was receiving good quality of care. As a result, they were reluctant to ask for help:

> "*I want to do everything myself. I want to do everything myself. If I do it myself then I know that everything will be all right. So, I feel less worried when I do everything myself.*" (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

Although the participants described the value of having family and friends, some of them felt that their family was their responsibility and no one should have to look after their family, as already described in the major category 'Feeling Obliged':

> "*I know that there are some things which are my responsibility and I have to do them myself. I am not expecting someone to come and take it off my hands. He is my husband and I have to take care of him. If something happens to me, I expect him to take care of me*." (Participant 2; Wife; Outpatient treatment; Hypertension)

The participants also described how relying on others for support led to worrying about whether the support person has altruistic or reciprocity intentions. Hence, they chose to do everything on their own:

> "*Firstly, I do not like telling people what to do. Secondly, I do not want the person to tell me that when I was in need, he helped me and thus, I have to help him when he is in need*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

In addition, the participants described how they did not like seeing other people interfering too much in the care of the patient and as a result, found it difficult to ask for help:

> "*I just want to be me and not let someone control me. I do not want somebody saying that I have got to do this and that. I am and I will do what I have got to do. I want to control the situation myself. I think that has something to do with it*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*It affects me badly when I see my brother-in-law trying to influence my husband's opinion. He interferes too much when my husband needs to make a decision. That affects me badly at times. Hence, I prefer to do everything myself rather than ask him for help*." (Participant 13; Wife; Inpatient treatment; Hypertension)

The above excerpts continue to emphasise the concept of 'exerting control'. The participants seemed to want to exert control over the caregiving situation. This will be discussed in further detail when describing the core category 'Making Concessions'. The participants described how support from family and friends should not be suffocating because forceful or suffocating support can be unhealthy for the patient:

> "*In Maltese families, more often than not, when something happens, people just go in. They just go in and the person cannot breathe. And I do not think that that is healthy for the patient. I have seen this. You suffocate them … They want to get so much involved. It is good that they are involved but it is very important that they give space to the patient.*" (Participant 9; Husband; Inpatient treatment; Chronic migraines)

However, one of the participants described how the fact that she had decided to do everything on her own meant that the burden of caregiving was harder:

> “*If I am able to do it than I will do it. For example, after the operation, the community nurse came. She came twice and then I asked her to do it myself. So, if you can do them yourself, then you will do them. Injections for example. However, this has led to more burden on me*.” (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

7.8 Summary of the Major Category ‘Changing Biography’

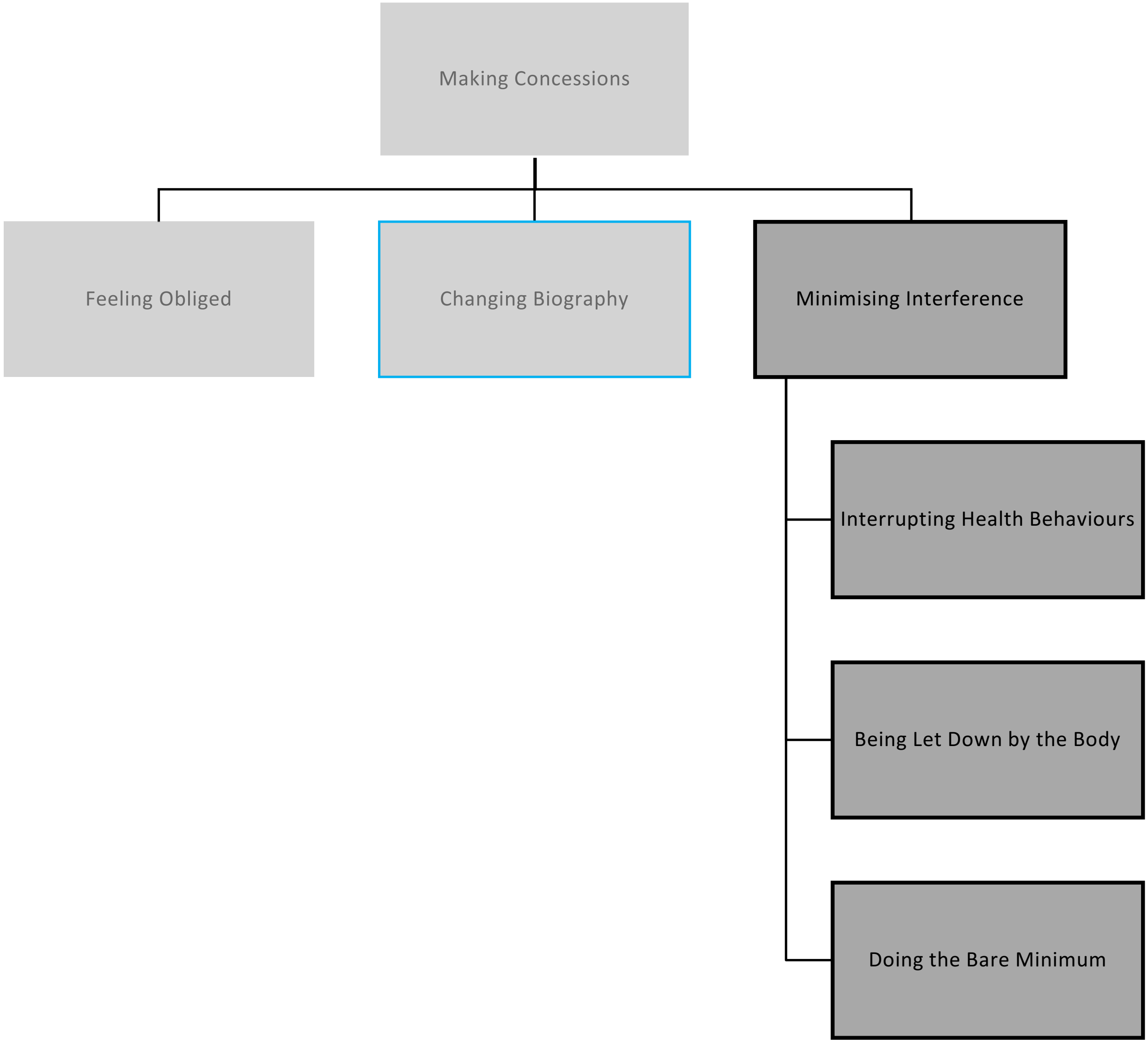
The systematic review presented in Chapter Two revealed that there is a lack of literature on which aspects of the caregiving role cause carers to neglect themselves. Therefore, the major category ‘Changing Biography’ contributes to existing knowledge by: (i) describing the process of how caregiving causes carers to neglect themselves and change their life to accommodate the care of the patient and; (ii) highlighting the contextual factors which influence this process. This category describes how carers become immersed into the caregiving world in which they start prioritising the care of the patient. In addition to their own responsibilities such as, household responsibilities and work, the carers have to take on the responsibility for doing a number of caring tasks. As a result, carers have to change their daily routine in order to incorporate these new responsibilities. This leads to carers becoming extremely busy and their daily lives becoming more restricted. Due to the time-intensive nature of caregiving, carers have to give up other priorities in life, such as social relationships. Furthermore, due to the unpredictable nature of the cancer trajectory, they have to change their mind set and start thinking more about the present rather than the future. In addition, analysis of the interview data also revealed that carers experience different degrees of biographical change throughout the cancer trajectory. The degree of biographical change does not depend on the phase of the cancer trajectory in which the carer is caring for the patient, but rather on other contextual factors which include: (i) type of caregiving; (ii) having other priorities; (iii) having support from others and; (iv) willingness to find and accept support. These findings strongly resonate Schlossberg’s (1981) description of the three sets of contextual factors which impact the process of transition. These include the characteristic features of the critical event causing the transition, the characteristic features of the social context, as well as personal characteristics. Similarly, it can be stated that the degree of biographical change experienced by carers depends on these three sets of contextual factors: (i) the characteristic features of the critical event, that is cancer diagnosis and the caregiving role itself; (ii) the characteristic features of the social context, including having other priorities and having support from family and friends; and (iii) the characteristic features of the personal context, including one’s willingness to find and accept support from others. This connection will be explored further in Chapter Ten.

Chapter 8 Minimising Interference

8.1 Introduction

This chapter describes the major category ‘Minimising Interference’, as illustrated in Figure 5. This category describes how the participants tried to minimise the interference between their chronic conditions and the care of the patient with cancer. This major category is made up of three subcategories ‘Interrupting Health Behaviours’, ‘Being Let Down by the Body’ and ‘Doing the Bare Minimum’. The first two subcategories describe why the participants had to minimise the interruption between living with their chronic conditions and caring for the patient. The first subcategory ‘Interrupting Health Behaviours’ describes how taking up the caregiving role impacted how the participants lived with their chronic conditions. The second subcategory ‘Being Let Down by the Body’ describes how the participants’ chronic conditions impacted the patient’s care. The remaining subcategory ‘Doing the Bare Minimum’ describes how the participants tried to minimise the interference between living with their chronic conditions and caring for the patient.

Figure 5: The major category ‘Minimising Interference’ and its subcategories.



To understand whether cancer diagnosis impacted how the participants lived with their chronic conditions, the researcher first asked the participants how they used to live with their chronic conditions before taking up the caregiving role. Before cancer diagnosis, the participants engaged in different tasks when living with their chronic conditions. Some of the participants strictly followed their treatment regimen and regularly checked that their chronic conditions were under control:

> “*When my sister was diagnosed with cancer, I already had high blood sugar. However, before she had cancer, I used to be very vigilant about my chronic conditions. I used to take all the medications on time … I used to check my blood sugar two to three times a day to make sure that it was fine*.” (Participant 12; Sister; Inpatient treatment; Diabetes)

> “*I used to go to the diabetes clinic every six months to have my bloods taken and to have my eyes checked out*.” (Participant 24; Husband; Outpatient treatment; Diabetes)

> "*My blood pressure was controlled. I used to take one pill in the morning and another one in evening and I tried my best not to get stressed*." (Participant 25; Child; Inpatient treatment; Hypertension)

Others engaged in healthy behaviours, such as engaging in some form of exercise and controlling their diet:

> "*Before my wife was diagnosed with cancer, I used to go for a walk every day. For about half an hour and sometimes, even for an hour. Afterwards, I used to go to work and until then I was feeling fine*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I used to take care of what I eat. I used to follow a strict diet before my husband was diagnosed with cancer*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*Because of my diabetes, I used to pay attention to what I eat. I always tried to eat a healthy diet and go for a walk in the evening to keep my blood sugar controlled*." (Participant 24; Husband; Outpatient treatment; Diabetes)

Other participants used to engage in some form of activity which promoted rest and relaxation, as well as relied on the patient himself or herself to take care of them:

> "*I used to stop and take frequent breaks. I also used to do crafts to help me relax*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

> "*He has always done everything. He did everything. Always has. He looked after m*e." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I used to lie down on the sofa and read a book to rest*." (Participant 21; Wife; Outpatient treatment; Arthritis)

The researcher went further and asked the participants why they used to engage in these different tasks before cancer diagnosis. It seems that the participants engaged in these different tasks when living with their chronic conditions for two reasons. Firstly, the participants wanted to avoid those situations or activities that aggravate the signs and symptoms of the condition. For example, one of the participants who suffers from fibromyalgia described how, before cancer diagnosis, she used to take frequent breaks throughout the day to rest and prevent experiencing a flare up of her condition:

> “*Every now and then, I used to sit down and rest. When I start feeling tired, I used to stop whatever I was doing and rest. Then I continue once I was feeling better. I used to do this all the time*.” (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

Secondly, the participants wanted to monitor the progression of their chronic condition in order to prevent future complications. In one of the above excerpts, one of the participants described how he used to go to the diabetes clinic to have his eyes checked out. When encouraged to elaborate further on this, the participant stated:

> “*The doctor tells me that diabetes can cause heart and vision problems. So, I have them checked out regularly so as to avoid any problems*.” (Participant 24; Husband; Outpatient treatment; diabetes)

However, when the participants were asked how the cancer diagnosis had impacted their chronic conditions, all the participants explained that taking up the caregiving role had impacted different aspects of their conditions. One of the participants perfectly articulated this impact when she described how her “*health went haywire*” whilst taking care of her sister:

> “*I take medications for my diabetes. However, when my sister was sick, my health went haywire. At times I used to take the medications, other times no. You start going against the rules which you are supposed to be following. I started smoking because I was nervous … my health deteriorated. It became worse, worse, and worse. Eventually, I ended up having two stents done*.” (Participant 12; Sister; Inpatient treatment; Diabetes)

This made the researcher question how cancer diagnosis and taking up the caregiving role impacted how the participants lived with their chronic conditions. The major category ‘Changing Biography’ described how caregiving interrupted the daily routine of the participants. Similarly, caregiving interrupted how the participants lived with their conditions.

8.2 Interrupting Health Behaviours

After cancer diagnosis and taking up the caregiving role, the participants experienced a change in how they lived with their chronic conditions. One of the participants who had Addison’s disease described how she used to start the day slowly and then stop when she started feeling tired in the evening:

> “*The first half an hour after I wake up, I used to take it easy. I switch the kettle on and start doing small things. By the end of the day, I would be dead tired. So, I say ‘That is all*

> *for today' and then, I continue the next day*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

However, after cancer diagnosis, since she had to care for her husband, as well as take over other responsibilities, she could not stop whenever she felt tired, but she had to continue working late into the night:

> "*On certain days, since I take care of my husband and I have taken over some of his responsibilities, I keep on working late into the night. Sometimes, it will be 11 o'clock and I still have not gone to sleep. It has really affected me the fact that I cannot go and rest whenever I wish, but I have to continue working late into the night to finish off everything*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

Another participant also recounted a similar experience:

> "*Before, if I started feeling tired, I could stop and continue on another day. But now, whatever the workload, it has to be done. I have to do it. Obviously, apart from the increased workload due to my husband, I also have the extra responsibility of cleaning everywhere. That has to be done by force. Whether you want to or not. It has to be done. It has to be done because it is going to affect his health. I cannot say that I can stop and do it on another day, as I used to do before. Now I have to do it because it is going to affect his health*." (Participant 2; Wife; Outpatient treatment; Hypertension)

Therefore, these two participants had adjusted to living with their chronic conditions by taking frequent breaks. However, after cancer diagnosis, they had to take on new roles and responsibilities which left them with no time to rest. This illustrates how, after cancer diagnosis, these participants were restricted in their ability to avoid situations or activities that aggravated the signs and symptoms of their conditions. This continues to emphasise the notion of 'losing control' and how cancer diagnosis and the caregiving role controlled the participants' lives. This will be described further in the core category 'Making Concessions'.

