One Year Caring: A Longitudinal, Narrative Study on Men's Perspectives of Caring for a Female Partner with Cancer

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Declaration

I hereby declare that:

- This work has not been submitted for any other degree or professional qualification.

- This thesis is the result of my own independent work.

Jenny Young

December 2020

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This thesis is dedicated to my son Samuel – my inspiration for researching male perspectives.

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Abstract

Background

In Scotland and countries such as the US and Canada, 4 in 10 family carers are men. Yet in the main, increasing evidence on the extent of men's involvement in care has not transferred to the research literature around men's *experiences*. In particular, there is a significant lack of qualitative research that explores men's perspectives of masculinity and the social structures and discourses that shape it.

Aim

To explore the perspectives of men who are caring for a partner with a cancer diagnosis in Scotland.

Method

Eight men participated in narrative interviews. Seven were interviewed three times over the course of one year and one further participant was interviewed once. Participants were aged from 32-76 years old, were all White British and in heterosexual relationships. The study included a range of cancer types. Interviews were transcribed and analysed after each interview and also longitudinally, using a structural and performance approach to narrative analysis. The overarching theoretical framework was social constructionism.

Findings

Data analysis was written into eight individual stories and four scenes. Those scenes are: 'In that moment life changes'; 'Caring but not a carer'; 'Opening the valve' and 'Repercussions'. The men drew on different discourses of masculinity in order to frame caring in masculine terms. At times this evoked feelings of fragmentation and conflict, particularly over the manipulation of emotions. By concealing feelings such as worry, fear and loneliness to their partner, they were fulfilling expected norms that position men as being stoical and invulnerable. Yet, this was often done as an act of love and protection rather than due to a discursive need to be the 'strong' one.

Conclusion

To my knowledge, this is the first longitudinal, narrative study to explore the experiences of caring for a partner with cancer from the perspective of men. I have identified a new depth of understanding as to why men in caring roles may report feelings of strain. Acknowledging the limitations of the study design, in terms of transferability and representation of the study findings, different relationships (for example, same-sex or other family member) will have particular dynamics and consequences for how the role is experienced. Nevertheless, the findings from this study have interrelated implications for research, policy and practice. I recommend that this work is used to spark further action on carer identification and engagement with men who are less likely to identify with the role; yet would benefit from a range of different supportive interventions.

CHAPTER ONE: INTRODUCTION

Across the world, due to circumstances such as illness, frailty and disability, people provide unpaid assistance and support to their relatives, partners and friends. Within policy and literature this person is usually referred to as a 'carer' or 'caregiver'. The National Health Service (NHS) defines a carer as:

> '*Anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.'*
> (NHS Scotland, 2020).

In the UK, one in six adults (9.1 million people) is a carer (Age UK, 2020[1]). However, the carer population is increasing at a faster rate than population growth, due to an ageing population, more effective treatments for illnesses such as cancer and a decline in local authority funding (Carers Trust, 2020). In 2011, Macmillan Cancer Support calculated that there were 1.1 million people caring for someone with cancer in the UK. By 2016, this had increased to 1.4 million (Macmillan Cancer Support, 2016). Caring can impact on many aspects of someone's life, bringing both rewards and challenges. Therefore, rising demand for informal care makes it increasingly important to have a comprehensive understanding of carers' experiences.

Carers are arguably one of the most vital components of the care system. Shifting care from the health service to family members saves the economy £119 billion a year (Carers UK, 2019). Carers play a pivotal role in providing physical care and emotional support. For those caring for someone due to cancer, carers provide a vast and complex combination of general assistance and cancer-related support that can vary depending on proximity and relationship to the care receiver and the type and stage of cancer and treatment. For example, clinical care (administering medication and wound care), monitoring treatment side-effects, domestic tasks (cooking and cleaning), bathing and dressing, transport, accompanying the care receiver to hospital visits and emotional support – which covers a

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[1] This research was based on polling carried out by YouGov in May 2020. It was reported as part of Carers Week- see www.carersweek.org.

broad array of actions such as listening, comforting, reassuring and protecting the care receivers' wellbeing through instilling positive beliefs and hiding any negative emotions (Larkin et al., 2019). Due to their proximity to the care receiver and the nature of the relationship, spousal carers are most likely to be the primary carer and provide the most hours of care (Jeong et al., 2020).

Caring for someone with cancer differs to other caring experiences (Morris & Thomas, 2001). Following a cancer diagnosis an individual can experience concerns across a range of domains, including physical, financial, spiritual and emotional. I know this is the case, as for the last seven years I have been employed as a researcher working on projects for the charity Macmillan Cancer Support. These projects mainly focus on the person diagnosed with cancer, with the aim of understanding what patients are concerned about and how cancer professionals and supportive services can help to reduce these concerns. Yet, as I interacted with patients in outpatient clinics or in their home to conduct interviews, more often than not the patient was with a partner or a family member. I became aware of the people who were close to the patient, who helped them to complete a questionnaire, jogged their memory when they were asked to recall information, or who spoke on their behalf when they were too tired or overwhelmed to do so. In one project, I observed patients who had been diagnosed with head and neck cancer. A number of these patients had difficulty speaking and swallowing, so, without a family member present, the ability to convey information between the patient and the oncologist would have been lost. Carers play an active and vital role but they function on the periphery, secondary to the needs of the patient. This sparked my interest in understanding this 'hidden' carer perspective.

In essence, the motivation underpinning the research for Macmillan Cancer Support was to gather evidence that moved away from the biomedical model in order to embrace a psychosocial model of cancer support. Such a shift recognises that cancer does not just impact on people physically, but emotionally and socially too. I had the opportunity to work on a project that focused on a particular way of supporting patients through a process called Holistic Needs Assessment (HNA). This project opened my eyes to the wide-ranging, unpredictable and complex nature of cancer. People tend to be most concerned about situations like their job, money and family rather than the physical nature of the illness. Emotions and support needs may fluctuate depending on a combination of clinical and personal circumstances. Through the HNA process there is therapeutic value in giving people the space to talk and feel that their experiences are normal. Therefore, best practice suggests that this process should be repeated over time. I took all of these insights into this research – underpinned by the belief that to improve outcomes for people with diverse needs requires a *holistic* understanding of their perceptions and experiences.

There are more than 200 types of cancer (WHO, 2018). However, breast, prostate, lung and bowel account for more than half (53%) of all new cases in the UK (Cancer Research UK, 2019). Around half (45%) of patients diagnosed with cancer receive surgery to remove the tumour and just under 30% receive either radiotherapy, chemotherapy or a combination of both (Cancer Research UK, 2019). In contrast to caring in, for example, the context of frailty, the carer of someone with cancer is usually thrust into the role and the disease can progress rapidly. Factors such as uncertainty around outcome, and clinical factors such as the prognosis and treatment side effects, will bring particular challenges and information/support needs for the carer (Morris & Thomas, 2002). While caring begins at diagnosis, people affected by cancer can continue to have medical and psychosocial needs for the rest of their lives, with long-term consequences for the patient and the carer (Jacobs & Shulman, 2017). For that reason, although positive aspects of the caring experience have been identified (Young & Snowden, 2017), there is now a large evidence base that identifies the ways in which caring is characterised by worry and distress (Olson, 2014; Seal et al., 2015).

1.1 Impact of caring

Research on the impact of caring is predominantly quantitative, using questionnaires to measure variables such as anxiety, depression, 'burden[2]' and quality of life. Additional challenges reported in the literature include weight loss/gain, risk of cardiovascular disease, insomnia, loneliness and financial strain through disruptions to employment (Coumoundouros et al., 2019; Teixeira et al., 2019; Pinquart & Duberstein, 2005). Yet, despite policy and clinical guidelines that recognise the need to focus on the carer experience (Department of Health, 2018; National Institute Clinical Excellence (NICE), 2020)

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[2] A term used by other scholars, synonymous with distress. However, it has been suggested this may be an insensitive term to use from the care receiver's point of view. I discuss this further in chapter two.

there is robust evidence to indicate that large numbers of carers are not receiving support. A systematic review (Lambert et al., 2012) identified that 16-68% of carers report unmet support needs. Failure to identify carers and support their needs is leading to caring relationships breaking down, the carer's and patient's health and wellbeing deteriorating and a subsequent increased pressure on health and social care (Nicholas, 2003).

Two justifications for these substantial problems have been identified. Firstly, carers do not always recognise themselves as carers. It can take, on average, two years for someone to acknowledge their role as a carer (NHS England, 2015). Secondly, carers do not know where to go for support or do not feel comfortable accessing support (Sinfield et al., 2012). To add to the complexity, there is no direct link between feeling distressed and taking actions to reduce distress. Evidence indicates that carers can feel guilty accessing support when they are not the one who is ill and they may hide their distress in order to protect their partner or family – something that has been particularly associated with men (Boele et al., 2017; Mosher et al., 2015; Tan et al., 2014).

However, quantitative (and particularly cross-sectional) research does not focus on how people who care engage in making emotional and cognitive sense of their family and caring circumstances, that is, *why* caring can be so challenging. Quantitative research is not appropriate when the aim of the research is to explore the complexities and contradictions within a concept such as gender. Qualitative research has identified the tensions, transitions and reflections (positive and negative) when caring for someone with cancer (Seal et al., 2015), for example, feeling a sense of personal growth, changes in relationship dynamics, existential worries, fear of the cancer returning, feeling out of control, balancing competing demands on time and a 'loss of self' are all issues that the carer negotiates while, in some circumstances, also managing work responsibilities and caring for children.