Analysis also revealed how caring for the patient with cancer also interrupted other activities which the participants used to engage in when living with their chronic conditions before cancer diagnosis, such as exercise and weight management:

> "*I stopped going for a walk even though my GP had told me that walking is better than just taking medications*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*My doctor tells me to take care of my weight because if I lose weight, I will be able to control my blood pressure, diabetes and cholesterol. And in fact, I used to make sure that*

> *I follow a strict diet and that my blood results are ok. However, when my husband was diagnosed with cancer, I started binge eating. I do not have control anymore. Before, I used to take care of what I eat. Now it seems that I am addicted to overeating. And when he started going for his chemotherapy, and spend three days in Malta, I used to eat very unhealthy food. I used to go and buy something from the canteen … now that I have lost all control over eating, I eat everything, I eat this, I eat that. In fact, I had lost 12 kilos in four months. Now I have gained all those kilos back since my husband has been diagnosed with cancer*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Whilst, before cancer diagnosis, some of the participants used to go for regular check-ups to monitor the progression of their chronic conditions, after cancer diagnosis, they would not go for a random check-up but would only attend for follow-up appointments booked by their physician:

> "*No, I have not considered going for a check-up at this time. I did go to see my fibromyalgia doctor three months ago because I had a follow-up appointment booked months before my husband was diagnosed with cancer. I do not consider going for a check-up unless I have an appointment already booked. I have not felt the need to go for a check-up. You know, I could go afterwards, possibly. But I have not felt the need to go for a check-up because I can control the pain by taking the extra medications and resting a bit more*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

In fact, some of the participants complained about the lack of follow-up appointments for their chronic conditions. This lack of follow-up resulted in the participants being left alone when living with their conditions:

> "*I wish that there is follow-up so as to check my condition. To check my stents and things like that. I want to go for a follow-up to check that I am in the clear. That there are no more obstructions*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*What affected me also was that in my last appointment with the doctor, I had lost weight and the blood results were fine, and he told me that I did not need to go to hospital anymore. When I used to go to these appointments, I used to take care of my blood sugar so that the doctor will not find it high. Now, it is all in my hands, and that has affected me badly. I did not like the fact that they crossed me off the hospital list.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

The participants also described how before cancer diagnosis, they used to visit their doctor at the first sign of problems with their chronic conditions, such as the presence of signs and symptoms. However, now they think twice before going to the doctor:

> "*Now, I am not as I used to be before. Before I used to go to the GP at the first sign of pain. Now, I only go to the GP if the pain persists for a few days*." (Participant 15; Friend; End-of-life; Multiple chronic conditions)

> "*Before, when I used to get these frequent episodes of shortness of breath, I used to go to the health centre for a check-up … just to see whether I should change my treatment or not."* (Participant 20; Child; End-of-life; Lung disease)

When the participants interrupted their health behaviours, they started experiencing exacerbations of their chronic conditions. One of the participants described how because she did not rest, she started experiencing flare ups of her condition:

> "*But I am just moving around all the time and never rest. And that affects my back because I am not resting. You know, I know I have got to rest but I do not*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

This participant, as well as other participants, experienced an increase in fatigue or pain whilst caring for the patient with cancer:

> "*I start to get tired, and I get pains. The tiredness, I think more than anything. It is more fatigue rather than tiredness. Sometimes, you cannot put one foot in front of the other. You are so tired. You are so fatigued that you cannot do anything*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I used to be tired and in pain especially after spending a whole day with her whilst she was having chemotherapy. After some time, she could not walk and so, she used to grab hold of me because her legs were starting to give in. And she was a heavy woman. But I never minded that I was in pain as long as I could do everything to help her.*" (Participant 15; Friend; End-of-life; Multiple chronic conditions)

One of the participants described how the osteoarthritis in her hip had severely deteriorated whilst she was caring for her husband due to lack of rest and weight gain. As a result, at the time of the interview, she was waiting to undergo a total hip replacement:

> "*My hip became worse. I started feeling more and more pain. Now, I am in so much pain that I cannot stand up for a long time. Before my husband was diagnosed with cancer, I*

> *used to take frequent breaks but after, I used to continue working and doing the housework late into the night. I also started to gain weight which did not help. So, I started feeling more and more pain. Now, I am waiting to undergo a hip replacement. Hopefully next month*." (Participant 21; Wife; Outpatient treatment; Arthritis)

Another participant described how she started experiencing complications because she did not monitor her diabetes:

> "*… my health deteriorated. It became worse, worse, and worse. Eventually, I ended up having two stents done*." (Participant 12; Sister; Inpatient treatment; Diabetes)

Caregiving impacted the participants' chronic conditions because they had to push their limits in order to try and finish off all their work responsibilities or house chores and at the same time, take care of the patient with cancer. As a result, they started suffering the consequences:

> "*I know things that I should not be doing but I still do them. House things and things in the house that I should not do but I still do it. I will suffer afterwards. But these things have to be done especially now that my husband is in hospital and there is no one else in the house who can do them*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I know that I should be resting as much as possible because of fibromyalgia especially when it flares up. However, I cannot spend the entire day in bed and not doing anything. I have to keep on working even though I know that my fibromyalgia will get worse*." (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

One of the participants described how, before cancer diagnosis, he used to experience chronic migraines once or twice per week. However, after cancer diagnosis, the episodes of migraines increased. This participant described how the migraines increased because, after cancer diagnosis, he had to give up his work in order to take on new responsibilities previously done by his wife:

> "*Me as a person, I am a workaholic. And since my wife started with all this, I just gave away all my business. I do not go to work anymore. I just stopped. Suddenly. And it did affect me. It was very difficult at first. In the first two or three weeks, I found it very difficult to adjust with my wife as such and I started having these frequent migraines. I was worrying about the business and at the same time, about my wife*." (Participant 9; Husband; Inpatient treatment; Chronic migraines)

Caring tasks also impacted the participants' chronic conditions:

> "*Once she wanted to take a bath. A bath, because she was scratching so much because of the treatment, and she was getting desperate. It was a total struggle. A struggle because at one point I did not know how I was going to get her out of the bath. I did not know what I was going to do but she wanted to take a bath, and she did take a bath … At that time, I did not feel the pain. Then I went home, and I swallowed whatever pain medications I could find because I was in so much pain*." (Participant 15; Friend; End-of-life; Multiple chronic conditions)

The above excerpts illustrate how the change in relationship dynamics between the participant and the patient influenced how the participants lived with their chronic conditions. The relationship dynamics changed as the patient took up the 'sick role' and became reliant on the participants, who not only had to perform caring tasks, but also had to take up new responsibilities previously held by the patient. As a result, the participants found it more difficult to find time to take care of themselves:

> "*I only think about her. About whether she is in pain or not. Whether she is comfortable or not. I spend most of my time next to her … I do not think about myself*." (Participant 16; Husband; End-of-life; High blood cholesterol)
>
> "*I do not think about myself. I do not think about myself. I do not take care of myself. I try. But to take care of the patient means less time to take care of yourself. I am taking care of myself much less, much less*." (Participant 20; Child; End-of-life; Lung disease)

In addition, the above excerpts illustrate how the change in biography caused by cancer diagnosis and taking up the caregiving role impacted how the participants lived with their chronic conditions. Some of the participants also described how the emotional impact of cancer and its treatments also affected their health behaviours:

> "*I think it is because of the worry. With worry I started eating everything that I see. Before I had control over what I eat, and I never felt very hungry or wanting to eat everything. However, since the cancer diagnosis, I feel like eating something all the time, always wanting to eat something … sadness and nervousness. I eat food and sweets which I should not be eating*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Another participant also described how the uncertainty which accompanies cancer and its treatments caused her to experience problems with her heart condition:

> "*When I was worried, I was having more problems with my heart. I used to have palpitations and chest pains. However, when his condition started improving, then my condition improved because I used to worry less and hence, have less anxiety attacks*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I started smoking because I was nervous … my health deteriorated.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

> "*When he started chemotherapy, I was so anxious about what was going to happen that I started smoking again … I had not touched a cigarette for over two years*." (Participant 22; Parent; Survivorship; Thyroid disease)

The first excerpt presented above suggests that the health of the patient with cancer and his or her degree of dependence in the ADLs seem to impact the participants' chronic conditions. In fact, analysis of the interview data revealed that there is a relationship between the degree of biographical change experienced by the participants and their conditions. For example, lack of support led to an increased degree of biographical change which in turn affected the participants' conditions:

> "*I do not like asking others for help. I do not even ask my children for help. I do not ask them for help, and I suffer because of that. I still take care of him even though my legs hurt. I do not even ask my children. Let alone ask other people who are not family*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*My children are all the time telling me that they want to come and help me. But I always end up doing everything myself because I hate asking them for help … but it gets tough sometimes especially since he is dependent on me*." (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

When the patient's condition deteriorated, the participants experienced an increased degree of biographical change which in turn resulted in the caregiving role impacting the participants' chronic conditions and their health behaviours, as clearly illustrated in the following excerpts:

> "*When he was really sick, I lost about 10 kilos. I used to cook for him and not for me at that time. Because you do not have the mind or the time to cook a separate meal for yourself. If he was eating broth, I would eat some broth with him, and that is all. You lose control in that way. Then when the patient's condition improves, you start taking care of yourself too*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> “*The pain increased. Before I did not use to have a lot of pain. And even when she started chemotherapy, I was not in pain. But then she started to deteriorate, and the pain started to increase because she is a heavy woman and I tend to lift her. So, the pain increased. I go back home and take a handful of pain medications. But I never mind the pain as long as the pain medications work and I can continue taking care of her*.” (Participant 15; Friend; End-of-life; Multiple chronic conditions)

Interestingly, the participants did acknowledge the importance of taking care of themselves to take care of the patient with cancer, as highlighted by many of the participants:

> “*Since you have to take care of him, you have to take care of yourself first. You cannot take care of the sick if you are sick yourself*.” (Participant 4; Wife; Outpatient treatment; Hypertension)

> “*I think the only advice is, and which I do not give to myself, is to look after yourself as best as you can as well. Look after yourself because that person needs you and you have got to think about yourself as well, which is difficult to do. I do a bit more now, but it is difficult to do. You really have got to sit down and think about that. If anything happened to you, who would look after the patient? I rarely do it myself*.” (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

The participants were also aware of the importance of seeking medical assistance early on to avoid complications. The participants were aware that delaying in seeking medical assistance can lead to two potential problems. Firstly, it can lead to serious consequences for the carer’s health. Secondly, it becomes a problem for the patient because there will be no one to take care of him or her:

> “*Let me tell you this. If something is going to happen, it will happen whether you go check it out or not. Now if you go and have it checked out and it is a problem that you can take immediate actions about it and you stop something small from becoming catastrophic, then you would be avoiding big problems. If you let it be, you can end up with two big problems. It would become a problem for the person you are taking care of and a problem for yourself. This is the same as when being in an aeroplane. If the cabin pressure decreases and you are accompanying children, what do they tell you? They tell you to first put on your own mask and then you help your children to put on theirs, because if something happens to you then there will be no one to take care of them. So, you have to take care of yourself in order to take care of the person you are caring for … If you do not take care of yourself even if you do not die, you may end up sick in bed or*

> *with only one leg because you have diabetes and you did not take care of yourself*." (Participant 2; Wife; Outpatient treatment; Hypertension)

The participants were also encouraged by other family members and friends, as well as health care professionals to take care of themselves:

> "*My sister tells me all the time to be careful of what I eat when I am with him in hospital*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*My husband is all the time telling me to rest and to take care of myself, especially when he sees me taking the pain medications*." (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

When the participants were asked why they still neglected their chronic conditions whilst caring for the patient with cancer, the participants all made reference to the positive and negative emotions, as well as the social norms described in the major category 'Feeling Obliged'. As a result, the participants prioritised the care of the patient with cancer above their own conditions:

> "*I do not think about myself … people also ask me about this 'Do you eat? Do you drink?' Yes, I do, although half the time I do not. I do not think about myself."* (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*She is your priority. Not even yourself would be your priority. She comes first and foremost before anybody else, including yourself and your family*." (Participant 10; Sister-in-law; Outpatient treatment; Arthritis)

In addition, some of the participants also neglected their chronic conditions because they attributed their signs and symptoms to old age or the stress of the situation rather than to their conditions:

> "*If I go up the stairs twice in a row, I start getting out of breath. But I think that this is something normal. I am not young anymore. I am 56 years old.*" (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I used to think that all the pains that I was feeling, the headaches and neck pains, were all because of the stress that I was experiencing.*" (Participant 18; Parent; Survivorship; Thyroid disease)

To summarise, due to positive and negative emotions, social norms, as well as symptom ambiguity, participants abandoned their chronic conditions as they turned their attention to the care of the patient with cancer. This resulted in the participants experiencing flare ups of their conditions, as well as major complications. Therefore, continuing on what was discussed in the major category 'Changing Biography', it seems that taking up the caregiving role did not only cause a disruption in the participants' biography by impacting their everyday activities, but it also interfered with the way they lived with their chronic conditions. Hence, this can also be considered as a biographical disruption. However, the participants were aware that flare ups as well as complications could hinder their ability to continue caring for the patient with cancer and hence, they tried their best to ensure that the caregiving role did not interfere with their chronic condition which may lead to major complications, as will be described in the next sections.

8.3 Being Let Down by the Body

The participants described how their chronic conditions in turn impacted the care of the patient with cancer. In fact, the level of care that they could provide depended in part on their conditions:

> "*If you are strong enough then you can take care of the patient. I was strong enough to take care of him. However, if you are sick then you have to take care of yourself by force in order to cope in this situation. By force. It depends on your condition. It depends on how the person is. Because I know people who both had cancer. I know people who needed a lot of help, both of them. So, it depends on the carer's condition. You cannot be sick and then be expected to care for the other person*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*The pain. I have arthritis … When I used to be in pain, I did not think about it. Even though I was in pain, I still went out instead of just staying inside and complaining how much I am in pain. So, I never took notice. However, when I started taking care of my friend. She was a heavy woman. So, I had some drawbacks and my pains started to increase. When she could not walk. The fact that she was heavy it was difficult for me to help her because of my pains.*" (Participant 15; Friend; End-of-life; Multiple chronic conditions)

The above excerpts illustrate how the contextual factors which mediate the degree of biographical change, specifically the type of caregiving, led to these participants abandoning their chronic conditions which, in turn, resulted in them experiencing more pain. The contextual factors which affect the degree of biographical change were described in the major category 'Changing Biography'. Due to this increase in pain, these participants found it difficult to care for the patient. Another participant described how the osteoarthritis in her knee had deteriorated so much whilst taking care of her husband, that she was waiting to undergo a total knee replacement. Consequently, she knew that she could not take care of her husband whilst she was in hospital and hence, she was awaiting a reply from a respite care organisation about the possibility of getting her husband into a nursing home until she recovers from the procedure:

> "*As time passed, the pain started increasing and increasing. Eventually, I ended up unable to stand for a very long time and was finding it increasingly difficult to help him. It was difficult to help him get washed and dressed. In fact, I went to the doctor … The doctor recommended that I undergo a total knee replacement*." (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

Another participant described how, whilst her husband was in hospital having chemotherapy, she also had to be admitted to hospital due to heart problems. As a result, she could not take care of him:

> "*I ended up being admitted in hospital whilst he was having his chemotherapy. So, at one point in time, we both ended up in hospital … I could not go and visit him because I was not allowed … My daughter ended up taking care of both of us*." (Participant 7; Wife; Survivorship; Heart disease)

The above two subcategories described why the participants tried to minimise the interference between their chronic conditions and the care of the patient with cancer, the reason being that both impacted each other. The next section will describe how the participants in this research tried to minimise this interference.

8.4 Doing the Bare Minimum

As described in the subcategory 'Interrupting Health Behaviours', the participants acknowledged the importance of taking care of their conditions and monitoring their progression in order to prevent future complications. Nevertheless, in the major category 'Changing Biography', it has already been discussed how the participants prioritised the patient's care, as they focused all their attention on caring for the patient and putting their lives on the backburner. Similarly, the participants prioritised the patient's care above their own health:

> "*You do not care about going for a walk or sticking to a diet. You do not even bother with these things … I did not even bother with doing such things. You do not even feel like going out. You are all the time thinking about him and hence, you do not think about doing anything else except making sure that you are there for him and help him … making sure that he is all right*." (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I used to get tired. I used to get very tired. However, I never stopped to think about the harm that I was doing to myself. I never did that*." (Participant 22; Parent; Survivorship; Thyroid disease)

Consequently, the participants did not want their chronic conditions to interfere with the care of the patient. One of the participants described how he actually had wanted to continue doing some exercise however, he found it difficult to find time to go for a walk because he had to visit his wife at the hospital:

> "*Before my wife was diagnosed with cancer, I used to go for a walk every day. For about half an hour and sometimes, even for an hour. Afterwards, I used to go to work and until then I was feeling fine. However, when they told me that my wife has cancer, I froze with fear, and I stopped going for a walk because I had no time. When she was in hospital, I used to go to hospital in the morning. Then, I used to go to work afterwards. Then, I come back to hospital after work. Then, I used to go home later at night and so I did not find time to do other things … Hence, instead of going for a walk, I used to go and visit her at the hospital*." (Participant 1; Husband; Inpatient treatment; Heart disease)

Therefore, due to the time constraints imposed by the caregiving role, the participants viewed health behaviours as an interference to the care of the patient with cancer and hence, they decided to abandon such behaviours. Another participant described how she had missed a follow-up appointment for her thyroid disease because she preferred to spend the time with her son in hospital. However, her son got angry at her for not attending the appointment. As a result, she decided to set up a new appointment because she did not want to upset her son:

> "*I did not go for my follow-up appointment. I wanted to stay next to him in hospital especially since he had just been in ITU, and he was very sick. I did not go. But when he saw me coming into the room, he got angry because he knew that I had an appointment on the day. So, I decided to set up a new one because I did not want to upset him*." (Participant 18; Parent; Survivorship; Thyroid disease)

This excerpt illustrates how the decisions made by the participants regarding their chronic conditions were not only based on the contextual factors mediating the degree of biographical change, but also on their sense of obligation, as described in the major category 'Feeling Obliged'. The participant's emotional attachment to the patient drove her sense of obligation to miss the follow-up appointment and to stay next to the patient. On the other hand, the feelings of guilt and the sense of obligation not to cause any emotional distress to the patient motivated her to set up another appointment.

The interview data also revealed that the participants were reluctant to go for routine check-ups of their chronic conditions because they were afraid that such medical visits may reveal something that required the carer to be admitted to hospital and hence, interfering with the care of the patient, as highlighted by some of the participants:

> "*Sometimes, I say to myself 'I need to go to the doctor'. But then I say to myself 'Who is going to take care of him? Who is going to cook for him whilst I am at the doctor's?'*" (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*I do not consider going at the moment. Because I do not want the doctor to tell me that I have something, and I need to go to hospital. Because if I go to hospital who is going to take care of my son*?" (Participant 23; Parent; Inpatient treatment; Hypertension)

Such worry about one's conditions interfering with the patient's care was highlighted by one of the participants when she stated that she was worrying about leaving the patient alone when she was in hospital:

> "*When I was in hospital, I was worrying a lot. I was worrying a lot because I had left my husband and mother all alone at home … I was worried because I was in hospital, and I had left them all alone here. Are you understanding? I was there and they were here all alone. What are they going to eat? Who is going to make them tea? For that reason, I was worrying … there is no one else who can take care of them*." (Participant 4; Wife; Outpatient treatment; Hypertension)

One of the reasons why the participants interrupted their health behaviours and did not seek medical assistance when they started experiencing exacerbations of their chronic conditions was because they thought they knew what they had to do to live with their conditions:

> "*Because I know myself. I know that I know how to take care of myself and of my condition. On the other hand, I do not know what my wife is feeling. I do not know what she is going through. So, I want to take care of her so that I can share her experience and I can help her make it through it*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I knew what I had to do to control my blood pressure*." (Participant 19; Parent; Survivorship; Hypertension)

> "*I know what I have to do when I am in pain. I have to rest*." (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

The participants were aware of what they had to do to live with their chronic conditions however, at that moment, they were unable to do so because of the burden of caregiving. Hence, there was no point in going to the doctor when they already knew what their doctor was going to say:

> "*But I do not want the doctor to tell me that I have to rest and calm myself because there are things that need to be done and I have to do them, because no one is going to do them for me, including him*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I used to get upset when my consultant used to get angry at me. I used to get upset because he does not know what I am going through*." (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I know from where the pain is coming from and there is not a lot to do except for taking pain relief medications. I know that I am abandoning myself. So, I know that the doctor is going to tell me to take care of myself. As long as the headache does not interfere with the care, I will not go*." (Participant 13; Wife; Inpatient treatment; Hypertension)

The above excerpts continue to illustrate how the participants avoided seeking medical assistance unless the symptoms of their chronic conditions interfered with the care of the patient. As long as the symptoms did not interfere with the care of the patient, the participants did not mind living with them:

> "*As long as the pain from my arthritis does not stop me from taking care of her, then I do not mind*." (Participant 10; Sister-in-law; Outpatient treatment; Arthritis)

> "*But I never minded that as long as the pain medications worked, and I could continue taking care of her*." (Participant 15; Friend; End-of-life; Multiple chronic conditions)

The above excerpt illustrates how after cancer diagnosis and taking up the caregiving role, the participants relied on their medications when living with their chronic conditions. Although the participants abandoned their health behaviours, they still continued to take their medications:

> "*I have a heart condition. I have stents. I have three stents. And I take a number of pills for my condition. At the moment, I am taking Aspirin, another pill for the stomach, and another pill for the cholesterol*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*If I start feeling the pain in my head and my blood pressure is high, I just follow the doctor's instructions and take one Amlodipine. And that is all I do*." (Participant 13; Wife; Inpatient treatment; Hypertension)

> "*I am on medications to control the pain and then, I have extra medications that I can take for immediate pain relief*." (Participant 27; Sister; Outpatient treatment; Fibromyalgia).

If their regular medication was not enough and they started experiencing an exacerbation of their conditions, the participants often ended up taking higher doses of medications to alleviate the symptoms. One of the participants described how she is taking a higher dose of medication than recommended by her doctor:

> "*At the moment, I am taking a higher dose ... and I think it is important that I tell you this … I am taking a higher dose than was recommended by my consultant for a woman of my age.*" (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

When asked why, the participant highlighted:

> "*Because I have to continue working. If I decrease the dose than that would mean that I start getting tired more easily and hence, I cannot continue working and do what is needed to be done. I have to clean all the time especially when it comes to his dogs. At the moment, I am cleaning more than I used to do before. Not that I did not use to clean. But now I have to clean all the time especially where the dogs sit and where he stays because the dogs are always with him. I have to clean all the time because of infections. So, I have to continue taking a higher dose*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

This excerpt continues to illustrate how the participants prioritised the care of the patient above their own health. In fact, this participant did not think about the consequences:

> "*My decision to continue taking a higher dose was an easy decision. I need to continue working and so I need to take a higher dose. Without thinking about the consequences. I did not think about myself. I just want to do the work that needs to be done. I did not think about myself. That came automatic to me. I was not feeling strong enough and so I continued taking the extra half a dose. And I took it once and I took it again and now, I am taking it every day. But I do not think about myself. I do not think about the harmful effects of taking it. I know that it will affect me one day, but for now I need to take it to continue doing the work. I just thought that I need to be strong enough to get through*

> *this and so, I have to continue taking the other half*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

In the major category 'Changing Biography', it was described how the participants changed their time orientation towards the present. As a result, the participants did not think about the future consequences of not managing their chronic conditions but only considered how their conditions could impact the care of the patient with cancer. They did acknowledge the fact that they may not be able to care for the patient if they do not take care of themselves. However, they did not dwell on this thought because they did not know what would happen in the future and they did not want to feel guilty for not doing their best to support the patient because of their conditions.

Some of the participants fought through the increase in pain and tried to forget about it so that they could continue caring for the patient with cancer:

> "*I try to fight the pain and not let the pain win.*" (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

> "*Yesterday my back was bad, yesterday. I just forgot about it. You know what I mean. I knew I was in pain, but I just forgot about it. I did what I had to do*." (Participant 27; Sister; Outpatient treatment; Fibromyalgia)

Some of the participants tried other activities to alleviate the symptoms, such as breathing exercises and spreading out the workload:

> "*First of all, it is not serious. I have hypertension and hence, I do know that if I am going to worry or get angry, it is going to increase. Then you learn. You learn certain exercises. Breathing exercises, that help you to control your blood pressure. For example, yoga exercises*." (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*I think at that time when I realised that I was starting to not feel right, I just thought to calm down. I think I wanted to do things straight away and I realised that I could not … I just had to settle myself down and calm down to do it and that used to help me. If my head started to get really bad, instead of going on and on and on, I would stop and try and go back the next day.*" (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

In fact, the participants exhausted all options available to them before they sought medical assistance. One of the participants, who had hypertension, described how she had felt several chest pains when her husband was diagnosed with cancer and thought that she was having a heart attack. However, instead of going to her physician, she spoke to one of her friends who happened to work at the hospital:

> “*For example, since my husband has started chemotherapy, I have felt a chest pain three times, like a bubble in my chest and it is inflating and causing pressure. And I spoke to one of our friends who happens to work at the hospital, and he told me that it is all stress. He told me not to worry. It is all stress. Because I was feeling like I was having a heart attack.*” (Participant 2; Wife; Outpatient treatment; Hypertension)

On the other hand, when the medications and other activities did not work and the participants continued experiencing an exacerbation of their chronic conditions, they finally sought medical assistance because they did not know what else they had to do to alleviate the symptoms:

> I: “*Why did you go to the doctor recently?*”
>
> P: “*Because I started feeling this pain in my head. Even though I took the medications, they did not work, and the pain got worse. So, I went to the doctor to have it checked out and he reviewed my treatment*.” (Participant 13; Wife; Inpatient treatment; Hypertension)

One of the participants described how she went to the physiotherapist for some exercises for her knee. Then she kept on doing these exercises at home:

> “*I went to the physiotherapist for some exercises. But I only went twice. Now, I do them here on my own*.” (Participant 21; Wife; Outpatient treatment; Arthritis)

When this participant was asked why she went to the physiotherapist, she stated:

> “*I went because I could not walk and so, I had to go. I could not walk and so, I could not take care of my husband. They took an x-ray, and I took some painkillers and together with the exercises I felt better*.” (Participant 21; Wife; Outpatient treatment; Arthritis)

The above excerpt continues to emphasise the concept of ‘Minimising Interference’. The main reason why this participant sought medical assistance was because the exacerbation of her chronic condition started interfering with the care of her husband. By seeking medical help, she prevented further complications and the physiotherapist assisted her to get better and to start walking again so that she could care for her husband. Medical assistance helped her to walk again and hence, decrease the interference with the patient’s care. Another participant also described how she sought medical assistance when she started experiencing symptoms which she could not relate to her diabetes:

> "*After my sister was diagnosed with cancer, I went to the toilet, and I noticed blood with my urine. I did not know what had happened because I had never seen blood with my urine before. So, I went to the doctor, and he informed me that I either had an infection or a polyp. He performed a scan and he said that it might actually be a polyp and that I might need to undergo a TURP. On my way home, I started crying because I did not know what was going to happen and who was going to take care of my sister whilst I was in hospital. Eventually, the results showed that it was just an infection*." (Participant 12; Sister; Inpatient treatment; Diabetes)

The above excerpt continues to illustrate how the participants were afraid of being admitted to hospital because this would interfere with the patient's care. Furthermore, the participants only sought medical assistance when they were concerned that their symptoms could interfere with the patient's care. Therefore, this illustrates the dilemma faced by the carers. On one hand, they are aware that seeking help could lead to hospitalisation and hence, they would be unable to continue caring for the patient. On the other hand, they are aware that not seeking help could lead to complications which could make it harder to care for the patient. In fact, later in the interview, this participant stated:

> "*When I saw all that blood and I did not know what it was, I went straight to the doctor because I was afraid that I had something serious and so, I could not continue taking care of her. So, I went to the doctor so that if I have something serious, we can deal with it immediately so that it will not stop me from taking care of her. That was my first thought. On the other hand, I know that high blood sugar will not interfere with her care*." (Participant 12; Sister; Inpatient treatment; Diabetes)

Therefore, the increasing severity of the signs and symptoms of the chronic conditions led to the participants experiencing increased physical impairment. This in turn influenced the participants' decision to seek medical assistance. Analysis of the interview data revealed that the type of chronic condition and their treatment burden affected how the participants' chronic conditions impacted the care of the patient with cancer and vice versa. Treatment burden represents the work that the participants had to do when living with their chronic conditions, such as managing their medications, changing lifestyle behaviours, going for follow-up visits, and undertaking tests. Those participants who were diagnosed with conditions which involved a low treatment burden, such as hypertension and high blood cholesterol, found it easier to continue living with their conditions, because they just continued taking their medications:

> "*I have high blood pressure. I take one pill in the morning and one pill in the evening. With regards to that, nothing has changed*." (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*That it can only be controlled by taking the Amlodipine. There is no other way.* (Participant 13; Wife; Inpatient treatment; Hypertension)

On the other hand, those participants who were diagnosed with chronic conditions which involved a higher treatment burden, such as diabetes and fibromyalgia, found it more difficult to continue living with their chronic conditions and consequently, experienced more flare ups of their conditions. The management of such conditions involved more time-consuming activities such as resting, cooking healthy meals and hence, the participants found it difficult to perform such activities due to time constraints. In one of the above excerpts, the participant recounted:

> "*Before, I used to take care of what I eat. Now it seems that I am addicted to overeating. And when he started going for his chemotherapy, and spend three days in Malta, I used to eat very unhealthy food. I used to go and buy something from the canteen … now that I have lost all control over eating, I eat everything, I eat this, I eat that. In fact, I had lost 12 kilos in four months. Now, I have gained all those kilos back since my husband has been diagnosed with cancer*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

When asked why she used to eat very unhealthy food, she stated:

> "*I never found the time to prepare food at home. So, I always used to buy food from the canteen*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

In fact, this participant was diagnosed with hypertension, diabetes, high blood cholesterol, and depression. She described how she only found it difficult to manage her diabetes:

> "*I am only afraid of my blood sugar because with food, the blood sugar increases immediately. My blood pressure, blood cholesterol, and depression are controlled. However, my blood sugar increases all the time*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Analysis of the interview data also revealed that debilitating chronic conditions, such as fibromyalgia or arthritis, were more likely to interfere with the care of the patient with cancer than other conditions, such as mental health disorders. In an interview with one participant who was diagnosed with depression recounted how her condition did not interfere with the patient's care because she had continued taking her antidepressants:

> “*I never had any problems with my depression when he was having his chemotherapy and the operation. With depression, as you know, sometimes you are fine, other times you are not. But I was fine. I continued taking my medications, keeping the same dosages*.” (Participant 26; Wife; Survivorship; Depression)

Interestingly, another participant in this research reported that she did go for routine medical check-ups and not only when she experienced an exacerbation of her chronic condition:

> “*I went to my GP, and she started me on some medications to lower my blood pressure. I had to take one in the morning and one in the evening. Then, I went again to her a couple of weeks after and she told me that the blood pressure is decreasing.*” (Participant 4; Wife; Outpatient treatment; Hypertension)

When this participant was asked to describe why she went for a routine check-up, she described how her husband had continued to live a normal life:

> “*My husband continued living a normal life. He continued living a normal life. Therefore, although I have to take care of him, I still find time to go to the health centre.”* (Participant 4; Wife; Outpatient treatment; Hypertension)

The above excerpt illustrates how the degree of biographical change experienced by the participants also impacted whether they could perform health behaviours. Therefore, the above excerpt continues to illustrate the relationship between the two major categories ‘Changing Biography’ and ‘Minimising Interference’. Since her husband continued living a normal life, this participant experienced a decreased degree of biographical change and hence, found time to go for a routine medical check-up. Other participants also described how a decreased degree of biographical change meant that they could perform certain health behaviours:

> “*Now that he has finished treatment and we only need to go to hospital once every month … I have started doing some exercises again*.” (Participant 14; Wife; Survivorship; Heart disease)

> “*After she finished her chemotherapy, I started drawing again … Now I have more time on my hands since I do not have to go to hospital every day*.” (Participant 17; Husband; Survivorship; Hypertension)

> “*Since she has been at home, it has been better than when she was in hospital because I find more time for myself. I do some exercises and I go to work*.” (Participant 24; Husband; Outpatient treatment; Diabetes)

In addition, Participant 4 was the only participant in this research who was recently diagnosed with her chronic condition:

> "*So, I have only been recently diagnosed with high blood pressure. I think it has been since January. Not even six months. So, I take care of it. I take care of it. I go and have it checked regularly*." (Participant 4; Wife; Outpatient treatment; Hypertension)

The participant stated how she still felt that her condition was still not under control:

> "*My doctor told me that not everyone is the same. She told me that there are some people whose blood pressure decreases immediately and others whose blood pressure keeps on fluctuating. Up and down. Up and down. Mine keeps on fluctuating, so it is not totally under control. Therefore, I have to continue going to my doctor until it is under control*." (Participant 4; Wife; Outpatient treatment; Hypertension)

Therefore, her recent diagnosis and consequently, her lack of knowledge on how to manage her chronic condition meant that she had to continue seeking medical assistance, especially since she was afraid that if she did not keep it under control, she would end up in hospital again and would be unable to take care of her husband:

> "*I had to continue going to the doctor because it was still not under control. And I did not want to end up in hospital with a high blood pressure. Then, who is going to take care of my husband and my mum?*" (Participant 4; Wife; Outpatient treatment; Hypertension)

Therefore, those carers who had been living with their chronic conditions for a long time, knew how to live with their conditions and hence, tended to try and control their conditions themselves. On the other hand, this participant still sought medical help frequently because she was only diagnosed with her condition a few weeks prior. Thus, how the participants lived with their chronic conditions whilst caring for the patient with cancer also depended on the temporal course of their conditions.

The major category 'Changing Biography' revealed how those participants who were caring for the patient in the treatment phase considered this change in their biography as being temporary. On the other hand, those participants who were caring for the patient in the survivorship phase or at the end-of-life, considered the changes in their biography as becoming their new life routine. This made the researcher question whether these different perceptions impacted how the participants lived with their chronic conditions throughout the cancer trajectory. A temporary disruption may mean that the carer may not mind relying only on medications for a short time. However, relying on medications in this way for a long time may lead to future complications. The interview data revealed that the participants continued to rely on medications when living with their chronic condition throughout the whole cancer trajectory. One of the participants described how she was still relying on her medications for her diabetes, even though she had been caring for her sister for a long time:

> "*For example, I go and buy a packet of sweets. I never used to have sweets at home. Since my sister has been diagnosed with cancer, I go and buy a packet of sweets every day. Sometimes. I eat two or three packets a day. So, my blood sugar goes up … Then I just take my medications. This has been going on for quite some time now.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

In fact, this participant experienced first-hand the consequences of not managing her chronic condition for a long time:

> "*My health has deteriorated a lot. It has deteriorated a lot. Not only have I ended up having two stents done a couple of weeks ago, but my doctor has also informed me that I have macular oedema in my eyes. The sugar has attacked my eyes.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

Nevertheless, even though this participant is experiencing the consequences of not managing her chronic condition, she still continued to perform unhealthy behaviours because of the negative emotions and the time constraints associated with the caregiving role:

> "*I know that I have to be careful because I could lose my eyesight in a few years' time. So, I know that I have to take care of myself. Even my husband tells me all the time that I have to take care of myself. But I cannot just abandon her. Sometimes, I spend more than twenty-four hours next to her. I do not cook for myself. I end up binging on sweets or buying fast food. It is not just the lack of time though. Being sad and angry all the time have also made me give up on myself.*" (Participant 12; Sister; Inpatient treatment; Diabetes)

Therefore, the research data revealed that since the caregiving role changed the participants' time orientation towards the present, the way they lived with their chronic conditions depended on the contextual factors mediating the degree of biographical change experienced, as well as the severity, treatment burden and temporal course of their chronic conditions, rather than their perception of the possibility of future complications. The next section provides a summary of the major category 'Minimising Interference' described in the previous sections.