Qualitative research specifically with men in caring roles has highlighted particular approaches to caring that make their experiences unique. They include a reluctance to seek out support, feelings of isolation (which can be related to the lack of support), difficulty expressing emotions and providing emotional support, reframing caring as a need to protect, but also feeling a sense of purpose and closer bond to the care receiver (Robinson et al., 2014; Lopez et al., 2012).

However, there are evidence gaps. There is very little longitudinal and/or narrative research on carer experiences (within the context of cancer). This is a considerable oversight. Narrative research has been embraced by different disciplines as a way of understanding identity, perceptions, actions and meaning within particular social and cultural contexts (Andrews et al., 2013). Therefore, illness narratives (but predominantly from *patients*), have provided insight into the nature of disrupted experience and the meaning attached to it (Bury, 2001). What is more, the study of narrative has identified the link between identity, perceptions and deeper cultural levels of meaning attached to illness and suffering. The sociologist Arthur Frank's (2013) identification of three types of narratives theoretically recognises that structural, moral and temporal orientations can shape the lived experience of illness.

As such, a longitudinal approach is well-suited to a study about caring due to illness as it recognises that, over time, people's perspectives and relationship dynamics may stabilise and change. Subsequently, their emotional and behavioural responses may fluctuate in multiple and contradictory ways. The narrative scholar Catherine Riessman encourages analysts to embrace the idea that lives are 'messy' and to expect the stories collected about people to be messy in turn (Riessman, 2015). I am fond of this analogy and so I took her advice into my own study.

1.2 Key issue

Globally, the majority (70%) of unpaid care is carried out by women (Miller & Cafasso, 1992; Eriksson et al., 2013). However, men also provide a substantial amount of care, with around four in ten carers being men in the United States (44%) and Scotland (41%), and around half (49-51%) of all carers in Canada (Baker et al., 2010; The Scottish Government, 2015; National Alliance Caregiving, 2020). Yet, in the main, increasing evidence on the extent of men's involvement in care has not transferred to the research literature around men's *experiences*. I conducted a systematic review to assess the gender balance of study samples of family carers of someone living with cancer. Overall, 35.5% of participants were men and 64.5% were women (Young et al., 2020). Therefore, as less is known about male experiences, with implications for the conceptualisation of care, I decided to solely focus on the perspective of men. Applying a longitudinal narrative approach to understand male carer accounts is novel. I am therefore taking the study of male caring, within the context of cancer, in a new direction.

The research question is:

- *What is it like to be a male and care for a partner with a diagnosis of cancer?*

This overarching research question is supported by the following sub-questions:

- What is the relationship between caring and masculinity?
- What are the challenging and positive aspects of this caring role?
- What is it like to care for a partner over one year?

1.3 Interpretation

There has been a small but growing interest in men caring in older age due to circumstances such as Alzheimer's disease or dementia (Milligan & Morbey, 2016). Nevertheless, within the psycho-oncology[3] literature, the evidence base is limited. Therefore, my research makes a significant contribution to the current body of research by making a largely invisible group visible to the psycho-oncology field. Reflecting on why men have been overlooked, there is a tendency in psycho-oncology to focus on the experiences of women with breast cancer but there may also be differences in the willingness of men and women to take part in research. Scholars have reflected upon sampling issues in qualitative research, including difficulties in recruiting men (Brown, 2001). Another and wider issue is attitudes towards men. Farrell et al. (2016) discuss the notion of the male 'empathy gap', proposing that male distress is often overlooked since men are positioned in society to offer, rather than to receive, protection. Accordingly, researchers who are interested in emotionally complex topics may not always prioritise male experiences.

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[3] An interdisciplinary field that focuses on the physical, psychological, social and behavioural impact of cancer on patients and carers/family members.

This is of particular interest to me. Ten years ago, I volunteered for the organisation The Samaritans. I became aware of the high rates of suicide among men – it is the biggest cause of death in men under 45. I found this upsetting, as the two closest people to me in my life are male, my husband and my son. Suicide, of course, is a complex phenomenon and there are no specific reasons why rates of suicide are so high in men. However, it is known that men are less likely to ask for help or express suicidal feelings. Since then there have been a number of campaigns to raise awareness about male suicide and I feel there has been progress in terms of it being less of a taboo subject. I am also heartened to hear my son talk about initiatives in his school that encourage conversations about emotions and feelings, so for him, as he grows up, it will (hopefully) become the norm to reflect on and openly discuss his mental health. What seems important is the need to change the narrative from boys and men being seen as ‘strong’ to them being considered and allowed to be just as vulnerable and in need of support as women.

As I reflect on men who find themselves in a caring role, there is both a societal presumption and expectation that more women care. However, if this is not questioned, with the evidence that men provide a substantial, and in some cases greater amount of care than women, it will reinforce the idea that women *should* provide more care and it silences the contribution of men. There are similarities between men and women in terms of their approach to the role and their perceptions of the positives and challenges. However, there are some significant differences. Men and women are not homogenous groups – they live in different structural contexts with different distributions of power, opportunities and responsibilities. This will expose men and women to different types of stressors and protective factors and they will react with different appraisals, coping strategies and emotions.

1.4 The study

Eight men, all white and with Scottish or Irish nationality, participated in this study. They were recruited from a range of sources including a Scottish cancer service, the social media (Twitter and Facebook) accounts of two charities and word of mouth. They were aged from 32 to 76 years old, six were employed and three were retired. The overarching theoretical framework within this study was social constructionism. Social constructionism places emphasis on interactions and relationships and the meanings that are generated through these interactions. The idea of a socially constructed identity moves understanding away from the idea of identity being an internal, fixed product of the self to the processes in which someone may inhabit or embody an identity and how this is initiated and sustained.

My route to accessing and understanding identity (alongside emotions and perceptions) was through a narrative interview. Through storytelling, over one year, the participants in this study used language to give expression, build identities and have their experiences endorsed. For that reason, I have presented my findings across two chapters; one chapter focuses on eight individual detailed stories and one is a series of scenes, with each scene representing a move forward in time and a significant moment or transition. The four scenes are:

1. ‘In that moment life changes’
2. ‘Caring but not a carer’
3. ‘Opening the valve’
4. ‘Repercussions’

Presenting my findings in this way allowed me to highlight the way actions, behaviours and identity positioning change and fluctuate over time. I found Goffman’s (1959) dramaturgical metaphors useful in exploring conflict and tension between the participants’ ‘front stage’ and ‘backstage’ (referred to as the ‘male mask’) due to the gender norms and values that operate within a society. I also drew on positioning theory (Davies & Harré, 1990) and discourse theories (Gee, 2004; Foucault, 1972) to capture the ways in which the men enacted socially significant identities through language, interactions and beliefs. Accordingly, an understanding of the discourse of informal care is not just an issue of semantics but something that has significant social consequences.

A dominant discourse in Western culture includes ‘hegemonic masculinity’ (Connell, 1995). Although it should not be assumed to be ‘normal’, only a minority of men might enact it. However, it is symbolic and ‘normative’ as it legitimises behaviours, expectations and attitudes. In this study, the men’s movement between hegemonic performances of masculinity to contrasting forms of masculinity represented by, for example, vulnerability and expressions of love, was complex. For example, by concealing their emotions they were fulfilling expected norms that position men as being stoical and invulnerable. Nevertheless, it was done as an act of support and within a desire to protect. This is significant as concepts such as love and nurturing can be disregarded in studies on male caring. Furthermore, it draws attention to the way that men may redefine the carer role in masculine terms. At times, prioritising their partner's wellbeing before their own reinforced feelings of courage and autonomy. Thus, there was also a protective nature in their alignment to traditional forms of masculinity.

Emotion management (as theorised by Hochschild, 1985) is an unrecognised source of stress in male carers. The expectation to perform masculinity in a certain socially acceptable way can feel inauthentic, causing dissonance between a 'real' versus a performed self. Thus, caring, for men is paradoxical. It can fulfil, leading to feelings of purpose, but it can also cause distress. However, identifying the extent to which men undertake emotion management makes their contribution and perceived difficulties more valued and visible.

The findings from this study have implications for research, policy and practice. The two broad and interrelated areas for future work are related to the issues of carer identification and engagement, particularly amongst 'hidden' groups of carers such as men. In essence, my view is that the multifaceted and far-reaching impact of caring must be viewed through a gendered lens. Masculinity as an ideology has been problematised due to evidence reporting that men are less likely to seek help, that they engage in more risky behaviour, and have higher rates of suicide. Therefore, it is imperative that when evidence is available which highlights alternative representations of masculinity it is used to push against constrictive assumptions and beliefs.

1.5 Structure of this Thesis

This thesis presents a longitudinal, narrative study on caring for a female partner with cancer from the perspective of men. In this opening chapter (**chapter one**) I have set the scene; documenting why the topic of this research is relevant and important. I set out my justification for focusing only on male carers and I provide an overview of the findings and their potential application towards future research and policy.

In **chapter two**, the literature review, I will examine a broad selection of policy, academic literature and commissioned research from the third sector in order to ground this study in current debate. I will outline a carer profile, considering the tasks and responsibilities that carers engage in and why these responsibilities can be challenging. I will then discuss the positive and challenging impact of caring, moving onto a discussion about the role of gender. The final section of this chapter focuses especially on male caring, highlighting that this is a unique perspective but there is limited research on men who care for someone due to a cancer diagnosis.