8.5 Summary of the Major Category 'Minimising Interference'

When living with their own chronic conditions, the participants engaged in tasks which did not interfere with the patient's care. The participants abandoned certain health behaviours due to time constraints and mostly relied on taking medications. Therefore, the participants resorted to doing the least possible when living with their chronic condition, keeping it at the level of side involvement and without allowing it to interfere with the care of the patient. Hence, they did the bare minimum in terms of living with their own chronic conditions.

Before cancer diagnosis, the participants adjusted their lifestyle and daily routine so as to avoid situations or activities that aggravate the signs and symptoms of their chronic conditions. On a day-to-day basis, the participants adjusted to the sometimes variable manifestations of their chronic conditions. Furthermore, they worked hand in hand with health care professionals to construct an effective adjustment strategy to prevent future complications. However, after cancer diagnosis and taking up the caregiving role, the participants changed the way they lived with their chronic conditions so as to minimise interference with the patient's care. Cancer diagnosis brought about a change in their biography and hence, they had to adapt to this new situation. Before cancer diagnosis, the participants adjusted their daily routine according to their chronic conditions. However, after cancer diagnosis, the participants could not do so because their daily routine was controlled by the patient's cancer and its treatment. Therefore, whilst before cancer diagnosis, the chronic condition was the dominant focus of attention for the participants, now after cancer diagnosis, the dominant focus of attention was the caregiving, whilst the chronic condition was considered as a side-involvement. Hence, after cancer diagnosis, the participants tried to adjust to the caregiving situation whilst preventing their chronic conditions from interfering with this process. Therefore, the participants lived with their chronic conditions whilst caring for the patient with cancer by doing the bare minimum to minimise interference with the patient's care.

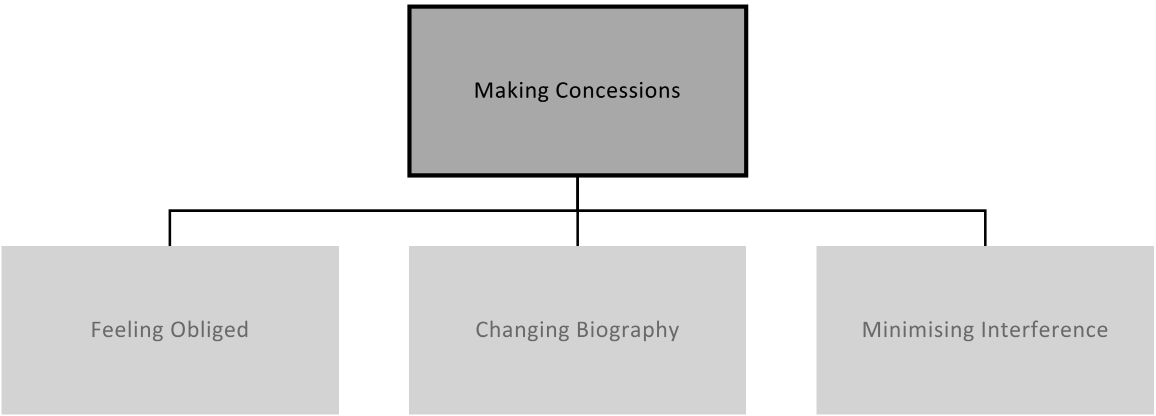
These findings resonate strongly with Bury's (1982) concept of biographical disruption and how chronic illness disrupts the individual's daily life. Similarly, the participants viewed their chronic conditions as a disruption of the caregiving role. Therefore, the impact of the participants' chronic conditions on the caregiving role can also be considered as a biographical disruption. This connection will be explored in further detail in Chapter Ten. The next section will describe the core category 'Making concessions' which was the main theme that was common across all the major categories (Glaser, 1978).

Chapter 9 Making Concessions

9.1 Introduction

This chapter describes the core category ‘Making Concessions’, which explains the social process of how carers live with their chronic conditions whilst caring for the patient with cancer, as illustrated in Figure 6. The interview data revealed that carers live with their chronic conditions and at the same time, care for the patient by making concessions throughout all the phases of the cancer trajectory.

Figure 6: The core category ‘Making Concessions’.



9.2 Exploration of the Core Category ‘Making Concessions’

Upon cancer diagnosis, carers immediately become immersed in the caregiving world in which they start prioritising the care of the patient with cancer. The major category ‘Feeling Obliged’ described how positive and negative emotions, as well as social norms influence carers to feel a sense of obligation to care for the patient. In fact, carers seem to report little to no choice in assuming caregiving responsibilities. Consequently, they immediately start changing their biography in order to incorporate the new roles and responsibilities brought about by the cancer diagnosis and the caregiving role, as described in the major category ‘Changing Biography’. In order to incorporate these new roles and responsibilities, carers start making concessions in their biography. Carers give up other priorities in life, such as social relationships and leisure activities, in order to make time to care for the patient. Carers start making concessions in their daily routines in order to have more control over the caregiving situation, as clearly illustrated by the phrase “*I want to*” in the following excerpts:

> "*If there is something that I can do for her, I want to know.*" (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I want to do everything myself. I want to do everything myself. If I do it myself then I know that everything will be all right.*" (Participant 5; Wife; Outpatient treatment; Multiple chronic conditions)

> "*I want to control the situation myself.*" (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I want to see exactly everything that is happening. I want to see everything that she is taking.*" (Participant 9; Husband; Inpatient treatment; Chronic migraines)

Carers are aware that they do not have control over certain aspects of the patient's cancer and its treatments. They cannot control how the patient is doing physically or mentally but they can exert control over the caregiving situation by providing their full support to the patient with cancer. As a result, carers seek to be actively involved in the patient's care, as illustrated by the following excerpts:

> "*I hope that she is telling me everything. I hope that she is telling me what she is feeling and if she needs help or not. I cannot do anything about her cancer but at least I can help her get through the chemotherapy*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*I do not have anything serious. I just have to continue taking the medications and check my blood pressure regularly. However, I do not know what he is going through*." (Participant 4; Wife; Outpatient treatment; Hypertension)

> "*Sharing first of all. I feel that I have to know so that I can encourage her when she is feeling down. Do you know what I mean? So, we are walking the journey together. Obviously, she is going through it more than I am. But we are in this together. We are sharing the experience. We are passing through this stage in our lives*." (Participant 9; Husband; Inpatient treatment; Chronic migraines)

Such control over the caregiving situation is important for carers because it fulfils their sense of obligation to care for the patient with cancer. Therefore, carers will seek to maintain this sense of control throughout all the phases of the cancer trajectory. Nevertheless, there are times when carers cannot actively participate in the patient's care for a number of reasons, such as health problems or other priorities. In such cases, carers ask others, whom they trust, such as family members or health organisations, to take control of the caregiving situation for them:

> "*I will try and get him into a nursing home before I undergo the procedure*." (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

As carers make concessions in their biography in order to exert a greater sense of control over the caregiving situation, they start losing some control over their daily routine. Instead, the carers' daily routines become more controlled by the patient's condition and the caregiving role. Carers cannot plan their daily routine but instead, it is the patient's condition and the caregiving role which control what they will accomplish on any particular day. They also lose control over their social relationships, as well as their future because they do not have control over the uncertainties of the cancer diagnosis and its treatments, as clearly illustrated in the following excerpts:

> "*The only thing that holds us back is my husband's cancer, especially when he starts feeling very tired*." (Participant 2; Wife; Outpatient treatment; Hypertension)

> "*I do not have control anymore*." (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

> "*Your plans depend on his routine*." (Participant 21; Wife; Outpatient treatment; Arthritis)

Nevertheless, carers do acknowledge that there are other duties and responsibilities, such as doing housework and going to work, which still need to be fulfilled whilst caring for the patient with cancer. Therefore, carers will try to strike a balance between caring for the patient and at the same time, carrying out these important duties and responsibilities.

The level where carers strike a balance between caring for the patient with cancer and the rest of their biography does not depend on the phases of the cancer trajectory but rather on other contextual factors, including (i) type of caregiving, (ii) having other priorities in life, (iii) having support from family and friends, and (iv) willingness to find and accept support from family and friends. Therefore, it is these factors which determine the number of concessions that carers have to make in their biography in order to care for the patient. For example, if a particular carer experiences a higher burden due to the type of caregiving, they are more likely to have to make more concessions in their daily routine in order to dedicate more time to the care of the patient.

Carers consider striking the right balance between caring for the patient with cancer and the rest of their biography when they are able to finish off all the important priorities, such as work responsibilities and house chores, and at the same time, still continue to care for the patient, as illustrated in the following excerpts:

> "*When you manage to finish off everything that you had to do. When you are positive about this. And even though there is suffering, when you manage to finish off everything you feel positive*." (Participant 3; Wife; Inpatient treatment; Multiple chronic conditions)

> "*You really have to dig in and take care of yourself because then, I would have arrived at the stage where I could not cope with the situation and be able to finish off everything and at the same time, care for him. I would be no good*." (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*At the end of the day, the fact that you have managed to finish off everything that you had to do, that gives you satisfaction that you managed to finish off all the housework*." (Participant 10; Sister-in-law; Outpatient treatment; Arthritis)

In addition to their daily routines, carers also start losing some control over their chronic conditions. Whilst caring for the patient with cancer, carers find it more difficult to maintain healthy behaviours, such as exercise and healthy eating. Nevertheless, carers do acknowledge the fact that they still have to maintain some sense of control over their conditions in order to continue caring for the patient. As a result, carers try to maintain this sense of control by doing the bare minimum, such as relying on their medication regime. Doing the bare minimum means that carers will engage in activities which take the least possible amount of time from their day and hence, they would have more time to care for the patient and carry out other important duties and responsibilities in their biography. This means that carers start making concessions with regards to how they live with their conditions. Therefore, by doing the bare minimum, they strike a balance between maintaining a sense of control over their conditions and at the same time, maintaining a sense of control over the caregiving situation and other important aspects of their biography.

Analysis of the interview data underlines that this is not an easy balance to strike for the carers. Carers see their caregiving role as becoming part of their life, invading all aspects of their daily life, including how they live with their chronic conditions. At the same time, carers consider their conditions as outside forces which can interfere with the care of the patient with cancer, as clearly illustrated by the use of the word "*the*" instead of "*my*" in the excerpt "*being let down by the body*". Carers do acknowledge that caregiving interferes with how they live with their conditions and that worsening of their conditions can in turn lead them to experience complications which can be severe. In addition, they also acknowledge the fact that worsening of their conditions may prevent them from taking care of the patient. However, they cannot choose to abandon the caregiving role. At the same time, they cannot allow their conditions to deteriorate to a point that they cannot care for the patient because this would mean that they would still end up abandoning the caregiving role. Hence, they have to maintain some sense of control over their chronic conditions in order to continue caring for the patient. At the same time, they are aware that they cannot do certain activities that they used to do before the cancer diagnosis because these will interfere with care of the patient due to time constraints. Thus, they resort to the doing the bare minimum, as described in the major category ‘Minimising Interference’.

As described above, the level at which carers strike a balance between maintaining a sense of control over the caregiving situation and the rest of their biography depends on a number of contextual factors rather than the different phases of the cancer trajectory. Similarly, these factors will also influence at what level carers strike a balance between living with their chronic conditions and at the same time, not allowing this to interfere with the care of the patient. For example, if a particular carer experiences a higher burden due to the type of caregiving, they are likely to resort to doing the bare minimum by relying only on their medications for their conditions and abandoning other healthy behaviours. On the other hand, those carers who experience a lesser burden may find more time to do other healthy behaviours rather than just relying on their medications.

How carers maintain a sense of control over their chronic conditions will depend on three contextual factors: (i) the temporal course of the chronic conditions; (ii) the treatment burden and (iii) type of chronic conditions, as described in the major category ‘Minimising Interference’. Those carers who would have been diagnosed with their chronic conditions for a long time, often tend to try and manage their conditions themselves. On the other hand, those carers who have recently been diagnosed with their chronic conditions often continue to seek medical assistance to help them with the management of their conditions. These carers continue to seek medical assistance because they lack the knowledge needed to manage their conditions and are afraid that it will start interfering with the patient’s care. On the other hand, those carers who have had their conditions for a long time, would have gained this knowledge over time and hence, they perceive that they know how to manage their conditions:

> “*I know what I have to do to take care of myself. I need no one to tell me what I have to do. I have to eat well, and I have to sleep well*.” (Participant 2; Wife; Outpatient treatment; Hypertension)
>
> “*I take medication which helps. And I have to really be careful of what I am doing. I know what I can do and what I cannot do*.” (Participant 8; Wife; Inpatient treatment; Multiple chronic conditions)

> "*I know from where the pain is coming from and there is not a lot to do except for taking pain relief medications. I know that I am abandoning myself. So, I know that the doctor is going to tell me to take care of myself. As long as the headache does not interfere with the care, I will not go*." (Participant 13; Wife; Inpatient treatment; Hypertension)

Those carers who were diagnosed with chronic diseases which involve a higher treatment burden, such as diabetes and fibromyalgia, would often need to dedicate more time to manage their conditions in order to prevent them from worsening and cannot just rely on taking medications. Hence, these carers may need to dedicate more time for their conditions, time which they would prefer to spend caring for the patient with cancer. On the other hand, other carers who were diagnosed with chronic conditions with a lesser treatment burden, such as hypertension, may only need to rely on taking medications when living with their conditions and thus, may find more time to care for the patient. Similarly, those carers who were diagnosed with debilitating conditions are more likely to experience flare ups of their conditions due to the demanding tasks associated with the caregiving role. Such flare ups would interfere with the care of the patient and hence, these carers may need to dedicate more time for their conditions in order to prevent such flare ups.

The indicators which demonstrate whether carers have struck the right balance between the care of the patient with cancer and living with their chronic conditions or not, include the absence of signs and symptoms associated with the conditions and the ability to manage such signs and symptoms without interfering with the care of the patient:

> "*I used to be tired and in pain especially after spending a whole day with her whilst she was having chemotherapy. And that time, she could not walk and so she used to grab hold of me because her legs were starting to give in. And she was heavy woman. But I never minded that I was in pain as long as I could do everything to help her*." (Participant 15; Friend; End-of-life phase; Multiple chronic conditions)

> "*If you are coping then you are fine. However, if you can no longer cope than you have to take care of it and go to the doctor. If you are still all right than you can continue doing what you are doing. I do cope with my knee. I can live with the pain, by taking Panadol or other pain medications*." (Participant 21; Wife; Outpatient treatment; Arthritis)

Whilst carers often refuse help with caring for the patient with cancer because they want to have a total sense of control over the caregiving situation, on the other hand, carers are willing to concede some of the control they have over their chronic conditions to others. In fact, carers express the need for health care professionals to help them with the management of their conditions. They want health care professionals to set up appointments for them and to continue following them up whilst they are caring for the patient with cancer:

> "*I wish that there is follow-up so as to check my condition. To check my stents and things like that. I want to go for a follow-up to check that I am in the clear. That there are no more obstructions*." (Participant 1; Husband; Inpatient treatment; Heart disease)

> "*What affected me also was that in my last appointment with the doctor, I had lost weight and the blood results were fine, and he told me that I did not need to go to hospital anymore. When I used to go to these appointments, I used to take care of my blood sugar so that the doctor will not find it high. Now, it is all in my hands, and that has affected me badly. I did not like the fact that they crossed me off the hospital list.*" (Participant 6; Wife; Outpatient treatment; Multiple chronic conditions)

Therefore, carers want health care professionals to share some of the control that they need to maintain control over their chronic conditions and not just tell them what they have to do:

> "*I used to get upset when my consultant used to get angry at me. I used to get upset because he does not know what I am going through*." (Participant 11; Wife; Outpatient treatment; Multiple chronic conditions)

Therefore, whilst carers seek to maintain total control over the caregiving situation, often refusing help from others in the process, on the other hand, with regards to their chronic conditions, they want health care professionals to share the control over the management of their conditions so that they can put more effort in the care of the patient with cancer. These findings resonate strongly with the notions of the Self-Determination Theory (Deci and Ryan, 1985). It seems that the participants strived to have more control over the caregiving situation in order to satisfy their need for autonomy which further motivated them to continue caring for the patient. They were willing to relinquish some of their autonomy with regards to the care of their chronic conditions as this allowed for more autonomy in caring for the patient. Furthermore, gaining more control over the caregiving situation and actively participating in the care of the patient, also satisfied their need for relatedness which motivated them further to keep caring for the patient. The connection between the grounded theory of this research and the Self-Determination Theory (Deci and Ryan, 1985) will be explored in further detail in Chapter Ten.

The factors which influence how carers strike a balance between maintaining a sense of control over their conditions and at the same time, maintaining a sense of control over the caregiving situation can change whilst caring for the patient. The patient's condition can either deteriorate or improve. Other priorities may come into play, such as the need to resume work or to take care of other family members. Furthermore, carers may gain or lose support from others. As a result, the balance between living with their conditions and the care of the patient may become disrupted. For example, if the patient’s condition deteriorates, the caregiving burden increases, carers may lose some of the control that they have over the caregiving situation. In order to regain this control and hence, strike a balance again, carers would need to dedicate more time to care for the patient. Hence, they would need to change the way they live with their chronic conditions in such a way that they would concede some of the health behaviours in order to make more time to care for the patient. Similarly, the factors which determine how carers maintain a sense of control over their chronic conditions can also change whilst caring for the patient with cancer. For example, carers may experience a flare up of their chronic condition which can result in the carers experiencing more severe physical disabilities and a higher treatment burden. If carers are unable to control this flare up and hence, maintain the balance, and the chronic condition starts interfering with the care of the patient, they may need to concede some of the control that they have over the patient’s care in order to focus more on their chronic condition until they strike a balance again.

9.3 Conclusion

This chapter described the core category of the social process of living with a chronic condition whilst caring for the patient with cancer. It illustrated how the participants lived with their chronic conditions and at the same time, cared for the patient by making concessions. The next chapter will provide a discussion of the findings of this doctoral research in relation to the extant literature.

Chapter 10 Discussion

10.1 Introduction

Chapter Three highlighted the debate which exists about when to conduct a literature review in grounded theory research and the rationale for conducting a more detailed literature review once some categories from the data had been developed. Thornberg and Dunne (2019) argue that an initial literature review is conducted at the onset of the research process before data collection begins. As described in Chapter Three, the aim of the systematic review of reviews (see Chapter Two) was to identify a gap in the literature and inform the research question (Dunne and Üstűndağ, 2020; Thornberg and Dunne, 2019). On the other hand, a more detailed literature review is carried out during the data collection and analysis processes and is informed by the emerging categories (Thornberg and Dunne, 2019). This chapter discusses the findings of a detailed literature review in relation to the findings of this doctoral research.

The search terms that were utilised to conduct this detailed literature review included ‘theory’, ‘caregiving' and ‘chronic conditions’, as well as other search terms mirroring concepts which were emerging from the developing theory, such as ‘disruption’, ‘motivation’ and ‘control’. Including these search terms ensured that the emerging categories guided the literature search and hence, guided the theoretical sampling of the literature (Thornberg, 2012). These search terms were searched for in the electronic databases SCOPUS and PubMed.

Several theories were found from the searches. These theories were read through and compared to the emerging categories to identify which extant theories fit with the data and hence, could be considered to enhance further theory development. This was a highly interactive process in which the researcher’s coding and emerging categories guided him to the relevant literature, which in turn sent him back to his codes and emerging categories with new lenses and questions and so on and hence, increasing the researcher’s theoretical sensitivity. This illustrates another example of the constant comparative method.

It is important to explain here that although the systematic review of reviews identified several theoretical frameworks which have been employed in the explaining of the phenomenon being studied however, not all of these theoretical frameworks will be considered in this chapter. Charmaz (2014) points out that when using grounded theory, the researcher should ensure that existing theoretical concepts earn their way into the discussion and should only be included if directed by the emerging categories and not because they have been used in previous studies on the phenomenon being studied.

10.2 Experiencing Dual Biographical Disruption

Carers experience two forms of disruption. Firstly, the caregiving role disrupts the carers' daily life and the way they live with their chronic conditions. Secondly, carers view their chronic conditions as a disruption of the caregiving role. Considering the notions of disruption and change in daily life, Bury's (1982) biographical disruption model was deemed appropriate to consider in relation to the study findings to support category development.

Bury (1982) states that chronic disease is a major event which causes a disruption to an individual's daily life. He explains that biographical disruption has four characteristic features:

i. Biographical disruption leads to a break or transformation of the individual's identity. The previous identity is interrupted and replaced by a new identity which corresponds to the new situation. One feature that defines an individual's identity is actions and in fact, major disruptive events cause a disruption of taken for granted behaviours, roles, and responsibilities (Bury, 1982).

ii. Biographical disruption leads to changes in social relationships (Bury, 1982). Bury (1982) explains how individuals tend to withdraw from social interactions and experience increased social isolation.

iii. There is a need for mobilisation of resources by involving experts and other resources in order to overcome the disruption (Bury, 1982).

iv. There is a change in the availability and use of resources available to the individual (Bury, 1982). Bury (1982) explicates that even though an individual's need for various resources increases during biographical disruption, it becomes more difficult for the individual to access these resources.

Therefore, taking up the caregiving role can also be considered as a source of biographical disruption. Firstly, the caregiving role impacts taken for granted everyday activities and routines, such as exercise, sleep, and work. As a result, carers have to change their daily routine in order to incorporate the new roles and responsibilities associated with the caregiving role. Secondly, carers highlight the importance of mobilising resources, such as social support, in order to overcome the disruption. And finally, although carers may need resources, they may find it difficult to access such resources. On the other hand, the carers' chronic condition is also a source of biographical disruption because it disrupts the caregiving role which becomes an important part of the carers' daily life.

Category development was enhanced using Bury's (1982) biographical disruption model in the following ways. Firstly, in the early stages of data analysis, three separate categories were developed: 'Changing Daily Life', 'Changing Social Relationships', and 'Changing Self-Identity'. However, by engaging further with Bury's (1982) biographical disruption model, a link between these three separate categories was identified, that is they all represent a change in an individual's biography. Therefore, these categories were elevated to a more conceptual level by developing the major category 'Changing Biography'. Secondly, Bury's (1982) biographical disruption model introduced the concept of 'biographical disruption'. Therefore, considering that carers seem to experience two forms of biographical disruption which are happening at the same time and impact each other, this process was named dual biographical disruption, a concept which will be used when describing the grounded theory in Chapter Eleven.

This process of dual biographical disruption contributes to knowledge by highlighting two important points. Firstly, since the caregiving role is also considered a source of biographical disruption, this suggests that a chronic condition may not only be a source of biographical disruption, as suggested by Bury (1982), but may also be impacted by the biographical disruption caused by another major disruptive event. The biographical disruption caused by taking up the caregiving role may cause carers to experience a deterioration in their chronic conditions which may in turn disrupt their care of the patient with cancer. This first point leads to the second point, that is, since the biographical disruption from another major disruptive event can impact an individual's chronic condition, then a chronic condition can still cause a disruption in an individual's daily life even though they would have been diagnosed with it for a long time. In fact, the study findings suggest that carers who have been diagnosed with their chronic condition for a long time are at an increased risk of experiencing a deterioration in their chronic condition, which could in turn impact the care of the patient. On the other hand, Bury (1982) only makes reference to the diagnosis of a chronic condition as a source of biographical disruption and not something that continues over time.

The search for theories on the concept of 'disruption' also led to the discovery of two theories of transition (Schlossberg, 1981; Selder, 1989). These theories were considered because they specify how the person's behaviour is influenced by attributes of the social environment, such as the historical time and physical place, as well as social structures, such as institutions and family units. Therefore, considering this notion of how the social context impacts an individual's behaviour, these theories were deemed appropriate to consider since this research explored social processes (Thyer et al., 2012).

Category development was enhanced using these two theories in the following ways. Firstly, both Schlossberg (1981) and Selder (1989) describe a transition as an adaptive process which is triggered either by a critical event, or a change in the individual or his or her environment and denotes a movement from one particular phase to another. Transitions result in changes in the individual's routines, roles, and relationships. Therefore, navigating transitions requires taking care of these disrupted routines, roles, and relationships and managing them is essential for successful transition outcomes (Schlossberg, 1981). The study findings highlight how carers experience a change in their life and relationships when they take up the caregiving role. This change is brought about by the patient's cancer diagnosis, which is the critical event. Therefore, caregiving can also be conceptualised as a transition process, a concept which will be used when describing the grounded theory in Chapter Eleven.

Secondly, further reading into Selder's (1989) theory allowed for category development by prompting the researcher to question whether carers viewed their change in biography as either temporary or permanent, since Selder (1989) claims that an important task in the transition process is recognising the permanency of change as this helps to reduce uncertainty and increase engagement in the transition. Interestingly, the study findings illustrate how some carers view the change in their biography as temporary, whilst others consider it as permanent. In fact, those carers who are caring for the patient with cancer in the treatment phase tend to consider this change as temporary and such acknowledgment motivates them to continue caring for the patient so that the patient can recover from the cancer and continue with life as it was before cancer diagnosis. This contradicts Selder's (1989) claims that individuals need to acknowledge the permanency of the change in order to deal with the transition.

Finally, Schlossberg's (1981) theory of transition focuses on variability and the fact that individuals experience change in different ways and that even the same individual can experience change in different ways at different stages of his or her life. In fact, this theory focuses on the factors which influence how an individual experiences change and how he or she adapts to this change. Such factors include the characteristic features of an event or situation, the importance of the environment and the community, and the importance of personal characteristics, including competence and state of health. Therefore, Schlossberg's (1982) theory was deemed appropriate to consider since the study findings highlighted that carers experience change in their biography to different extents. In fact, reading further into this theory enhanced the researcher's theoretical sensitivity and prompted the researcher to re-analyse the empirical data to determine the presence of factors that impact the extent to which carers experience the change in their biography. The study findings suggest that the type of caregiving and hence, the characteristic features of the critical event, that is the caregiving role, influence the experiences of carers. Moreover, the findings suggest that the carers' other priorities in life and support from family and friends are also important influencers when carers take up the caregiving role and hence, this highlights the importance of the social and community context. In addition, the findings also highlight the important role that the carers' personal characteristics, such as their willingness to accept social support, have on their experience of living with a chronic condition and at the same time, caring for a patient with cancer.

In summary, Bury's (1982) biographical disruption model and the transition theories by Schlossberg (1981) and Selder (1989) help to explain further the process of transition experienced by carers and the resulting dual biographical disruption. Nevertheless, these theories mainly contribute to one particular category. As described in the previous chapters, other categories were found which are not explained in the aforementioned theories. One of these elements is the description of the factors which motivate carers to care for the patient with cancer even though they are living with a chronic condition themselves and hence, to embark on the process of transition and face the resultant dual biographical disruption. These factors will be discussed in the following section.

10.3 Feeling Motivated to Care

The study findings describe how positive and negative emotions, as well as social norms motivate carers to take up and prioritise the caregiving role. This notion of motivation prompted the search for theories related to the concept of 'motivation' which might enhance category development. This led to the discovery of the Self-Determination Theory (Deci and Ryan, 1985), which has already been applied successfully to explain the experiences of informal carers (Dombestein, Norhein and Lunde Husebo, 2020). Furthermore, this theory does not only consider how personality facilitates motivation but also considers the role of the social context. Hence, considering this inclusion of the social context, this theory was deemed appropriate since this research also dealt with social processes (Deci and Ryan, 2015).

According to Self-Determination Theory (Deci and Ryan, 1985), an individual would be motivated to perform a particular task if he or she satisfies the following needs: competence, autonomy, and relatedness. Competence refers to an individual's ability to perform the task. Autonomy refers to the individual's ability to perform a particular task on his own, as opposed to being controlled by outside forces. On the other hand, relatedness refers to the need of individuals to develop satisfying relationships with others (Deci and Ryan, 1985).

Self-Determination Theory (Deci and Ryan, 1985) enhanced category development by introducing the concepts of ‘autonomy’ and ‘relatedness’ and hence, elevated the category to a more abstract level. The study findings illustrate how carers give up on other priorities in life, such as social relationships and leisure activities, in order to make time to care for the patient with cancer. Carers make such concessions in their daily routines in order to have more control over the caregiving situation. Therefore, by taking into consideration the notions of Self-Determination Theory (Deci and Ryan, 1985), it seems that carers strive to have more control over the caregiving situation in order to satisfy their need for autonomy which further motivates them to continue caring for the patient. The carers’ desire to satisfy this need for autonomy motivates them to prioritise the care of the patient with cancer and put themselves on the backburner. In fact, the findings highlight how carers express the need for health care professionals to help them with the management of their chronic conditions throughout the whole cancer trajectory and hence, are willing to share some of their control over their chronic conditions. This suggests that carers are willing to relinquish some of their autonomy with regards to the care of their chronic conditions as this allows for more autonomy in caring for the patient with cancer. Additionally, according to Self-Determination Theory (Deci and Ryan, 1985), as carers gain more control over the caregiving situation and actively participate in the care of the patient with cancer, this also satisfies their need for relatedness and hence, motivates them further to keep caring for the patient. Therefore, by considering Self-Determination Theory (Deci and Ryan, 1985), it seems that carers value autonomy and relatedness needs as being important motivational factors for caring for the patient with cancer even though they are living with a chronic condition themselves.

Another two theories identified, related to the concept of motivation, were the Theory of Reasoned Action (Fishbein and Ajzen, 1975) and the Theory of Planned Behaviour (Ajzen, 1985). These two theories have been extensively used in the literature on caregiving and chronic illness. However, for the purpose of this research, the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) was chosen, which synthesises the major behavioural constructs from these theories and Social Cognitive Theory (Bandura, 1986). Although the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) comes from the field of psychology, it also holds a socio-ecological perspective, recognizing that even with the strongest intentions, there may be situational or environmental constraints that make behavioural performance more difficult or impossible. Considering the fact that this research explored how the caregiving role impacts carers’ behaviour with regards to their chronic conditions, then this theory was deemed appropriate to consider in relation to the study findings.

According to the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010), the most important determinant of behaviour is the intention to perform that behaviour. Without motivation the individual is unlikely to perform a particular behaviour. There are three predictor variables of behavioural intention, which are attitude, perceived norm, and perceived agency. The first, attitude, is the individual's attitude towards the behaviour and hence, whether an individual determines whether a particular behaviour is favourable or unfavourable to perform. This decision is based on emotional processes, that is the emotional response associated with a behaviour, as well as cognitive processes, that is whether the behaviour is worth doing or not (Fishbein and Ajzen, 2010). This corroborates the study findings. The emotional connection between the carer and the patient with cancer makes it necessary for the carer to take up the caregiving role and prioritise the care of the patient above their own health. In addition, the fear of ending up alone if the patient dies, and the feeling of guilt for abandoning or causing physical or emotional harm to the patient also motivate the carer to prioritise the care of the patient. These form the emotional process. On the other hand, the need to abide by reciprocity norms, that is, the need to take care of the patient in order to repay for what the patient had done for the carer, makes taking up the caregiving role worth doing and hence, forms the cognitive process. Therefore, it seems that carers' decision to take up the caregiving role is also based on both emotional and cognitive processes. Integrating the different factors into processes helped to elevate the category to a more abstract level.

Nevertheless, the study findings further elaborate on notions of the Integrated Model of Behavioural Prediction by explaining that emotions may not necessarily be a response to a particular behaviour, as suggested by Fishbein and Ajzen (2010), but could be a response to the contextual factors of the situation or event which is motivating an individual to perform a particular behaviour. Carers feel motivated to care for the patient with cancer not just because of the positive and negative responses which arise from caring or not caring for the patient, but also due to the emotional connection that they have with the patient as emphasised by love and respect.

The Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) also considers the perceived norm which is an overall perceived social pressure to perform the target behaviour. The study findings highlight that carers also seem to be influenced to care for the patient as obliged by social norms, such as marriage. Finally, the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) also identifies perceived agency as an important construct which impacts the intention to perform a particular behaviour. Fishbein and Ajzen (2010) describe how perceived agency depends first of all, on self-efficacy, which is one's confidence to perform a skill. It also depends on perceived control, which is the control over the behavioural performance. In this research, the behavioural performance was doing the bare minimum and most participants resorted to performing this behaviour because they thought they knew how to live with their chronic conditions.

The Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) also identifies knowledge about how to perform a particular skill and the degree to which various environmental factors make it easy or difficult to carry out the behaviour, as important constructs which impact the intention to perform a particular behaviour. The study findings contribute to the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) by elaborating further on the environmental constraints. In this research, the environmental constraint was the caregiving role which impacted how carers lived with their chronic conditions. A number of factors were found which can impact the degree to which various environmental factors make it easy or difficult to carry out a particular behaviour. Social factors, such as having other priorities in life, having support from family and friends, and the ability of an individual to find and accept support from family and friends, impact the degree of biographical disruption which in turn can make it more difficult for carers to carry out their health behaviours. In addition, the study findings further contribute to the Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010) by highlighting the impact of social support on the intention to perform a particular behaviour. As described in the previous sections, carers express the need for social support from health care professionals to help them perform a particular behaviour, that is, the management of their chronic conditions throughout the whole cancer trajectory.

In summary, the above section provides further insight into the processes involved which motivate carers to take up the caregiving role and to prioritise the care of the patient throughout the cancer trajectory. The next section will describe another element of the study findings, that is how carers actually live with their chronic conditions whilst caring for the patient with cancer.

10.4 Living with One’s Own Chronic Condition

The concepts of ‘exerting control’ and ‘losing control’ were evident in all the emerging categories. Therefore, this notion of control prompted the search for theories related to the concept of ‘control’ which might enhance category development. This led to the discovery of several theories of self-management. Self-management has been defined as the practice of activities that individuals initiate and perform on their own behalf in order to achieve health related outcomes (Gobeil-Lavoie *et al.*, 2019). However, such theories did not earn their way into the discussion because the way the participants lived with their chronic conditions was determined by whether their conditions interfered with the care of the patient rather than health related outcomes.

Nevertheless, an important element of self-management did find its way into the discussion, self-efficacy.

In his Social Cognitive Theory, Bandura (1986) defines self-efficacy as an individual's belief to succeed in a particular situation. Similarly, the study findings revealed that the participants did not seek medical assistance when they started experiencing exacerbations of their chronic conditions because they thought they knew what they had to do to live with their conditions. Hence, this concept was deemed appropriate to consider in relation to the study findings to support category development.

Reading further into the concept of self-efficacy enhanced theoretical sensitivity by prompting the researcher to question which factors may influence the participants' belief that they can manage their chronic condition on their own. The study findings revealed that those participants who had been living with their conditions for a long time tended to try and control their conditions on their own. This collaborates the Bandura's claims that self-efficacy is mainly influenced by mastery. Younger (1991) in her theory of mastery describes how individuals who have mastered their chronic conditions tend to try and control their conditions themselves because they would have achieved a sense of perceived control over their conditions, and would have gained the knowledge on how to manage exacerbations of the signs and symptoms of their conditions if these happened again in the future. Similarly, in this research, participants who have been diagnosed with a chronic condition for a long time, often tried to control their condition themselves by doing the bare minimum, when they started experiencing health problems. Therefore, the concept of mastery will be used when describing the grounded theory in Chapter Eleven.

Nevertheless, the study findings further elaborate on the notions of Younger's (1991) theory of mastery by suggesting that although the participants might have achieved actual mastery in living with their chronic conditions over time, they might have done so in situations which were different from the one presented by cancer diagnosis and the caregiving role. Therefore, this highlights the importance of considering the contextual factors embedded in the process of mastery which seem to be overlooked in Younger's (1991) theory of mastery. For example, in her theory, Younger (1991) argues that mastery is characterised by stronger social relationships with others. However, this research demonstrated that accessibility and use of social support depends on contextual factors, such as the ability and willingness of an individual to find support and to accept this support. One term which can be used to define the importance of considering contextual factors in the process of mastery is contextual mastery. This explains that an individual has achieved mastery of a particular skill, such as living with their chronic condition, in different situations. Secondly, Younger's (1991) theory of mastery does not take into consideration the future consequences of mastery but rather values the present situation. In fact, the study findings demonstrate how carers often change their time orientation towards the present and do not think about the future consequences of not managing their chronic conditions but only consider how their conditions could impact the care of the patient with cancer in the here and now. Therefore, perceived mastery will more often than not focus on the present situation rather than on future consequences.

10.5 The Cancer Caregiving Experience Model

Fletcher *et al.*'s (2012) conceptual model of the caregiving experience of cancer patients, referred to as The Cancer Caregiving Experience Model, was deemed appropriate to consider. This model is not based on primary research, but takes into account empirical literature on the cancer caregiving experience published between 2000 and 2010. This model was developed with the intention to complement the major theoretical models of stress and coping (Antonovsky, 1987; Lazarus and Folkman, 1984; Pearlin *et al.*, 1990).

Fletcher *et al.* (2012) propose a stress process model that has three main elements: the stress process, contextual factors, and the cancer trajectory. The stress process consists of five broad constructs: primary stressors, secondary stressors, appraisal, cognitive-behavioural responses, and health and well-being outcomes. Primary stressors are patient-related factors, and the resulting caregiving demands which initiate the stress process. Patient-related factors include cancer site and stage, prognosis, functional ability of the patient, as well as treatment-related symptoms. Caregiving demands are the activities carers undertake in response to the illness including assisting the patient with ADLs, managing cancer symptoms and treatment side effects, handling patient behaviours and emotions, coordinating or administering treatments in the home, and driving the patient to treatment and hospital appointments. Secondary stressors are stressors which arise due to the caregiving role, such as role changes and changes in family structure and dynamics, financial stress, employment changes, and disruption of daily routine. Cognitive appraisal is how an individual evaluates the stressor and the meaning that he or she gives to the stressor. Therefore, this is referring to whether the carer considers the stressor as a burden on them or as an ordinary expectation, and whether they are confident to deal with the stressor or not. On the other hand, cognitive and behavioural responses are the thought processes and actions that take place in response to appraisal of the cancer situation. Therefore, the individual will consider whether the stressor exceeds or not the resources at hand and what they can do to cope with the stressor. Finally, the appraisal and cognitive and behavioural responses impact the carer's well-being in terms of overall quality of life, mental health, physical health, mastery, as well as increased levels of satisfaction and personal growth. On the other hand, contextual factors, such as the carer's personality, gender and age, affect the carer's experience throughout the cancer trajectory. Furthermore, the model postulates that the stress process is occurring at any time throughout the cancer trajectory and that it is likely to be experienced differently in different phases of the cancer trajectory (Fletcher *et al.*, 2012).

The study findings resonate strongly with certain elements of Fletcher *et al.*'s (2012) Cancer Caregiving Experience Model, in that patient-related factors, caregiving demands, as well as disruption of daily routine were identified as important elements which impact carers' well-being. However, Fletcher *et al.*'s (2012) model only focuses on a single outcome, that is the impact of the caregiving role on the carers' well-being. As a result, if health care professionals apply this model to the experiences of carers, then their focus will only fall on how they can assist carers with the caregiving role in order to prevent it from impacting their well-being. However, carers often seek to gain autonomy in caring for the patient with cancer and hence, may not readily accept the assistance of health care professionals in caring for the patient. On the other hand, the study findings illustrate that health care professionals should also focus on the other process of biographical disruption experienced by carers, that is the impact of their well-being on the caregiving role, a process which is not considered in Fletcher *et al.*'s (2012) model. In fact, the Cancer Caregiving Experience Model (Fletcher *et al.*, 2012) does not explain the consequences of a change in the carer's well-being due to the caregiving role and how such a change can impact both primary and secondary stressors and hence, have a direct impact on the same stress process, that is the caregiving role. The study findings suggest that carers are willing to relinquish some of their autonomy with regards to the care of their chronic condition as this allows for more autonomy in caring for the patient with cancer and hence, are more willing to accept the support from health care professionals with activities concerning their self-care. Therefore, rather than helping carers with the activities of caregiving, the study findings suggests that health care professionals should focus on helping carers with activities concerning their self-care. Furthermore, this model argues that the cancer trajectory has an important contribution to the stress process. This prompted the researcher to re-analyse the empirical data to determine whether the cancer trajectory plays an important role in the process of how carers live with their chronic conditions. Interestingly, the study findings revealed that this process does not depend on the phases of the cancer trajectory but rather on other contextual factors already described above. Table 18 provides a summary of the extant theories described in this chapter and how they contributed to the developing theory and its categories.

Table 18: Summary of the extant theories considered during data analysis.

Theory	**Contribution to Developing Categories**
Bury's (1982) Biographical Disruption	• Elevated the theory to a more conceptual level by aiding the development of the major category 'Changing Biography'. • Introduced the concept of 'biographical disruption' and hence, aided the development of the process of dual biographical disruption.
Schlossberg's (1981) Theory of Transition	• Introduced the concept of 'transition'. • Prompted the researcher to re-analyse the empirical data to determine the presence of factors that impact the extent to which carers experience the change in their biography.
Selder's (1989) Theory of Transition	• Introduced the concept of 'transition'. • Prompted the researcher to question whether carers viewed their change in biography as either temporary or permanent.
Self-Determination Theory (Deci and Ryan, 1985)	• Introduced the concepts of 'autonomy' and 'relatedness' and hence, aided the researcher to elevate the developing category to a more conceptual level.
Integrated Model of Behavioural Prediction (Fishbein and Ajzen, 2010)	• Prompted the researcher to merge the factors which influence carers to care for the patient with cancer into emotional and cognitive processes and hence, elevate the developing category to a more conceptual level.
Bandura's self-efficacy (1986) and Younger's theory of mastery (1991)	• Aided the researcher to elevate the developing category to a more conceptual level by introducing the concept of mastery.
Fletcher *et al.*'s (2012) Cancer Caregiving Experience Model	• Prompted the researcher to question whether the cancer trajectory impacts how carer live with their chronic conditions.

10.6 Considering Other Theoretical Models

Other theoretical models were considered when reviewing the literature however, it was decided not to include them in this discussion. Ambrosio *et al.* (2015) describe living with a chronic condition as a complex multidimensional process with the final desired target being to achieve ‘positive living’. This process incorporates five attributes: acceptance, coping, self-management, integration, and adjustment. The individual has to develop these five attributes in order to be able to live positively with their chronic condition (Ambrosio *et al.*, 2015). Similarly, Kralik (2002) uses the term ‘ordinariness’ to describe how individuals aim to incorporate their chronic condition into their daily life, whilst Kralik *et al.* (2004) argue that only after accepting one’s chronic condition can an individual move on to living positively with their condition. However, these models were not deemed appropriate because, in this research, the main aim of the carers was not to achieve positive living or ordinariness, but to minimise interference with the patient’s care.

Several theoretical models on stress were also considered but not deemed appropriate to include in this discussion, including Lazarus and Folkman’s Transactional Stress Theory adapted to caregiving (Haley *et al.*, 1987), Stress Process Model (Pearlin *et al.*, 1990), and Theory of Coherence (Antonovsky, 1987). These models do collaborate the findings of this research, in that caregiving is a stressful situation. Nevertheless, the outcome of interest in these models is carers’ well-being and quality of life. On the other hand, in this research, the main outcome of interest for the carers was preventing their chronic condition from interfering with the patient’s care.

The Meaning Making Model, recently developed by Park (2010), was also considered but not included in this discussion. This model posits that individuals attempt to provide a meaning to their chronic condition by integrating their own understanding of the condition together with their global meaning to reduce the discrepancy between them (Park, 2010). However, this model was not deemed appropriate because this research investigated social processes rather than meaning making processes.

In his Theory of Chronic Disease and the Life Cycle, Rolland (1987) explains that there are three time phases of a chronic condition: the crisis phase, the chronic phase and the terminal phase. If one considers cancer as a chronic condition and compares these time phases to the cancer trajectory, then the crises phase represents the diagnosis phase and start of treatment, the chronic phase represents the rest of treatment and survivorship phase, whilst the terminal phase represents the end-of-life phase. Rolland (1987) states that in each phase there are certain factors independent of the chronic condition which will impact how the family adapts to the situation whilst caring for the patient. However, the findings of this research contradict Rolland’s (1987) claims since the carers' experiences do not depend on the phase of the cancer trajectory in which they are caring for the patient but rather on other contextual factors, including the type of cancer and the type of caregiving. Moreover, Roland's (1987) description of the centripetal pull on the family across the chronic condition trajectory suggests that carers should easily access support, especially during the crises and terminal phases, due to the increased availability of support from other family members. However, this research highlighted that carers may actually be unwilling to find and accept support. Furthermore, family members and friends may be reluctant to assist carers either because they cannot handle the emotions associated with cancer or because of the stigma involved.

It appropriate to state that both Ambrosio *et al.* (2015) and Kralik (2002) use the terms 'disruption' and 'extraordinariness' respectively to describe when an individual with a chronic condition is exposed to a stressful situation or crisis. However, both Ambrosio *et al.* (2015) and Kralik (2002) fail to describe how individuals live with their chronic conditions whilst going through such situations or crises. On the other hand, this research explored how carers live with their chronic conditions whilst going through a stressful situation, that is caregiving.

10.7 Conclusion

In summary, this chapter discussed the study findings in relation to extant theories to illustrate how these theories aided category development. The next chapter will describe the overall grounded theory which was developed from the categories described in Chapters Six to Nine.

Chapter 11 The Grounded Theory

11.1 Introducing the Theory of Biographical Compromise

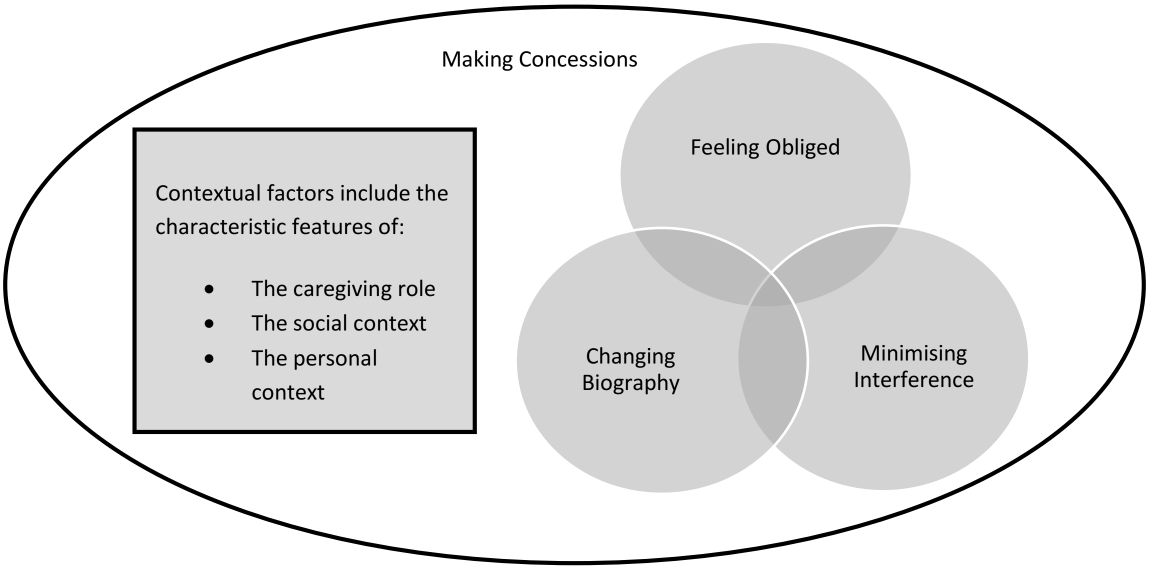
Upon cancer diagnosis, carers feel obliged to take up the caregiving role. They have little to no choice in assuming caregiving responsibilities for the patient with cancer and putting themselves on the backburner. This obligation to take care of the patient stems from both emotional and cognitive processes. These processes are present throughout the whole cancer trajectory. The emotional processes which make it necessary for carers to take up the caregiving role include the emotional connection between the carer and the patient as emphasised by love and respect, the fear of ending up alone if the patient dies, the feeling of guilt for abandoning the patient and the possibility of causing physical harm and emotional distress to the patient. On the other hand, cognitive processes include the need to obey social, reciprocity, and gender norms.

When carers take up the caregiving role, they immerse themselves in a process of transition, a transition from life before cancer diagnosis into a new life routine marked with all the uncertainties which accompany cancer and its treatments. This transition causes carers to experience a process of dual biographical disruption. The grounded theory suggests that this process of dual disruption actually encompasses two distinct processes which are happening at the same time, and which impact each other. The first process of biographical disruption is caused by the caregiving role which disrupts the carers' daily life and the way they live with their chronic conditions. Carers start making concessions in their daily life in order to incorporate the new roles and responsibilities associated with the caregiving role and to gain a greater sense of control over the caregiving situation. This leads to carers becoming extremely busy and their lives more restricted. Furthermore, due to the time-intensive nature of caregiving, carers give up on other priorities in life, such as social relationships. Additionally, carers also change how they live with their chronic conditions. Gaining a greater sense of control over the caregiving situation helps to satisfy their need for autonomy and relatedness and hence, further motivates them to continue caring for the patient and prioritise his or her care above their own. On the other hand, the second process of disruption is caused by the carers' chronic conditions. Carers consider their chronic conditions as an interference which disrupts the care of the patient. The physical limitations imposed by the chronic conditions, as well as the time constraints imposed by health behaviours, such as physical exercise and medical visits, disrupt the carers' ability to care for the patient.