Chapter three presents my theoretical approaches. The overarching framework is social constructionism. Taking identity as my starting point I navigate through the concepts of social identity and carer identity by drawing on positioning theory and discourse. I identify a dominant gender discourse – hegemonic masculinity – and discuss its normative influence on the way men may self-position and be positioned by others (for example, their partner). One example of a performance of masculinity that adheres to a hegemonic ideal is the avoidance of femininity, such as expressing emotional distress. However, that is not to say that men do not engage in emotional management. By drawing across Goffman (1959/79) and Hochschild's (1985) seminal work I discuss the concept of a 'real' versus a performed self, with novel implications for understanding male caring.

In **chapters four** and **five** I set out my methodology and method. I identify and justify the narrative focus and present Labov & Waletzsky's (1967) structural approach and Riessman's (2008) performance approach to narrative analysis. I document all stages of the research process covering ethical issues, recruitment, transcribing and analysis. I discuss longitudinal interviewing and reflexivity in qualitative research.

Chapter six is the findings structured as eight individual caring stories. This is in keeping with a holistic narrative approach. Extracts from the interviews were identified to highlight positioning, emotional reactions, performed identities and how the participants used the narrative genre to describe, entertain and inform. I focus on the structure and content of the narratives and identify the influence of wider social and cultural discourses. Commonalities between the participants' perspectives are presented in **chapter seven**. I have written this analysis as a series of scenes, with each scene representing a move forward in time and a significant moment or transition in the carers' experiences.

Chapter eight is my discussion. I ground my findings in theory and literature and set out the original contribution that this study makes to literature on male caring. The conclusion and implications for research, policy and practice alongside study limitations are in **chapter nine**. I recommend that work needs to be done to increase the identification and visibility of male carers and that carers are conceptualised as being more than one homogenous group.

CHAPTER TWO: LITERATURE REVIEW

Structure of the chapter:

- *Review methodology*
- *Policy and informal care*
- *The carer profile*
- *Gender roles*
- *Men and informal cancer care*

Overview

The purpose of this chapter is to situate my study within existing policy and literature. This narrative review begins by examining the policy that has contributed to the development and conceptualisation of informal care. I then move onto literature that focuses specifically on caring for someone with a cancer diagnosis. In this section I cover time spent caring, perceived difficulties and the impact of caring – which includes challenging and positive aspects of caring experiences. The penultimate section of the review then examines the role of gender. This brings into focus the way that gender and caring are closely linked. This discussion on gender builds the foundations for the final section which focuses specifically on male caring. There is a small body of evidence on male caring that has provided the impetus for this longitudinal narrative study. I will present this evidence and discuss how my study responds to current gaps in the evidence base on male caring.

During the course of my PhD (2015-2020), I have published two systematic reviews that complement this narrative review. The first[4] (see appendix one), conducted at the start of my PhD, focused specifically on positive caring experiences. I noted that there was little consensus as to whether being male or female was associated with a greater likelihood of having a positive experience whilst caring. I concluded that further qualitative analysis was needed to provide insight into how meaning and behaviour may be associated with the role of gender. In the literature studied in the review, this differed depending on context, culture

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[4] See Appendix 1: Young, J & Snowden, A. (2017). A systematic review on the factors associated with positive experiences in carers of someone with cancer. *European Journal of Cancer Care,* 26(3).

and the theoretical approach taken by the particular researcher. Accordingly, this review stimulated my interest in gender and informal caring as there was a level of complexity associated with gender roles that warranted further study.

Turning to the literature on gender and caring, it was evident, after just a cursory look, that male carer accounts are under researched. However, I wanted to investigate this claim in a more systematic manner. This led to my second published systematic review that quantified the number of males and females in cancer carer samples[5] (Young et al., 2020).. I found, in the first review to do so, that cancer carer research samples are unbalanced. On average, only 35.5% of carer research samples (in the context of cancer) contain male participants. Therefore, men are underrepresented in cancer carer research. This review also raised questions about *why* there are less men in carer samples, which I will discuss further in chapter five. Consequently, these reviews sit alongside this narrative review as a rationale for applying a qualitative methodology to understand in greater depth the relationship between masculinity and caring experiences.

2.1 Review Methodology

The aim of this review was to conduct a broad search to find empirical research, review articles, policy documents, grey literature and reports produced by the third sector[6] relating to non-professional caring and cancer in order to summarise, explain and interpret the evidence on informal cancer care. All study designs were deemed to be acceptable for inclusion in this review. This was done using the following electronic databases: PsycINFO, Psychology and Behavioural Sciences Collection, PubMed, CINAHL, Google Scholar, AMED, MEDLINE in 2016, and then again in 2020. The initial search terms were:

Carer (1)	Cancer (2)

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[5] Young, J., Kyle, R. G. & Sun, A. (2020) Gender differences in research samples of family carers of adults with cancer: a systematic review. *International Journal of Care and Caring*. https://doi.org/10.1332/239788220X15984632524776

[6] An umbrella term to include a range of organisations that are not public or private sector, for example, charities.

Care* OR Partner OR Informal care* OR Spousal care* OR	Cancer OR Oncology OR Neoplasm OR

Table 1: Search terms for literature review

Using Boolean operator 'AND' Columns 1 and 2 were combined. Further reading highlighted additional literature so journal hand-searching techniques were also used through this part of the search. I then repeated the search using the carer and cancer terms but also with the following gender-related terms (separated with 'OR') Gender; Masculinity; Male and Men.

The initial search included studies published in English from January 1995 to August 2017 and the repeated search was from September 2017 to June 2020. This time period was chosen as caring as a research topic began to develop in the mid-1990s, coinciding with policy initiatives and the rise in community care (Heaton, 1999). The initial search generated 3,483 records through database searching and eight records (such as policy documents and charity reports) through hand-searching. I screened the records based on the following criteria:

- Inclusion criteria: (1) adult carers of a family member/spouse/partner over 18 years old who has received a cancer diagnosis; (2) any type of cancer; (3) studies involving patients and carers (4) written in English.

- Exclusion criteria: (1) Carer or care receiver is under 18 years; (2) bereaved carers; (3) carer of a friend/colleague (i.e. not family); (4) psychometric testing; (5) protocols; (6) conference proceedings; (7) country and culture specific papers.

Exclusions were made to help keep the dataset manageable and focused. Paediatric and bereaved carers face unique experiences and challenges that warrant separate attention. I excluded studies about psychometric testing as they do not develop understanding on carer experiences or outcomes. I excluded papers that focused on specific cultural groups (for example, Hispanic carers) as they were less relevant to the experiences of White British carers in the UK.

I did not undertake formal scoring of the quality of the papers, as this was a narrative (rather than systematic) review, and because there was heterogeneity in the study designs and methods. Nevertheless, where applicable I have commented about individual studies in relation to factors such as the design of the study, strengths and weaknesses, and overall relevance of the results to other research.

After screening the title and abstract and applying the inclusion and exclusion criteria, 3,021 records were removed. The main reasons for exclusion included duplication, not relevant (not cancer), end of life/bereaved carers, or a paediatric sample. If all inclusion criteria were present then the full text was read (n=462 articles). I have not included every article in the review, as my main focus, as detailed in the last section, was on men who care.

This was a deliberately broad search. While my focus is on men, I wanted to ground my interpretation in wider thinking about the role in terms of what carers do and what they find challenging and rewarding. In doing so, it actually helped to identify where a more gender-sensitive approach to the caring accounts would be useful. Of note, was that while I principally focused on caring within the context of cancer, as the male cancer carer literature base is small I also reviewed articles where men were caring due to circumstances such as Alzheimer's disease. This literature is confined to the final section of this review.

2.2 Policy and Informal Care

Less than 50 years ago the term 'carer' was not commonly used in the English language. It was only in the 1980s and 90s that individuals who provided unpaid assistance were recognised as 'carers' (Heaton, 1999). This catalyst for change occurred as The NHS and Community Care Act (1990) stated that people who need community services should get those that they are entitled to. The ethos was that people who need care should be able to remain in their homes. Consequently, recognition of the increasingly important role that carers contribute to society, and the need to provide personalised support services, has grown. In the UK, informal care is now a feature of health and social care policy (NICE, 2020; Department for Health 2018; Scottish Government, 2018). However, this has taken many years against a backdrop where carers' needs were usually seen as secondary to those of the care receivers (Morris & Thomas, 2001). Documenting the process that has seen the term 'carer' enter political and health discourse reflects changing perceptions and expectations around this role and the interaction between policy makers, researchers and pressure groups. Moreover, it has elevated the term 'carer' as a social identity inscribed within legislation (Pickard, 2001).

The number of carers is increasing in the UK. The 2011 census documented an 11% increase from 2001 (Carers UK, 2019). In 2020, it is estimated that there are 9.1 million carers in the UK (Age UK, 2020). Accordingly, all four nations within the UK have their own carers strategy. Reflecting the evolution of these strategies, The Carers and Disabled Children Act 2000 (a UK-wide Act), gave carers the right to ask for an assessment of their own needs, irrespective of whether the person they were caring for was having their needs assessed. This Act also allowed, for the first time, Social Services departments to provide services directly to carers. While this demonstrates progress and greater autonomy for the carer, the assessment was only available to any carer who provided or was intending to provide regular and substantial care. With complexity arising as to what constitutes 'regular' and 'substantial' care, a further Act was passed in 2016. The Carers (Scotland) Act 2016[7] gave local authorities a responsibility to assess a carer's need for support, where the carer appears to have such needs. This replaced the legislation around the carer providing 'regular and substantial care' to qualify for an assessment.