This grounded theory illustrates that, although these two processes of disruption are distinct, it is important to consider the interplay between them. As previously described, carers incorporate the new roles and responsibilities associated with the caregiving role by giving up on other priorities in life. They start making concessions in their daily routines in order to make time to care for the patient and hence, have more control over the caregiving situation. As carers make concessions in their lives in order to gain a greater sense of control over the caregiving situation, they start losing some control over their chronic conditions. This loss of control over their chronic conditions can be seen by the fact that, whilst caring for the patient, carers find it more difficult to maintain healthy behaviours, such as exercise and healthy eating. This may lead to carers experiencing complications with their chronic conditions which can be severe, and which may in turn prevent them from caring for the patient. Therefore, the first process of disruption caused by taking up the caregiving role may impact the carers' chronic conditions. This may in turn lead to a deterioration of the carers' chronic conditions, which in turn may cause the second process of disruption, that is it disrupts the carers' ability to care for the patient. Therefore, the grounded theory highlights the importance of looking at the interplay between these two processes of disruption rather than one process affecting the other when describing the experiences of carers. As a result of this interplay between these two processes of disruption, it can be said that carers actually experience a single process of dual biographical disruption.

Due to the interplay between these two processes of biographical disruption, carers do acknowledge the importance of striking a balance between maintaining a sense of control over their chronic conditions and at the same time, maintaining a sense of control over the caregiving situation. They cannot choose to abandon the caregiving role. At the same time, they cannot allow their chronic conditions to deteriorate to a point that they cannot care for the patient because this would mean that they would still end up abandoning the caregiving role. Hence, they have to maintain some sense of control over their chronic conditions in order to continue caring for the patient. At the same time, they are aware that they cannot do certain health behaviours and activities that they used to do before cancer diagnosis because these will interfere with the care of the patient due to time constraints. Hence, they try to strike a balance between maintaining a sense of control over their chronic conditions and at the same time, maintaining a sense of control over the caregiving situation. They do so by doing the bare minimum in relation to their chronic condition. Doing the bare minimum involves engaging in activities which allow the carers to maintain some sense of control over their chronic conditions but at the same time, these activities will take the least possible amount of time from their day and hence, they would have more time to care for the patient and carry out other important duties and responsibilities in their lives. On the other hand, if the carers' chronic conditions deteriorate to a point that they are unable to care for the patient, carers will surrender some of their control over the caregiving situation in order to prioritise their well-being. Therefore, the major principle which drives the interplay between the dual biographical disruption is 'compromise' and hence, it was decided to call the process of dual biographical disruption experienced by carers who are faced with the prospect of living with a chronic condition and at the same time, caring for a patient with cancer, biographical compromise. Therefore, taking this into consideration, the theory which emerged from the data of this research was named the theory of biographical compromise. The extent of biographical compromise which carers experience is different for different carers and the same carer may experience different levels of biographical compromise throughout the cancer trajectory. This is because the extent of biographical compromise does not depend on the cancer trajectory but depends on three sets of contextual factors: (i) the characteristic features of the caregiving role; (ii) the characteristic features of the social context, including having other priorities and having support from family and friends; and (iii) the characteristic features of the personal context, including one's willingness to find and accept support from others and one's own chronic condition. The characteristic features of one's own chronic condition include (i) the type of chronic condition; (ii) its temporal course and the carers' mastery in controlling their chronic condition; and (iii) its treatment burden. Figure 7 illustrates the theory of biographical compromise, including the overlap between the categories and the contextual factors.

Figure 7: The theory of biographical compromise.



In light of the aforementioned process of biographical compromise, it is therefore important for health care professionals to keep in mind that carers who are faced with the prospect of living with their chronic conditions and at the same time, care for a patient with cancer, will often resort to making compromises to strike a balance between the two situations. These compromises may lead carers to experience a significant decrease in their well-being. This leads to a serious concern regarding the impact of the caregiving role on carers' chronic conditions with increased complications and accelerated progression as carers abandon health behaviours and delay follow-up care. This can have several consequences. Firstly, carers may be unable to continue caring for the patient which may require the patient to be admitted to hospital and hence, stretching already limited in-hospital services. Secondly, carers may require emergency hospital admissions and use of health care services themselves. Therefore, it is important for health care professionals to identify those carers who may be facing such a prospect in order to provide the necessary support and guidance so that carers can continue caring for patients and hence, continue saving the health care system extraordinary amounts of money and decrease financial burden on governments. The next sections will discuss the implications that the theory of biographical compromise can have on policy, practice, education, and research, as well as its contribution to knowledge.

11.2 Contribution to Knowledge

This research contributes to existing knowledge in a number of ways. Firstly, it identifies how carers live with their chronic conditions whilst caring for the patient with cancer. This is significant because it merges the two processes of living with a chronic condition and caring for a patient with cancer into one process, that of biographical compromise. The empirical literature and extant theoretical frameworks tend to explain these processes separately and not how these experiences are intertwined. Secondly, the theory of biographical compromise highlights which contextual factors impact how carers live with their chronic conditions whilst caring for the patient. Hence, it provides important information which can be utilised to develop carer assessment tools to identify those carers who are struggling more and provide the necessary support as early as possible. In fact, this grounded theory illustrates that the extent of biographical compromise does not depend on the phase of the cancer trajectory that the patient and carer are in, but on these contextual factors. Thirdly, the findings illustrate how all the carers in this study would prefer health care professionals to assist them directly in the management of their chronic conditions and hence, this emphasises the importance of integrating the care of the carer as part of the overall care plan of the patient with cancer. Finally, this research also contributes to knowledge with regards to the methodological aspect by suggesting the use of the intertwining translation process in constructivist grounded theory.

11.3 Implications for Policy and Practice

A recent White paper by the European Cancer Patients Coalition and Eurocarers (2019), highlighted the importance of initiating carer identification programmes, making carers aware of the available support programmes, and assisting them to seek such support programmes. However, in order to be able to directly assist carers in seeking support, health care professionals require tools and indicators which can help them identify those carers who require support and the type of support that they require. This way health care professionals can signpost them to the necessary information, advice, and support as early as possible. The contextual factors identified in the grounded theory of this research can help in the development of such tools which can facilitate health care professionals' work by guiding them on what to ask carers. Such tools can guide health care professionals to ask more focused questions rather than just the usual broad question of 'how is caring for the patient affecting you?'. This is important since carers may find it difficult to express how the care of the patient is impacting them, especially if such questions are asked in front of the patient. Therefore, this grounded theory guides health care professionals to ask more focused questions, such as questions related to their other priorities in life, their support systems and their chronic conditions. By flagging those carers who are struggling more and provide the necessary support, then there is the possibility that these carers can continue to care for the patient with cancer and thus, avoiding a crisis and even emergency hospital admissions for both the patient and the carers themselves. Therefore, health care professionals, such as nurse navigators, nurse coaches, and clinical nurse specialists, who are actively involved in the coordination of the patient's care, need to also be actively involved in the coordination of the carers' health care needs and the signposting of carers to health services in order to follow them closely throughout the cancer trajectory, at a time when they are mostly at risk of experiencing a deterioration of their chronic conditions. It is appropriate to state that the development of such tools has already been suggested elsewhere (Marín-Maicas *et al.*, 2014). Marín-Maicas *et al.* (2014) argue that such tools should be developed based on five important attributes that comprise living with a chronic condition from the carers' perspective: (i) accepting the caregiving role; (ii) coping with caregiving burden; (iii) self-managing one's own health; (iv) integrating the caregiving role into one's daily life; and (v) adjusting to a 'new normal'. Therefore, the findings of this scoping review and the present research can be used to develop these carer assessment tools.

The integration of such tools as a means of assessment of the carers' needs and experiences can be facilitated by developing a system of carer assessment and include it as one of the government proposals for health and social integration recently published by the Department of Health and

Social Care (2022). Unfortunately, this recent document only focuses on the importance of facilitating the contribution of carers to the patient’s care plan, assisting carers to maintain the patient’s independence and quality of life, and maintaining clear lines of communication with carers and keeping them involved in the patient’s care plan. It fails to highlight the importance of assisting carers to care for themselves in order for them to be able to continue caring for the patient with cancer. In addition, the theory of biographical compromise illustrates how although carers may be aware of the support available to them, they may be reluctant or find it difficult to access such support as they put all their effort in the care of the patient. Hence, it is not just a question of identifying carers and providing information on the support available to them, but rather carers seem to expect health care professionals to assist them directly in seeking such support, especially with regards to the management of their chronic conditions. Taking into consideration these notions, the following strategies are proposed.

In order to integrate health and social services in a continuum of care, a case manager is assigned responsibility for the co-ordination of care of the patient with cancer and their carer. This case manager can be a nurse navigator, since nurse navigators already have the required skills and expertise to coordinate care and support individuals to overcome healthcare system barriers (Oncology Nursing Society, 2017). This case manager would be responsible for assessing the patient’s and carer’s needs, developing a tailored care plan for both the patient and carer, organising and adjusting care processes accordingly, and monitoring quality of care. Hence, with regards to the carer, the case manager would (i) identify the family member or friend responsible for the care of the patient, (ii) perform an assessment of the carer’s needs, for example whether the carer is at risk of experiencing a deterioration in their health, especially if they have a chronic condition; and (iii) develop a care plan for the carer. In the UK, there is the Macmillan Cancer Support Personalised Care and Support Plan which enables personalised care by allowing patients with cancer to take an active and empowered role in the way their care is planned and delivered, with interventions and care tailored around the things that matter most to them. One component of this Personalised Care and Support Plan is the assessment of the patient’s holistic needs which can allow the case manager to develop a care plan (Macmillan Cancer Support, 2022). Similarly, a tool for assessing the carer’s needs can be integrated as part of the Personalised Care and Support Plan which can allow the case manager to assess the carer’s needs. Once the carer’s needs are identified, the case manager would develop a tailored care plan according to those needs and signpost them to the relevant services. This may include communicating with and referring the carer to his or her chronic health team who can assist the carer to better manage their chronic condition during this particular phase of their life and provide the necessary guidance with regards to medications, diet, and exercise amongst others. The case manager can also refer the carer to other services who can assist the carer with the care of the patient, including social workers and occupational therapists. The case manager would then ensure that the carer is being followed up with regards to his or her chronic conditions and conduct regular assessments to ensure that the well-being of the carer is maintained. Therefore, the case manager would be assisting carers to seek support with managing their chronic conditions. This is important since the theory of biographical compromise revealed that carers express the need for health care professionals to help them with the management of their chronic diseases.

In Malta and other European countries, the integrated care system has not yet been implemented and hence, care still depends on a hospital-based system. Therefore, the second strategy being proposed involves health care professionals, such as clinical nurse specialists and general practitioners, who form part of the chronic health team, to consider the characteristic features of the patients' social and personal contexts when drawing up care plans for patients with chronic conditions. It is advisable that the chronic health team specifically asks the patient with the chronic condition whether they have caring responsibilities. This grounded theory highlights how carers often live with their chronic conditions differently before and after cancer diagnosis and taking up the caregiving role. This means that the care plan of a patient who does not have any particular priorities in life will most probably be different from the care plan of a patient who has several priorities, such as work and taking care of young children or a sick person. Health care professionals tend to expect patients to follow their care plans without consideration of the patient's other priorities in life. Therefore, this finding has important implications for Chronic Disease Models, such as Wagner, Austin and Von Korff's (1996) Chronic Care Model which is a widely-used framework for organising and providing care for patients with chronic conditions. The Chronic Care Model identifies six fundamental elements that form a system that encourages high-quality chronic condition management: (i) Health system or a health organization; (ii) Clinical information systems; (iii) Decision support; (iv) Delivery system design; (v) Self-management support; and (vi) Community, including organizations and resources for patients (Wagner, Austin and Von Korff, 1996). Therefore, whilst the element 'self-management support' emphasises the patient's role in managing their chronic conditions and the need for health care professionals to support patients in becoming effective managers of their own health, it is important for health care professionals to be sensitive to the patient's social context and ask questions about the barriers to self-managing their chronic conditions.

Implementing these two strategies could also have important implications for the Comprehensive Model for Personalised Care, which is presently being implemented in the UK. This model focuses on achieving better health outcomes by providing specific personalised care to individuals. The Comprehensive Model of Personalised Care is a three-tier pyramid. The bottom level represents population-wide interventions which target to keep the population as healthy as possible. Such universal interventions include social prescribing and community-based support. The second tier targets people with long-term physical and mental health problems with the aim of helping these people to build knowledge, skills, and confidence to better manage their chronic conditions. Targeted interventions in addition to the universal interventions are used. These include health coaching, self-management education, and access to peer support. The upper tier targets people with complex needs who often have multiple comorbidities. These people require intensive specialist interventions to help them manage their chronic diseases to reduce unplanned service use. These interventions include the targeted and universal interventions, as well as the use of a multidisciplinary team. Therefore, it is possible that those carers living with a chronic condition and at the same time, caring for someone with cancer, may need to be targeted using the upper tier of the pyramid rather than the second tier. It is possible that targeted interventions, such as self-management education and access to peer support, may not be enough to prevent a deterioration in their chronic conditions. They may actually require intensive specialist interventions throughout the cancer trajectory, especially since carers express the need for health care professionals to help them with the management of their chronic conditions.

11.4 Implications for Education

This grounded theory highlights how positive and negative emotions, as well as social norms influence carers to prioritise the care of the patient above their own health, which can lead to serious consequences for the carer’s health. This emphasises the importance of setting up robust cancer care programmes which involve training and psychological support amongst others for carers of patients with cancer. Such programmes should not only focus on increasing carers’ awareness of taking care of themselves, since carers are already aware of this, and of the importance of seeking medical assistance early to avoid complications. Instead, such programmes should focus on providing guidance to carers on how to reach a compromise when faced with social issues of living with their chronic conditions and at the same time, caring for the patient with cancer. How this can be achieved, and which interventions should be adopted is not a question that can be answered from the findings of this research and further work should be undertaken in this area. Nevertheless, by following the Comprehensive Model of Personalised Care, members of the chronic health team or nurse coaches are ideally placed to provide training and education on how to self-manage one’s condition, as well as how to reach for support during these difficult times. It is important to keep in mind that, when designing such cancer care programmes, a ‘one size fits all’ approach does not apply and that such programmes need to consider the holistic care of the patient.

Education on how to assist carers to reach such a compromise should also be provided to all health care professionals as part of their post-registration education. Although the chronic health care team may be responsible for assisting carers to live with their chronic conditions whilst caring for the patient, other health care professionals in the cancer team, such as occupational therapists, are also well-placed to support these carers. These health care professionals often work closely with carers when drawing up a care plan for the patient (Micklewright and Farquhar, 2022). Education sessions should aim at increasing health care professionals' awareness of the fact that carers' needs do not depend on the phases of the cancer trajectory but rather on other contextual factors, which include (i) the characteristic features of the caregiving role itself; (ii) the characteristic features of the social context, including having other priorities and having support from family and friends; and (iii) the characteristic features of the personal context, including one's willingness to find and accept support from others and one's own chronic conditions.

11.5 Implications for Future Research

A number of interesting questions arise from this research. A similar study should be undertaken on how carers of patients with other illnesses, such as dementia, live with their chronic conditions whilst caring for the patient and examine whether the same theoretical elements are present. It would also be interesting to undertake a similar study looking at how individuals live with their chronic conditions in other situations which cause biographical disruption, such as being in an abusive relationship, pregnancy, child rearing, or starting a new employment, and examine whether the same theoretical elements apply or not. Such different research could contribute to the development of a formal theory on the process of biographical compromise.

This research was conducted only in Malta and hence, due to cultural differences between Malta and other countries, it is possible that the findings of this research may not apply to other countries. Pharr *et al.* (2014) found that cultural values and norms do shape the caregiving experience and that caregiving experiences differ significantly among ethnic groups. Therefore, it would be interesting to undertake similar research in other countries with different health care systems and cultures to explore how cultural differences impact how carers live with their chronic conditions whilst caring for the patient with cancer in order to determine whether the same theoretical elements are present or not.

Furthermore, future research should focus on developing and testing different interventions which can help carers to reach a compromise between living with their chronic conditions and at the same time, caring for the patient. Such interventions may involve the use of technology to facilitate the management of chronic conditions. Such technologies may be shared with health care professionals who can monitor the carer's health condition throughout the cancer care trajectory.