In essence, the overarching focus within policy is to support carers. In England and Wales the National Carers Strategy (Department of Health) stated that by 2018,

> *'Carers will be respected, have access to the integrated and personalised services they need to support them in their caring role; carers will be able to have a life of their own alongside their caring role; carers will be supported so that they are not forced into financial hardship by their caring role; carers will be supported to stay mentally and physically well and treated with dignity.'*

The idea of 'support' spans different approaches (Pickard, 2001). Stating that carers will be 'able to have a life of their own' ties in with the focus in policy to provide breaks or respite. For example, the Scottish (2016) Act states that each local authority must prepare information on short breaks and these 'must be accessible to, and proportionate to the

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[7] The Act became law on 1st April 2018

needs of, the persons to whom it is provided' (Carers (Scotland) Bill, 2016). Respite can be an effective way to alleviate strain (Vandepitte et al., 2016). However, there is also evidence to suggest that there is resistance due to factors such as perceived need, doubts about the quality of care, motivations to keep providing care, issues such as waiting times and not knowing how to access the break in the first place (Southby, 2017; Van Excel, 2007). In its 2015 policy document 'Scotland's Carers', the Scottish Government acknowledged that the evidence on respite and short breaks is not entirely conclusive.

Twigg and Atkin (1994) developed a typology of the relationship between welfare agencies and carers to document instances where carers are positioned as 'resources', as 'co-workers' who ensure the continuation of caring, or as 'co-clients' where there is a concern specifically for the needs of the carer. Consequently, Pickard (2001), in an examination of carer policy, suggested that in the case of respite carers are positioned as 'co-clients', as the focus of the intervention (respite) is on the carer. However, an alternative interpretation is that there is a focus on ensuring carers are supported to stay 'mentally and physically well' due to concern that the caring relationship will break down, with associated costs and strain to public services. This, suggests Pickard (2001), is an example of a dual focus on both the interests of the carer and an instrumental concern for ensuring that the caring continues.

Another form of support for carers are carer's assessments with the aim of identifying needs in and alongside the carer role. The Scottish Government's carer strategy views caring as taking place in a relationship (Scottish Government, 2019). Assessment should therefore be offered independently and together with the care receiver to identify shared and separate needs. Yet, research has found that carers are not always aware they have had an assessment or been given an opportunity for an assessment separate to the care receiver (Newbronner et al., 2013).

In order to try to support people to prevent 'financial hardship', the Scottish Government[8] offers, to those who are eligible[9], a welfare benefit called Carers Allowance. However,

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[8] The Scotland Act 2016 gave the Scottish Government new powers relating to social security and responsibility over certain benefits, including carer benefits.

[9] Eligibility – looking after someone for 35 hours a week or more, aged over 16 and do not earn more than £126 a week.

figures from the Scottish Government indicate that, in 2011, 101,880 people were entitled to Carers Allowance but only 50,575 were receiving it. This figure was lowest in the 65-plus age category, with only 2.9% of entitled people receiving Carers Allowance. By February 2019, there were 76,597 claimants and 69% of these people were female (Scottish Government, 2019). Judd et al. (2019) suggest that this reflects the fact that men are less likely to see themselves as carers, so the care they provide is viewed as being part of their relationship. Subsequently, as raised by scholars such as Twigg and Atkin in the mid-1990s, there are questions and concerns about the best way to support carers. These remain more than 20 years later.

In the clinical context, it has been suggested that there are many reasons why carers' needs may not be met. These include patients and carers being unaware of the existence of services that might help them, professionals not eliciting carers' problems or concerns, and poor co-ordination among professionals within a team or between services (NICE, 2004). For that reason, in 2020, NICE[10] produced new guidelines (Supporting Adult Carers, 2020) and one of their main justifications for doing so was recognition that a barrier to the provision of support for carers is identification. That is, carers do not think of themselves as carers but also they are not identified by health and social care professionals.

There is acknowledgment in these guidelines that, although The Care Act 2014 aspired to give carers more rights, greater independence and, ultimately, access to support, it is still the case that only 10% of carers are identified by a health and social care professional (NHS England, 2015). For that reason, these guidelines provide action-oriented recommendations in terms of identifying carers and supporting their needs, providing support (practical and emotional) and supporting carers during changes to the caring role, including an end of life caring role. This seems to be an encouraging step forward in terms of two key issues; carers recognising themselves as carers and shifting the responsibility for signposting support for carers towards health and social care practitioners. I will return to these guidelines when I discuss implications for practice, policy and research in the final (conclusion) chapter.

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[10] Applicable to England and Wales. In Scotland guidance is taken from the Scottish Government (2019), although different sectors have guidance. For example, general practices in Scotland are contractually required to have a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment (See -Carduff et al., 2014).

I will now present a 'carer profile' which is a synthesis of research to summarise and explain what carers do and how caring impacts on people's lives.

2.3: The Carer Profile

2.3.1 Time spent caring

The intensity of support given by the carer usually reflects the different needs of the care receiver. For instance, Kim & Schulz (2008) conducted a survey to explore the impact of caring. They reported, from a US sample of 608 adult carers, that cancer carers provided more hours per week (31 hours) and assisted with more care activities than carers of individuals with dementia (29 hours) or of the frail elderly (11 hours). Yet, this can vary depending on the patient's diagnosis. Yabroff & Kim (2009) also using data from a large survey of American carers (n=688), found that carers of patients with lung cancer, ovarian cancer or non-Hodgkin's lymphoma spent the most hours per day caregiving (>10 hours). Carers of patients with breast and bladder cancer, melanoma of the skin or uterine cancer spent the fewest hours per day (<7 hours). Hayman et al. (2001) reported, using data from a national survey distributed to elderly patients (n=2,022) in America with cancer, that having a history of cancer and undergoing treatment was associated with both an increased probability and intensity of informal caregiving. This highlights that particular clinical factors will impact on carer experiences.

Time spent caring can also vary depending on socioeconomic status. For example, Yabroff and Kim (2009) in the same study found that carers with less than a high school education and a lower income reported providing longer periods of care. Likewise, Macmillan Cancer Support (2011) reported that, after surveying 892 carers in the UK, people in the most deprived areas provided more hours of care a week. These findings draw attention to two things. Firstly, longer periods of care may be associated with higher demand for the care as there are higher rates of cancer in more deprived areas (Cancer Research UK, 2019). Secondly, informal care provided by the families of those experiencing illness has replaced or supplemented formal provision, particularly among those without financial resources to provide such care privately. These statistics bring into focus the demands placed upon those who may already have complex lives.

The relationship to the care receiver is also an important factor in understanding time spent caring. It is reported that spousal carers, due to their proximity to the care receiver, provide the most hours of care and are likely to be the primary carer (Jeong et al., 2020; Li et al. 2013; Kim et al., 2008; Chen et al., 2004). This remains the case in contrasting geographical settings such as the USA (Kurtz et al., 1995), and Taiwan and China (Chen et al., 2004). This time has been estimated at 36 hours a week (although in reality it is likely to be a 24 hours a day role) compared to those caring for a friend, which is estimated at eight hours a week (Macmillan Cancer Support, 2016).

Olson et al. (2014), branching away from the quantitative, psycho-oncology approaches to explore time spent caring, used a sociological framework of 'time-sovereignty' to understand carer experiences. They conducted longitudinal interviews with 32 Australian spousal carers and revealed a relationship between experiences of time and expressed emotions. Those who were providing 24 hours a day of caring, if they did not have other demands, for example because they were retired, felt able to meet all of their spouse's needs. Those who had other demands on their time felt out of control. Subsequently, those who were deemed to be 'time poor' wanted to prioritise practical support in the form of respite or financial support, whereas those who felt they had more time wanted to prioritise support groups or counselling. This study makes an important contribution to the literature as it draws attention to the wider context. Documenting hours spent caring is valuable but it is only one part of the picture. Illness can impact on the lived experience of time with, as Olson et al. (2014) identified, consequences for emotional experiences and support preferences. Therefore, exploring the relationships between carer circumstances, actions and emotions provides a more holistic conceptualisation of carer accounts.

2.3.2 What do carers do?

Carers provide a vast and complex combination of general assistance and cancer-related support that can vary depending on proximity and relationship to the care receiver, the type and stage of cancer, and treatment. For example, carers of someone with head and neck or oesophageal cancer report assisting with activities relating to feeding and breathing that carers of someone with, for example, breast cancer would not necessarily need to engage in (Balfe et al., 2017). Bond et al. (2016), who developed a Head and Neck Caregiving Task

Inventory, stated that more research should focus on the tasks that carers do in relation to specific cancers. This would help to inform cancer-specific information and support and develop understanding in an under researched area of the carer experience. Larkin et al. (2019), in a scoping review of carer-related research and knowledge, found that approximately 16% of carer literature is concerned with the type of care and caring activities, compared to 39% of the literature that focuses on the impact of caring.

Nevertheless, it is known that carer tasks span a combination of clinical, practical, social and emotional support. The early phase of becoming a carer can have a considerable impact on the individual as they adjust to their new role and learn new skills (Schumacher et al., 2000). For example, Meunier-Beillard et al. (2018), in a qualitative study on the identification of skills by partners of patients with colon cancer, found that new skills were acquired across several domains, including domestic and physical care. The authors considered that ‘new’ skills are acquired when the carer does not have any pre-established knowledge or understanding, which was particularly applicable to clinical skills.

Carers report carrying out a large proportion of clinical care, such as administering medication, wound care, assisting with drainage lines, managing symptoms such as nausea, fatigue and pain, and monitoring the side effects from treatment (McMullen et al., 2014; Hendrix et al., 2013; Yabroff & Kim, 2009). Ulgren et al. (2018), in a systematic review exploring how carers of cancer patients manage symptoms at home, found that half of the studies (n=10) in their review described categories of clinical support which included tube feeding, giving injections and dose titration (which is the process of adjusting the dose of a drug). Mollica et al. (2017) found that more than half of their sample (n=389) of American cancer carers performed some type of clinical task such as administering medication or changing bandages. Castellanos et al. (2019) explored the number and perceived difficulty of tasks completed by carers of patients with head and neck cancer. They reported that 65% of 82 carers were performing symptom management, with some of these tasks requiring nursing or technical skills such as tube feeding and tracheotomy care.