Finally, in the post-doctoral phase, the researcher plans to develop a newer version of an already existing tool, the Carer Support Needs Assessment Tool (Ewing *et al.*, 2013), based on the findings of this research, with the aim of conducting a study on nurses' experiences of carer support in the oncology setting when using such tools.

11.6 Strengths and Limitations

To assess the value of this doctoral research, Charmaz's (2014) criteria for evaluating grounded theory research were used. These criteria include credibility, originality, resonance, and usefulness (Charmaz, 2014). According to Charmaz (2014), credibility is concerned with whether the results are plausible in terms of breadth and depth of data gathered, the analysis, and the evidence presented for the claims made. Credibility was maintained by collecting data from a variety of carers using in-depth interviews. Furthermore, the constant comparative method was used when analysing the data. Moreover, excerpts from the interview transcripts were used to illustrate the findings of the study and these findings were discussed in relation to extant literature. On the other hand, this research demonstrates originality by the contributions it makes to existing knowledge, as already discussed in this chapter. Resonance is demonstrated by how the categories were elevated to a more conceptual level by developing the theory of biographical compromise. Whilst the usefulness of this research is reflected in the implications set out in this chapter. Appendix D further discusses how this constructivist grounded theory research was evaluated using Charmaz's (2014) criteria.

Although the aims of this research have been met, limitations are acknowledged. This was a small study which focused exclusively on carers of patients with cancer. A larger study that would have incorporated carers of patients with other conditions and functional limitations would add to the body of knowledge on this topic. Nevertheless, whilst acknowledging this limitation, at the same time this research provides some information in an under researched area. Furthermore, whilst every effort was made to recruit a diverse group of carers, only one carer with a mental health problem and one carer with cancer were recruited. Therefore, future research should focus on recruiting such types of carers. Moreover, although the researcher's substantial experience in cancer care may be considered a strength because it could improve interpretation nevertheless, this could also be a risk and affect the trustworthiness of data. Hence, the researcher kept a reflexive diary before, during, and after this research to identify his own preconceptions and beliefs. Additionally, independent mini audits of the data analysis were performed by the research supervisors in an effort to ensure that the researcher's preconceptions did not influence data analysis. In addition, there was the possibility of social desirability bias in the participants' responses. The participants might not have been completely honest in their responses, especially if they feared that their answer would put them in a negative light. Although it is not possible to exclude social desirability bias completely, steps were taken to minimise it, including maintaining a non-judgemental approach, offering confidentiality to the participants, as well as reassuring the participants that there were no right or wrong responses to the interview questions. Also, there is a possibility that participants were not able to recall all specific details of their experiences.

11.7 Conclusion

In conclusion, this grounded theory helps us understand how the complexities and sometimes contradictions of cancer caregiving interact to explain how carers live with their chronic conditions whilst caring for the patient with cancer. By focusing on the contextual factors identified in this theory, health care professionals can identify carers who are most at risk of experiencing a deterioration in their chronic conditions and provide the necessary support as early as possible.

Chapter 12 Conclusion

12.1 Why is this research needed?

Considering the fact that the global cancer burden is on the rise and that the majority of the world's population has a health problem, then it is likely that the number of carers caring for a patient with cancer and at the same time, having a chronic condition is also increasing. These carers are at a higher risk of experiencing physical and emotional problems which can have several implications. Firstly, these carers may experience a deterioration in their health and hence, the need to be admitted to hospital and use health care services. Furthermore, they may find it difficult to continue providing high quality patient care. These implications may significantly impact both the patient's and carer's quality of life and increase the financial toll on health care systems worldwide. In addition, there is a paucity of information in the area of how the problems and burdens associated with the cancer caregiving role affect aspects of the carer's life which are not related to patient care, in particular how they live with their chronic conditions.

12.2 Contribution to Knowledge

For the first time, the theory of biographical compromise demonstrates that carers try to reach a compromise between living with their chronic conditions and at the same time, caring for the patient with cancer. Carers tend to resort to doing the bare minimum in relation to their conditions in order to minimise interference with the patient's care. This leads to a serious concern about the impact of the caregiving role on carers' chronic conditions with increased complications and accelerated progression as carers abandon health behaviours and delay follow-up care. This can have several consequences. Firstly, carers may be unable to continue caring for the patient which may require the patient to be admitted to hospital and hence, stretching already limited in-hospital services. Secondly, carers may require emergency hospital admissions and use of health care services themselves.

The theory of biographical compromise also illustrates that the extent of biographical compromise does not depend on a particular phase of the cancer trajectory, but rather on three sets of contextual factors: (i) the characteristic features of the caregiving role itself; (ii) the characteristic features of the social context, including having other priorities and having support from family and friends; and (iii) the characteristic features of the personal context, including one's willingness to find and accept support from others and one's own chronic condition.

12.3 Implications

The findings of this research have several implications. Firstly, assessment tools for assessing carers' needs should be developed based on the findings of this research in order to draw up a personalised care plan for the carer. Secondly, robust cancer care programmes should be set up focusing on providing guidance to carers on how to reach a compromise when faced with social issues of living with a chronic condition and at the same time, caring for someone with cancer. Thirdly, health care professionals should be educated on how to provide personalised care to carers and assist them to manage their chronic condition and at the same time, care for the patient with cancer. Finally, further research should be conducted on carers of patients with other illnesses, such as dementia, as well as individuals experiencing other situations which cause biographical disruption, such as being pregnant, in order to contribute to the development of a formal theory on the process of biographical compromise. Future research should also consider how cultural differences impact how carers live with their chronic conditions whilst caring for the patient with cancer.

Appendix A Search Strategy for Embase (Ovid)

#1 exp caregiver/
#2 exp family/
#3 carer*.ti,ab
#4 caregiv*.ti,ab
#5 "care giv*".ti,ab
#6 spous*.ti,ab
#7 "support person*".ti,ab
#8 friend*.ti,ab
#9 unpaid.ti,ab
#10 informal.ti,ab
#11 supporter*.ti,ab
#12 relative*.ti,ab
#13 famil*.ti,ab
#14 partner*.ti,ab
#15 “significant other*”.ti,ab
#16 couple*.ti,ab
#17 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
#18 exp neoplasm/
#19 cancer.ti,ab
#20 neoplas*.ti,ab
#21 tumo?r.ti,ab
#22 malignan*.ti,ab
#23 carcinoma.ti,ab
#24 18 or 19 or 20 or 21 or 22 or 23
#25 exp quality of life/
#26 exp psychology/
#27 exp depression/
#28 exp anxiety/
#29 exp self care/
#30 exp adaptive behavior/
#31 exp health status/
#32 exp psychosocial care/
#33 exp satisfaction/
#34 exp mental stress/
#35 quality-of-life.ti,ab
#36 QOL.ti,ab
#37 QL.ti,ab
#38 HRQOL.ti,ab
#39 HRQL.ti,ab
#40 "self efficacy".ti,ab
#41 self-efficacy.ti,ab

#42 psycho*.ti,ab

#43 "physical outcome".ti,ab

#44 spiritual*.ti,ab

#45 emotion*.ti,ab

#46 social.ti,ab

#47 depress*.ti,ab

#48 self-care.ti,ab

#49 "self management".ti,ab

#50 self-management.ti,ab

#51 distress*.ti,ab

#52 "health service use".ti,ab

#53 "mental outcome".ti,ab

#54 coping.ti,ab

#55 experience.ti,ab

#56 "informational needs".ti,ab

#57 "unmet needs".ti,ab

#58 well-being.ti,ab

#59 wellbeing.ti,ab

#60 "well being".ti,ab

#61 "supportive care".ti,ab

#62 communication.ti,ab

#63 perception*.ti,ab

#64 cognition*.ti,ab

#65 "illness representations".ti,ab

#66 "subjective health status".ti,ab

#67 stress*.ti,ab

#68 self-report.ti,ab

#69 "self report".ti,ab

#70 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69

#71 "meta analysis".ti,ab

#72 meta-analysis.ti,ab

#73 review.ti,ab

#74 systematic.ti,ab

#75 search*.ti,ab.

#76 71 or 72 or 73 or 74 or 75

#77 17 and 24 and 70 and 76

Appendix B Guide for Approaching Potential Participants

You are encouraged to invite all carers of patients with cancer. However, it is important to remember that you may be approaching carers at a very difficult time. This requires communication skills, empathy and understanding.

Importance of this Study

It is important that potential participants understand the importance of this study.

Little research has been done in relation to how carers live with their chronic conditions whilst caring for the person with cancer. By gaining this information, we can better understand how a cancer diagnosis impacts the lives of carers and identify how to best support these carers.

Recruitment Window

If possible, it is ideal to approach carers face to face, ideally when they are accompanying the patient during one of his or her appointments or when they visit the patient in hospital or during one of your home visits.

Approaching Potential Participants

Spending time talking to carers one-on-one is the best way of improving their understanding of the study and why they are being asked to participate in this study.

It is important to acknowledge that this may be a difficult time for them and you understand if they do not feel they can cope with taking part.

Explain the study in layman terms. You can use the leaflet provided as a guide.

If the carers have taken the information sheet home, then best practice is to follow up on them and ask them whether they are interested in participating in study or not.

Explaining their Involvement

Explain to the carers that if they agree to participate they will be required to take part in an interview. They will only be interviewed once and the interview can take place either at their home or another place of their choosing or via telephone or via Skype. It will also take place at a time which is most suitable to them.

Explain to the carers that the interview does not necessarily have to last one hour and that they will be interviewed alone.

Everyone's Experience is Valued

It is important to explain that I am interested in everyone's experience.

Benefits to Taking Part

Participants have provided feedback that the interview has helped them to: (i) address their thoughts and feelings; and (ii) give something back and improve things for the future.

It is important to emphasise to potential participants that participation in this study is completely voluntary and they are free to accept or refuse to take part without giving a reason.

Appendix C The Interview Guide

Initial Open-ended Questions

Can you tell me more about yourself and the person you are caring for?

Tell me about your health.

Prompts

What conditions are you living with?

What was it like having a chronic condition before the patient's diagnosis? How, if at all, were you managing?

Tell me about what happened after the patient's diagnosis. How, if at all, were you managing then?

How, if at all, are you managing now? Have things changed over time?

Who, if anyone, influenced your actions? Tell me about how s/he influenced you.

What, if anything, influenced your actions? Tell me about how they influenced you.

How would you describe how you viewed your chronic condition/s before the patient's diagnosis? How, if at all, has your view changed since the diagnosis?

Intermediate Questions

Talk me through your usual day for when you caring for the person with cancer. (probe different times)

Prompts

What, if anything, helps you manage your chronic condition/s?

What problems/challenges might you encounter? Could you tell me the sources of these problems/challenges? (for example, practical problems, financial problems)

Are there any events that stand out in your mind? (for example, when the patient wasn't so well) Could you describe (each one) it? How did this event affect you? How did you respond?

Who has been the most helpful to you during this time? How has s/he been helpful?

Has any organisation been helpful? What did they help you with? How has it been helpful?

How do you know when you are managing things well/better? Is it something emotional or practical?

What does it mean to you having to care for the person with cancer and at the same time, managing your chronic condition/s?

What would life be like if you were managing well/better?

Ending Questions

What do you think would help you manage your chronic condition/s better?

What advice would you give someone who has a chronic condition and is caring for a person with cancer?

Is there something else you think I should know to understand your experience better?

Is there anything you would like to ask me?

Appendix D Evaluation using Charmaz's (2014) Criteria

D.1 Credibility

Charmaz (2014) presents six criteria with which to judge whether a study is credible or not:

i. **Does the research present intimate familiarity with the setting or topic?** – This research presents intimate familiarity with the topic by presenting a systematic review of reviews on the experiences of carers, and by discussing the study findings in relation to other existing theoretical models of caregiving and chronic conditions. In addition, Chapters One and Four provide a detailed description of the setting.

ii. **Are the range, number and depth of the data gathered sufficient?** – The recruitment techniques employed in this research were successful in recruiting a variety of carers, as described in Chapter Four. Furthermore, to facilitate depth to the data, data were collected using in-depth interviews. Moreover, probes were also used to encourage the participants to elaborate further on their experiences. Additionally, the interviews were conducted at a location and time which suited the participants to encourage them to feel more at ease to talk about their experiences. These interviews lasted on average around one hour and so facilitated a relatively lengthy interview with sufficient time to explore topics which were relevant to the participants. In addition, Chapter Five describes how theoretical saturation was achieved.

iii. **Were categories systematically compared?** – The constant comparison method was utilised when developing the categories, as described in Chapter Four. This involved the constant comparison of codes to codes, codes to categories, and categories to categories until the theory was developed.

iv. **Do the categories cover a range of empirical settings?** – The participants were recruited from different settings including the hospital setting and in the community setting, as well as from both public and private services. Furthermore, the participants were from different groups of carers with different chronic conditions and caring for patients with different types of cancers.

v. **Does the data gathered link rationally to the data analysis and subsequent arguments which emerge?** – The constant comparison across the Maltese and English languages in the intertwining translation process helped ensure the link between the translated excerpts and the developing theory and its categories. Therefore, by translating the short excerpts during the data analysis process, the researcher was constantly ensuring that the translated excerpts link rationally to the claims being made.

vi. **Has sufficient evidence been provided in the study to enable a detached reader to concur with the findings of the study?** – Excerpts from the interview transcripts were used in Chapters Six to Nine to illustrate how the theory and its categories were developed from the data.

D.2 Originality

Charmaz (2014) presents four questions as criteria by which to judge the originality of the research:

i. **Do the categories present fresh insights?** – This research contributes to existing knowledge by identifying how carers live with their chronic conditions whilst caring for the patient with cancer, a topic which has been mostly overlooked in the extant literature, as illustrated by the systematic review of reviews. Furthermore, this research highlights which contextual factors impact how carers live with their chronic conditions whilst caring for the patient. Therefore, it provides important information which can be utilised to develop carer assessment tools to identify those carers who are struggling more and provide the necessary support as early as possible.

ii. **Does the analysis provide a new conceptual rendering of the data?** – This is represented in this research by the grounded theory which was developed from the data, as described in Chapter Eleven.

iii. **What is the social and theoretical relevance of this work?** – The social and theoretical relevance of this work is reflected in the implications of the findings for policy and practice, education, and future research, as described in Chapter Eleven.

iv. **To what extent will the grounded theory challenge, extend, or refine current ideas, concepts and practices?** – Chapter Ten illustrates how the developed theory and its categories challenge and extend the notions of existing theoretical models of caregiving and chronic conditions. Most importantly, this research highlights the importance of considering the social context when drawing up care plans for patients with chronic conditions.

D.3 Resonance

Charmaz (2014) presents four questions for consideration with regards to resonance:

i. **To what extent do the categories present the fullness of the studied experience?** – In this research, this is illustrated by how theoretical saturation was achieved, as described in Chapter Five.

ii. **Has the research revealed the taken for granted meanings?** – This research highlights the importance for health care professionals to be sensitive to the patient's social context, which is often overlook in existing theoretical frameworks used for organising and providing care for patients with chronic conditions. Furthermore, this research also revealed how beliefs about coping strategies influence an individual's decision to adopt a particular coping strategy. This finding is often overlooked in existing theoretical frameworks.

iii. **To what extent have links been made between the larger collectivities or institutions and individual lives?** – Links between the larger collectivities and individual lives are presented in Chapters Six to Nine. For example, in this research, only one participant was recently diagnosed with a chronic condition and her experiences were compared to the experiences of the other participants who had been diagnosed with their chronic conditions for a long time.

iv. **Does the grounded theory make sense to the participants and does it offer them deeper insights about their lives and worlds?** – During the process of reflecting back upon the key issues the participants raised in the interviews, probes and prompts were used to help the participants to elaborate further on their experience. After the interview, some of the participants inquired about the findings and they did remark off record that they agree that there is a compromise involved, though the patient's health is always at the forefront. The participants were also provided with a summary of the findings after the analysis.

D.4 Usefulness

Charmaz (2014) offers four questions to consider whether the research has usefulness or not. These are:

i. **Can the analysis be applied in people's everyday worlds?** – This is reflected in the implications of the findings described in Chapter Eleven.

ii. **Do the categories capture generic processes and have these generic processes been analysed for tacit implications?** – As described throughout this thesis, steps were taken to elevate the categories to a more abstract and conceptual level in order to reflect generic processes.

iii. **Does the analysis identify the need for additional research in other substantive areas?** – Chapter Eleven highlights how similar research should be undertaken with carers of patients with other illnesses, such as dementia. In fact, Chapter One discusses why cancer and other chronic conditions can be considered as two separate substantial areas of interest. Moreover, similar research should be conducted with individuals with chronic conditions who are facing situations other than cancer caregiving, which also cause biographical disruption.

iv. **How do the study findings build upon existing knowledge?** – This is described in further detail in Chapter Eleven.

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