Practical and social care tasks include personal and intimate care such as bathing, eating, assisting with the toilet and dressing. The frequency with which carers report engaging in personal care is mixed. For instance, Lund et al. (2014), in a cross-sectional survey of 415 cancer carers (with varying relationships to the care receiver), reported that 20% of the respondents engaged in personal care. However, 15% of the sample were friends and siblings, so it is likely that, due to their relationship with the care receiver, it would be inappropriate to engage in this type of care. In addition, assistance with tasks such as bathing and dressing can reflect a decline in the care receiver's independence that is related to a more advanced stage of cancer. In that situation the carer may hire personal services (home help) to assist with this responsibility instead (Coristine et al., 2003). In contrast, 72% of the cancer carers (n=82) in the survey study by Zavagli et al. (2019) stated that they provided personal care, but all of these carers were living with the care receiver. Other practical tasks documented included domestic tasks (cooking and cleaning), arranging transport to hospital appointments, helping with treatment decision making, accompanying the care receiver to oncology consultations, filling in forms (for example, welfare payments) and making phone calls (Girgis et al., 2013; Ockerby et al., 2013).

However, the element of support that most carers report engaging in (irrespective of relationship status or cancer stage/type) is emotional support. Skalla et al. (2013), after surveying 172 American cancer carers with a range of cancer types, found that the most commonly identified (83% of sample) task was providing emotional support. Research undertaken by Macmillan Cancer Support (2016), which surveyed 892 carers in the UK, reported similar findings – that most carers (74%) reported providing emotional support. In comparison, 54% stated that they provide practical support such as help with shopping, cooking and cleaning.

However, 'emotional support' is a broad concept. It may include verbal and non-verbal communication relating to listening, comforting, instilling positive beliefs, reassuring and helping the care receiver deal with their feelings about cancer (Deschields et al., 2012; Jeong et al., 2020). It may also include protecting the emotional wellbeing of the care receiver. Oldertroen et al. (2019), in a qualitative study on men's experiences of caring for women with cervical cancer, noted that the men talked about wanting to 'protect and spare' the women from distress. Likewise, Seal et al. (2015) found that, in a meta-synthesis of qualitative studies on informal caring for someone with cancer, the carers wanted to hide their emotions to defend the care recipient. They tried to remain optimistic and strong when in front of the ill person and participants talked about 'donning a mask' to maintain a pretence that they were coping when they were actually struggling (Seal et al., 2015:501).

Consequently, emotional support does not always constitute a single measurable act. It can be both a gesture, an expression and a behaviour. Moreover, it may be hidden from view. That is, the emotional efforts involved in protecting a partner may not seem an obvious form of emotional support like 'listening' or 'reassuring' which are usually captured in survey scales. Subsequently, this form of emotional support may be overlooked because it is not easily quantified.

For that reason, scholars have turned to examining the nature and impact of emotional support in some detail. In general, there is a large body of evidence demonstrating the positive impact of emotional support on health (Namkoong et al., 2020; Tay et al., 2013; Prati et al., 2009; Reblin et al., 2008). From the patient perspective receiving emotional support is beneficial. Schroevers et al. (2010) examined the relationship between emotional support following diagnosis and post-traumatic growth in 206 cancer survivors. Their findings suggest that receiving emotional support from family and friends, characterised by reassuring, comforting, and problem solving, was an important resource that may help those with a cancer diagnosis to find positive meaning.

Likewise, there are benefits for the carer. A positive patient/carer dynamic characterised by the components of emotional support such as love and affection are associated with positive experiences in carers (Young & Snowden, 2017). Weiss (2004) conducted a study to identify correlates of post-traumatic growth (PTG) in husbands (n=72) of breast cancer survivors. Analysis indicated that perceived emotional support was significantly associated with the husband's personal growth. Furthermore, wives' PTG scores were significant predictors of the husbands' PTG scores. What was deemed to be important in this context was the *joint act* of supporting each other – there was a sense of coping 'as part of a whole' (Weiss, 2004:267). This suggests that the shared social environment, including the role of the relationship between the patient and carer, is an important component in benefiting from the delivery and acceptance of emotional support.

Further research done within carer/patient dyads by Luszczynska et al. (2007), who examined emotional support provided and received in 172 patient/carer dyads, reported that, in general, both members of the dyad reported high levels of support (both provided and received). However, one month after surgery (for gastrointestinal cancer), there was a significant decline in emotional support by male carers, whereas women continued to extend the same amount. Adding to this, Emslie et al. (2009) found in a secondary analysis of 33 interviews with individuals diagnosed with colorectal cancer and their partners, that women were more likely to report a lack of emotional support from their male spouse. However, the participants in this study described how they believed that their partners *could not* express emotional support, rather than they *would not*. This does suggest that there may be a gendered component to providing emotional support. However, it is important to emphasise that men and women may respond differently to situational factors. Accordingly, that may shape their motivation or ability to carry out different tasks.

For that reason, differences between men and women in terms of the 'type' of care they provide requires a consideration of factors such as gender socialisation, gender discourses and men and women's societal positioning within families and occupations (Gerstel et al., 2001). I will discuss these topics in greater detail in the next chapter. In summary, it has been considered that men take a more task-based, rather than emotional, *approach* to caring than women (Geiger et al., 2015). For example, Ussher and Sandoval (2008), after interviewing 13 carers of someone with cancer (seven women and six men), found that male carers primarily gave accounts of 'caring as a competency task' whereas women positioned themselves as 'all-encompassing expert carers'. The authors suggest that the cultural positioning of caring as an activity that is expected of women was an explanation for why the women in their study felt expected to take on a wide range of tasks and responsibilities, whereas mastery and competency sit within masculine hegemonic discourses.

However, *approaching* the caring role in a particular way (for example, as a task to be mastered) does not necessarily mean that men provide less emotional support. There is a degree of uncertainty here, in part because of the issue raised earlier – less is known about the types of tasks that carers engage in. Survey data provides an indication of the frequency of tasks but there has not been a detailed breakdown of the distribution of these tasks by gender. Further, as I have found, carer samples are usually skewed to a larger number of females (Young et al., 2020). In the study (Skalla et al., 2013) where I noted that 83% of carers offer emotional support, 84% of that sample were female. However, the point raised by Emslie et al. (2009), that men do not feel *able* to provide the emotional support, is an important one. It should be the motivation for developing further understanding of what tasks male and female carers engage in and why. Luszczynska et al. (2007) suggested in their implications for practice that medical professionals should be aware that women may be receiving less emotional support than men. However, I would suggest that scholars and practitioners should first go back a step and develop understanding of why this may be the case.

2.3.3 Perceived difficulty

Carers can find these tasks and supportive actions challenging for personal and resource-related reasons. Deshields et al. (2012) reported that, after administering a survey to 100 cancer carers in outpatient clinics in the US, 36% of their sample stated that providing emotional support was the hardest part of caring. Qualitative analysis from the free text boxes indicated that the challenges were related to knowing what to say when bad news was given and providing support to someone else when they were also in need of support. Tolbert et al. (2018), in a qualitative exploration of the experiences and needs of carers during and after the care receiver's treatment, found that the carers (n=10) discussed difficulties, particularly with emotional support and offering reassurance. For example,

> *'I could physically help her, I could get her food, but I couldn't get in her mind and tell her it was going to be OK.'* (Tolbert et al., 2018:38).

Hashemi-Ghasemabadi et al. (2016), in a qualitative study of carers of someone with breast cancer, discussed in their theme 'perceived inefficacy' – the way that the carers felt conflicted as they wanted to express love and care, but struggled with the care receiver's demands and expectations. This left them feeling frustrated, angry and then guilty as they felt they were being inefficient and incompetent in their role.

Another well-reported difficulty is providing physical and clinical care without any or adequate information and training. A questionnaire distributed to 677 carers of newly-diagnosed lung and colorectal cancer patients in the US found that 50% reported not getting adequate training to carry out clinical tasks (Van Ryn et al., 2011). Petricone-Westwood et al. (2020) surveyed partners caring for women with ovarian cancer (n=82) and 46% reported a lack of information from the healthcare professional. Furthermore, higher reports of problems with the quality of information and communication with the health professional was correlated with depression. Penner et al. (2012), using a descriptive phenomenological approach with carers of family members with head and neck cancer, found that a key responsibility amongst the carers was learning how to ensure their family member was receiving adequate nutrition through a feeding tube, managing symptoms and managing any complications arising from the feeding tube (for example, pain or leakage). The carers (n=6) felt ill-prepared, frustrated, anxious and often had disturbed sleep as they had to change the tube during the night.

Mollica et al. (2017) administered a questionnaire to carers (n=641, 80% were female) of patients with lung and colorectal cancer, assessing the care provided, the type of medical/nursing skills training received, burden, and the confidence in caring for their patient's physical needs. Of the sample, 58% (n=377) did not receive training for the tasks that they performed, and a lack of training was associated with burden. However, participants were only included in this study if they performed some form of physical/clinical task. Yet, it is unlikely that the carer would *only* perform this type of care. Therefore, when they completed the measure of burden it is not known if they were thinking about other elements of care, such as providing emotional support.

For those who had received training, the authors unfortunately did not provide any details on its components. Participants were just asked to indicate 'yes' or 'no' to the question 'have you received any training'. Without specifying what was meant by 'training' there may have been a wide variety of experiences. Details on the training format, adequacy, profession of the facilitator and time attended would have been insightful.

Across all of the different types of tasks that carers engage in, there are certain personal and situational factors that may amplify the level of challenge. Skills training appears to be a key area of need, but findings from a systematic review identified a lack of interventions that provide training in practical skills for carers (Applebaum et al., 2013). That is because carer interventions tend to focus on areas such as coping skills, communication skills and education (Waldron et al., 2013). Support and education are valued areas of intervention but perhaps, particularly with carers who are carrying out complicated medical tasks, interventions that combine practical skills, support and information would be helpful. It may seem an obvious statement to provide carers with the support they need but Ugalde et al. (2019) found that, in a systematic review exploring the implementation of cancer carer interventions, fewer than half of the 26 papers included in their review reported on the acceptability of the intervention from the carers' perspective. Only two studies included interventions developed with carers and no studies discussed actions to implement the interventions in practice. There is a clear need for more carer-led research in this area.

2.3.4 Perceived difficulty – understanding why

As touched upon above in the context of providing emotional support, the carers lacked confidence – they were not sure how to comfort and provide reassurance. In turn, this left them feeling ineffective. In tandem with receiving support through an intervention, certain beliefs and characteristics can help an individual to adapt (or not) to the caring role (Fletcher et al., 2012). These include self-esteem, self-efficacy, confidence, control, optimism and mastery (Young & Snowden, 2017). While there are distinct features to each of these characteristics, collectively they appear to have a protective function over the carer. Two studies using a questionnaire design and statistical methods (Butow et al., 2014; Cassidy et al., 2015) found an association between factors such as self-esteem, optimism and positive experiences. Gaugler et al. (2005) identified among 233 American carers (over 70% female) that mastery, which is the feeling of proficiency and ability, acted as a buffer against stress.

According to Bandura (1982), self-efficacy is the confidence or belief in one's capabilities to organise and execute the course of action required to produce given outcomes. In the context of caring, it is confidence in the ability to care for an individual's needs. Porter et al. (2008) found that carers who lacked confidence in helping their partner with pain and other symptoms had higher levels of anxiety and depression than those with higher levels of self-efficacy. Yeung et al. (2019) explored the association between emotional ambivalence, endorsement of male gender norms, self-efficacy and burden among Chinese husbands (n=176) of a partner with breast cancer. They found that ambivalence over emotional expression and endorsement of male gender norms was associated with higher burden and lower self-efficacy. Acknowledging that there wasn't a causal relationship between the variables, the implication is that in this sample of men confidence and feelings of burden were shaped by expectations embedded in male norms. Investigation into how these variables interact, or if they fluctuate over time in line with the patient's cancer trajectory, would be useful.

In general, the difficulty with cross-sectional research that explores associations between variables is that causality cannot be established. Therefore, it is not known whether attributes such as self-efficacy drive more positive outcomes or if the positive outcomes contribute to higher levels of self-efficacy. However, qualitative research such as the study by Hashemi-Ghasemabadi et al. (2016) with carers of someone with breast cancer provides understanding on the way that someone's confidence to carry out different tasks may vary. Indeed, it is possible that this feeling of flux between wanting to provide 'efficient' care and feeling ineffective is what impacts on the carer's confidence.

2.4 The Impact of Care

Given these points of discussion it is clear that there are many challenges associated with the carer role. For that reason the literature has predominantly conceptualised caring as stressful (Perz et al., 2011: Seal et al., 2015; Stenberg et al., 2010; Weitzner et al., 2020). However, positive aspects of the caring experience have been identified too. I will therefore discuss the impact of care under three sub-headings – health and wellbeing, social and practical challenges, and positive caring experiences.

2.4.1 Health and wellbeing

Caring can negatively impact on health and wellbeing, with associated individual and societal cost (Coumoundouros et al., 2019). In particular, spousal carers and partners have been identified as a vulnerable group as they report a lower quality of life than other carer groups (Manne & Badr, 2010). Research in this area is predominately quantitative, involving the measurement of factors such as distress, anxiety, depression and quality of life. The term 'carer burden' is often used as an umbrella term to encapsulate the physical, emotional, psychological, social and practical difficulties facing carers. While there is a considerable literature base that addresses this topic, scholars have considered that using the term 'burden' has potential derogatory connotations (Larkin et al., 2019). In light of that, I have only used the term if the authors of the studies I cite have claimed that this is what they were measuring or exploring.

Findings from a survey conducted by Macmillan Cancer Support (2016) of almost 3,400 carers in the UK, which explored the impact of caring on their health, found that up to 70% report one or more issues with their mental health, including anxiety and depression, and 25% felt isolated and lonely. Corroborating this, reviews and meta-analyses have also found a higher prevalence of psychiatric disorders, particularly disorders of anxiety and depression, in carers of someone with cancer when compared to controls (Mitchell et al., 2013). Geng et al. (2018), in a systematic review and meta-analysis on the prevalence and determinants of depression in 21,149 carers of someone with cancer (69% were female), noted the prevalence of anxiety at approximately 47% and depression at approximately 42%. Several associations or 'risk factors' were identified between depression and sleep quality, being a spousal carer, financial problems, duration of care (longer time caring) and female sex. The authors suggested that support, especially for women, may improve quality of life. The suggestion that female carers experience more negative outcomes, such as depression, than men is a debated issue that I will return to in the penultimate section on gender.

Common physical problems reported by carers include sleep disturbance, pain, fatigue, weight loss and weight gain (Stenber et al., 2010). Aranda et al. (2001) found that fatigue resulted in a reduced ability to concentrate, reduced motivation and decreased ability to perform usual activities. At a physiological level, research also suggests that the combination of prolonged stress and the physical demands of caregiving may impair the physiological functioning of carers and increase the risk of health problems. Teixeira et al. (2019) conducted a review to synthesise the psychobiological stressors associated with the provision of care in carers of patients with a range of cancer types. Their results suggest that cancer carers, in comparison with controls, present higher electrodermal (electrical activity of the skin) and cardiovascular reactivity, which may contribute to an increased risk of cardiovascular disease and immune suppression. While only five studies were included in this review, their results are similar to previous research conducted with carers in other caring contexts, such as autism and chronic pain (Moya-Albiol et al., 2011). However, the studies in this review did not control for the potential role of socio-demographic and psychological variables. Other studies suggest that factors such as gender (Moya-Albiol et al., 2011) may influence this association.

Qualitative research into why carers may feel anxious, stressed or depressed, and what it is like to perceive these difficult emotions, provides crucial insight. Interviews are primarily used to collect data along with focus groups (for example, Leonidou et al., 2018) or sometimes open-ended survey questions (Montford et al., 2016). Across the literature there is a mixture of 'carer only' and dyad (patient/carer) study samples. Common types of analysis include thematic and interpretative phenomenological analysis. There are very few studies that use a narrative approach to explore caring within the context of cancer. Indeed, none were deemed to be relevant for this section of the review on the impact of care[11].

Balfe et al. (2016) interviewed 31 carers (77% female) of someone with head and neck cancer and analysed the data using thematic content analysis. Carers spoke about being highly distressed and linked this to weight gain, weight loss, and poor sleep quality. The authors' interpretation of why they felt distressed was related to thoughts about death, fear of cancer recurrence, restrictions on their life (such as a lack of socialising), anxiety over leaving the patient alone, competing demands on their time, seeing the person suffer, and financial pressures due to giving up work or paying for extra expenses such as home help. A final theme in this study was 'loss'. The authors considered that this spanned every aspect of the participants' distress – loss of routine, loss of connection, loss of a sense of future and, ultimately, a loss of self. The idea of a 'loss of self' has predominantly been applied to the person experiencing the illness (Charmaz, 1983). However, the authors considered that this loss may be felt more intensely by carers as they need to keep their loss hidden and 'put on a brave face' (Balfe et al. 2016:2325).

The role of loss amongst carers of someone with cancer has been explored by other scholars under the concept of 'anticipatory grief' (Kelly, 2008). This refers to the sense of loss in both the present and the future, for example, a loss of freedom and hopes for the future (Rando, 2000). Olson et al. (2014), based on qualitative interviews with 32 carers of someone with cancer, suggested that carers report 'indefinite loss'. Indefinite losses are not certain and are particularly relevant to carers who are caring for someone with a life-threatening diagnosis but not in the terminal stages. Wong et al. (2019) identified similar ideas, using

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[11] For reference the papers that do use a narrative approach on carers of adults with cancer (not bereaved or end of life) are Schaepe (2011) and Gilbert et al. (2014). Something I have noted is that authors will claim to analyse 'narratives' or use a narrative approach in the abstract but then they describe, for example, thematic analysis in their method section.

photography and group discussions to explore distress in carers (n=7) of someone with pancreatic cancer. Themes included changes in identity and fear for the future. As an aside, Wong et al. (2019) recruited a more balanced sample of male and female participants (four females, three men). It has been considered that research methods such as photo-voice may encourage a higher proportion of males into research as it creates a way of engaging with men who may be less willing to participate in an interview. The experience can feel less structured, which is useful with complex or sensitive topics (Affleck et al., 2012). I will pick up this point in my method chapter (chapter 5).

A qualitative approach is appropriately used when little is known about the topic or when a concept should be explored rather than measured. Trudeau-Hern & Daneshpour (2012) using grounded theory, aimed to explore how spousal carers (six males/six females) connected their caregiving experiences to their health – the novel idea here was the qualitative exploration of a *process* of caring. The authors, using open-ended questions, wanted to facilitate the development of the participants' responses from diagnosis to the present which was, on average, 4.5 years. Questions were framed around the idea of capturing change – change in emotions, routines, health and relationships. Themes identified included the emotional journey, hardships, protective factors, need for connection, the unknown, and silent communicator.

This last theme relates to the point made by Balfe et al. (2016) about carers keeping their feelings hidden. Trudeau-Hern and Daneshpour (2012) found that most of the carers in their study admitted to not bringing up their emotions when talking to their spouse. These emotions, described in the interviews, included anger, fear and anxiety. Not wanting to offload these emotions onto their partner, the carers directed emotions such as anger towards the cancer. For instance, they wanted to 'fight' the cancer for their spouse. The authors interpreted this as an action phase, as it helped the carers to feel in control. However, neglecting their own needs had a negative impact on health. Issues such as insomnia, weight gain, chest pain and depression were also noted across the participants in this study. Research such as this, that focuses on the process of caring, is valuable as it moves away from the idea of capturing caring accounts with singular outcomes. However, the participants in this study were asked to retrospectively recall a period of, on average, four years. An alternative way to capture that process would have been as it happened through longitudinal interviews. However, it is recognised that often researchers do not have the time or the resources to conduct a longitudinal study.

2.4.2 Practical and social impact

Much of the focus in the literature is on the psychological and health impact of caring. However, the economic impact of caring also has major consequences for the individual and society. Bradley (2019) reviewed the source and impact of financial burden on carers of someone with cancer. Employment loss, reduced work productivity and out of pocket expenses were some of the challenges carers faced. This can be particularly difficult for the family if the carer is the higher wage earner and they are not entitled to any form of 'sick' pay. In a longitudinal study of breast cancer patients and their carers (n=89, 55% male), two-thirds reported that caring had an adverse impact on their work and three-quarters admitted to missing time from work. Loss of work and productivity has been associated with negative mental health and low quality of life outcomes (Mazanec, 2011).

Mosher et al. (2013) recruited carers (n=82) of someone with lung cancer and measured economic and social changes at baseline and then three months later. Of the sample, 74% noted adverse economic or social changes such as loss of involvement in usual social activities, reduced hours at work and loss of income. Loss of involvement in work and social activities has also been linked to loneliness and isolation in carers (Gray et al., 2020). However, the sample in the study by Mosher et al. (2013) was predominately white and middle class and 70% were women. Also, as the study was conducted in America, most of the participants had health insurance. That is not to say these individuals were not adversely impacted, but when considering economic issues the socioeconomic profile of the sample is important. For example, a UK-based study exploring the concerns of those who used a community cancer service noted that financial concerns were a major source of worry for people affected by cancer (patients and carers) but particularly amongst those who resided in areas of high deprivation (Snowden, et al., 2018). It is important to acknowledge that certain groups of people will be impacted by caring in different ways.

For that reason, Moor et al. (2017), recognising that most research on caring and employment has been conducted in small, single cancer site samples, provided population-based estimates of the effect of caring on employment. Overall, their results (taken from two large patient surveys n=1677 and n=2572) indicated that approximately 25% of carers make employment changes such as taking paid and unpaid leave, sometimes for longer than two months. Those who made employment changes differed from those who did not in terms of time since diagnosis and prognosis. Time spent caring and the economic burden was greatest in the acute treatment phase and at the end of life. Accordingly, in a Delphi study (Lambert et al., 2019) designed to draw out research priorities for carers of someone with cancer, high importance was given to understanding more about the 'cost' of caring in terms of time, productivity, employment and the financial strain.

2.4.3 Positive aspects of caring

Before moving onto the next section of this review, it is important to draw attention to the often overlooked positive aspects of caring. As the positive side of caring is under researched, I carried out a systematic review to develop understanding in this area (appendix one for the full review). The relevance to this study is the identification of various attributes that are associated with positive experiences. Despite the challenges associated with caring, a combination of internal and external factors enabled some carers to report positive experiences. These attributes were personal resources, finding meaning, and social support.

Personal resources included characteristics and beliefs, such as self-efficacy and optimism. Personal characteristics are a major element in conceptual models of cancer caring as they appear to mediate the impact of stress (Fletcher et al., 2012). Therefore, for the carer, identification of these characteristics is important as they may be susceptible to clinical intervention (Gustavsson-Lilius et al., 2012). I recommend that more understanding is required around *how* these characteristics may cause positive wellbeing or if they change over time. A suggestion is that these personal resources are used when an individual develops their coping strategies (Saita et al., 2015). However, given the complex nature of caring, coping strategies are also likely to be related to specific caring demands (Fitzell & Pakenham, 2010; Stamataki et al., 2014). Investigation into the direct and interacting relationship between these variables would be valuable.

The search and discovery of meaning is a key component in the psychological adjustment to stress (Hasson-Ohayon et al., 2015). At the centre of this process is appraisal. Three qualitative studies (Mehrotra & Sukumar, 2007; Ussher et al., 2013; Wong et al., 2009) identified that having attributes such as optimism and mastery enabled the carer to appraise the caring role in a meaningful way. In addition, Fitzell and Pakenham (2010), using regression techniques, found better adjustment outcomes when the carer appraised caring as offering them a personal challenge, rather than as being threatening and limiting opportunities for personal growth. The theory suggests that an individual gains positive value by appraising their situation as having provided benefit (Folkman & Greer, 2000). This is a well-established finding, particularly in the cancer patient population (Wonghongkul et al., 2006). However, more insight is needed within the carer population.

Kim et al. (2015) investigated the role of gender, motivation and quality of life among 369 family carers. They found that self-determined motives for caring played a larger role among men than women, that having a greater sense of autonomy was related to improved quality of life, including finding meaning. This study brings into focus the need to investigate positive experiences from the interrelated individual, social and cultural context within which they occur. Accordingly, it is unlikely that any of the factors identified here either act in isolation or can be considered one-dimensional. As such, the social context plays a vital role in carer perspectives. In particular, *social support* plays a key role in promoting positive aspects of caring but the process of accessing support is not straightforward.

2.4.4 Social support

The benefits of social support are well documented in the literature in terms of promoting and maintaining wellbeing, coping and adjustment (Nijober, 2001; Butow et al., 2014; Cassidy, 2013; Ownsworth, 2009). Social support has been defined by the National Cancer Institute (NCI) as ‘a network of family, friends, neighbours and community members’ (NCI, 2019). However, the phrase ‘social support’ is another umbrella term that is used in the carer (and wider health) literature to refer to a number of elements. It is common to read about the benefits of social support without any explanation as to what that actually means in terms of the type of interaction (for example, a phone call, a text message, a face-to-face conversation) and/or the intensity and frequency of the support. Related to this, Kinnane and Milne (2010) suggested that there is a lack of uniformity in the measurement of social support in the carer literature. Consequently, differences in the conceptualisation and measurement of social support will shape findings in terms of the role and influence of support.

Nevertheless, there has been some work to try and understand this concept in greater detail. Using a qualitative design, Law et al. (2018) aimed to understand who carers (and patients diagnosed with colorectal cancer) considered to be supportive and their function. Their findings indicated that the treating team (nurses, doctors, allied health professionals) played a major role in the carers' (n=10) support – especially in dealing with physical changes and side effects. Also, emotional support (listening, talking, reassurance) from friends, family and the treating team was identified as a key source of support. In particular, the strength of the bond/interaction was emphasised as being an important part of emotional support. These qualitative findings highlight the more subtle and interactional nature of support that is not as easily captured in quantitative studies.

Nijboer et al. (2001) suggested that it is useful to divide support into two broad categories – emotional and practical/problem-oriented, because different types of support may have a main or moderating effect on the carer. They found in their longitudinal study that carers (n=148) who received daily emotional support (such as a hug) had lower levels of depression, over a time period of six months, than those with low levels of emotional support. Other scholars have followed suit. Garcia-Torres et al. (2020) conducted a longitudinal study with 67 carers (65% female) to explore the predictive validity of different types of social support on levels of psychological wellbeing, six months after a partner's cancer diagnosis. They found that anxiety was predicted by lower levels of informational support. The close time from diagnosis was considered to drive the carers' needs for information. Jablonski et al. (2020) found that, in 61 male partners of women with cancer, a lack of practical support was associated with higher levels of burden. The authors of this study considered that this may be related to the fact that men tend to approach caring in a practical and task-based manner and therefore benefited the most from this type of support.

The extent to which support can have a positive impact on health outcomes was investigated by Kelley et al. (2019), who gathered data on social support (practical and emotional) and health (using a single item question) from lung and colorectal patient/carer dyads (n=928) at five months and 12 months post-diagnosis. Overall, across disease sites and time from diagnosis, personal perceptions of support were related to positive health outcomes. However, specifically at 12 months post diagnosis in the lung patient/carer dyads, patient social support was associated with carer self-reported health and vice versa. Acknowledging the limitations of only using a single question to assess health, rather than using a more detailed measure to capture different components of health, these results highlight that the 'day-to-day' interactions that occur between patients and carers are meaningful. The authors suggested that for social support incentives to be effective (for patients and carers) then a better understanding of the interactions that occur outside of the healthcare setting is required.

Taking this idea forward, Reblin et al. (2018) developed a tool called the Social Network Assessment Program (SNAP). This digital app asks carers to visualise their support network by asking questions about available sources of support across six domains, such as emotional, informational and financial. If carers identify less than three resources in each domain they are provided with recommendations about local community services or information sources on websites. In their pilot testing of the app with carers (n=30; 75% female) of someone with a brain tumour, Reblin et al. (2018) did not find any differences in burden, depression and satisfaction with social support between the control and intervention group. Further, depression actually significantly increased over time for both the control and intervention group.

On the surface this does not seem to be an effective intervention. However, it is fair to acknowledge that this app represents one of the few interventions to support carers in a self-directed way, rather than by trained professionals. This is beneficial from a resource and capacity perspective. Moreover, there is evidence (Gray et al., 2020) that carers feel that they cannot leave the person they are caring for. Thus, an app such as this would allow the carer to access support in the home. Of course, the self-directed nature of the app may be the very feature that individuals dislike, preferring instead to have personal interaction. Indeed, Applebaum et al. (2016), in a meta-analysis of existential distress, reported feelings of isolation and a lack of support from the health service among carers of someone with a brain tumour. Views on expectations around who (professional, organisation, family member) should provide support, and where it should be accessed, are important.

The findings of Reblin et al. (2018), that levels of depression increased over time (six weeks) does bring into question how useful this intervention is in terms of supporting carers. Clinical context, however, is important here. Caring for someone with a brain tumour can be particularly challenging due to cognitive decline, sensory loss, seizures and personality and behaviour changes (Arber et al., 2013). Therefore, it is likely that these carers will have needs and concerns that are beyond the scope of the self-directed app. The authors did acknowledge that more work needs to be done to develop the functionality of the app. While this seems sensible, I think it would be remiss not to consider a more detailed exploration of the data generated from the app, in terms of what types of support carers lack (and any differences amongst categories such as age, gender and ethnicity) and how an app such as this can be used in conjunction with other sources of support, such as 'drop in' support offered by the third sector. Qualitative research with oncology professionals has highlighted that patients and carers report optimal outcomes when they access support from a *range* of sources across the health, social and third sector (Young & Snowden, 2020).

However, a crucial issue to address, before any questions about the form and delivery of supportive interventions can be considered, are the challenges behind obtaining support and carer perceptions on accessing support. It has been reported that 70-80% of carers come into contact with a health professional (doctor, consultant, nurse). However, only 7-10% of health professionals identify carers (Macmillan Briefing, 2013). In the cancer context, more than one in three people who care for someone with cancer have not been recognised as a carer by any health or social care professional (NHS England, 2014). Therefore, if a potentially large number of carers are not being identified, it is reasonable to assume that they are not accessing support.

Olson et al. (2014) conducted longitudinal interviews with 32 Australian carers who looked after spouses with a range of cancers at varying stages. Exploring carers' support preferences, the authors identified that less than half of the sample were attending a support group. Interestingly, there were (unusually) more males than females in this sample (18 males and 14 females), so this figure may reflect the fact that some men are unreceptive to the idea of attending a support group (Olson et al., 2014). However, the carers who were not accessing support reported a lack of awareness and 'being left' to find out what they could themselves. Navigating the different health and social care systems is likely to be challenging for carers. A qualitative enquiry into the needs of UK-based carers (n=34) of men with prostate cancer, found that barriers to carers meeting their needs included feeling unsure who to ask for help, lack of confidence, a reluctance to broach sensitive subjects, and fears that their requests may adversely affect the care of the patient (Sinfield et al., 2012).

Even when support is offered, another issue is uptake. For example, the SNAP tool provided recommendations to community resources but there was no follow-up to ascertain if the carers actually accessed the support. Signposting or referring someone to support does not guarantee that they will use it. For example, Mosher et al. (2013) recruited 83 American family carers of someone with lung cancer who were considered to be distressed, as determined by the Hospital Anxiety and Depression Scale (HADS). They found that, although all of the carers reported clinically meaningful distress, only 13% were using mental health support, such as support groups or counselling. Similarly, Merckaert et al. (2013) reported that only 24% of carers (n=152) of cancer patients with a range of cancer types, who had moderate to severe distress, *wanted* any formal support. However, a younger age, a higher education level, and the patient's desire for support was positively associated with a desire for help.

These figures highlight that there is no clear link between feeling distressed and taking actions to help reduce the distress. A number of explanations have been offered as to why that might be the case amongst carers, including not perceiving the distress as a problem (Vanderwerker et al., 2005), the desire to deal with it personally by using their own coping mechanisms (Boele et al., 2017), stoic attitudes with the view that seeking help is a sign of weakness (Carolan et al., 2018), stigma associated with mental health services (Carolan et al., 2018), feeling too busy or immersed in caring to access support (Olson et al., 2014), guilt at accessing support when they are not the one who is ill (Mosher et al., 2015) and to protect their partner/family from emotions such as fear and anxiety (Tan et al., 2014; Applebaum et al., 2012). This latter point has been identified as a particular issue for men. Tan et al. (2014), in a qualitative exploration of coping in adjustment in melanoma patients and carers (n=14), found that for some male carers not disclosing distress enabled them to maintain a protector role in the family. This aligns with the observations of Spendelow et al. (2018), derived from their systematic review on coping and adjustment in male carers, that coping strategies driven by traditional masculinities such as the protector role can have positive value.

Accordingly, it is not enough to state that social support is beneficial for carers. Research has been conducted to try and understand how different types of support may be associated with positive outcomes, or not. A supportive network may include family members, health professionals and resources such as apps and community services – each one has different strengths and limitations. However, a significant challenge for carers is being signposted to the support in the first place. The desire to protect the care receiver from negative emotions, and feeling their needs are not worthy of attention, adds further complexity to an already challenging situation. Given these issues, drawing on data generated in a three-year UK study on the psychosocial needs of cancer patients and their main carers, Soothill et al. (2001) found that 43% of carers have significant unmet needs. Items of significant unmet need clustered around aspects of managing daily life, emotions and social identity. These were the same areas of significant unmet need for the patients. However, carers had more of these concerns, highlighting the need for tailored effective interventions.

Certain attributes and circumstances can intensify caring experiences, such as adverse clinical circumstances, a lack of information and training, disruptions to employment, and a lack of social support. In contrast, a supportive network and personal attributes such as confidence and mastery can act as a buffer against stress. A further element that has a profound impact on the reporting of carer experiences, but which has not received an appropriately detailed exploration in the literature, given the complexity, is gender.

2.5 Gender

In its simplest terms, gender is a sociodemographic characteristic that interacts with variables such as age, ethnicity, and socioeconomic status to impact on carer experiences. The theoretical components of gender will be discussed in the next chapter. In the psycho-oncology patient literature, there is an abundance of research about sex/gender differences (I am deliberately conflating the terms to mirror the literature) in terms of coping, disease progression, social resources, adjustment, quality of life and so on (Moynihan, 2002). However, reporting a difference does not always shed light on the reasons *why* there is a difference (Kim & Loscalzo, 2018). Even when the focus is on a sex specific cancer (for example, prostate cancer), there is less research on the way the cancer may interact with men's experiences and expressions of masculinity (an exception being Kelly, 2009) in favour of relying on epidemiological data (Gray, 2020). There is considerably less research exploring gender and sex/gender differences in the carer literature. However, what is notable across the entire field of psycho-oncology (patients and carers) is a distinct lack of research that considers how gender, as a *socially constructed phenomenon*, rather than a trait, interacts with outcomes, perceptions and experiences.

Kim & Loscalzo (2018) suggest that only a few studies to date have corroborated any gender theories within a cancer carer population. Yet, it is fairly consistently stated in the caring literature that female carers report higher rates of distress, depression and anxiety and lower quality of life ratings in comparison to male carers (Ketcher et al., 2019; Marks et al., 2002; Hagedoorn et al., 2000). Consequently, some scholars have concluded that women are more emotionally burdened, due to their caring circumstances, than men (Swinkels et al., 2019; Pinquart & Sorenssen, 2006).

Justifications are rooted in views about roles, self-conceptions and psychological reactions that emanate from specific ideological lenses, such as social inequality. For example, for sociologists, the social role theory of differences between men and women reflects the position of men and women in broader social hierarchies (Eagly & Wood, 2000). People then carry out gender roles as they enact different roles and positions in society, such as a parent or an employee (Eagly & Wood, 2000). Men and women may live in different structural contexts with different distributions of rewards, opportunities, responsibilities and privileges (Swinkels et al., 2019). This may expose men and women to different kinds of stressors. It has been suggested that the role of women in families makes them more nurturing and relationship-focused (Dorres et al., 2010). For female carers, this can result in compulsive caring, over-responsibility and added pressure, which is linked to distress (Forssen et al., 2005).

Related to this, Haggedorn et al. (2000) suggested that the carer role is more 'familiar' to women than men in terms of them taking greater responsibility and looking after the emotional needs of family members, which will impact on reported levels of distress. Kim et al. (2018) found similar theoretical justifications in their review, highlighting the difficulties that women may face as they juggle competing demands on their time, which they suggest is underpinned by the role strain theory. These are valuable interpretations, but they predominantly rest on the assumptions from certain perspectives (first developed in the 1950s) that suggest because women are more *likely* to provide caring roles, they are more susceptible to emotional vulnerabilities. Furthermore, it has been suggested that in certain circumstances these gender differences may diminish. Kim et al. (2006) found in a study of 429 carers of someone with cancer that male spousal carers were more distressed than female carers when their wives had poorer psychosocial functioning.

Swinkel et al. (2019) have added to the debate. Drawing upon data from carers (n=806; 57% female) in the Netherlands who care due to a range of circumstances (such as cancer, stroke and dementia), they examined gender differences in burden using structural equation modelling. Guided by the stress-appraisal model (Chappell & Reid, 2002), as opposed to theories on social roles, they considered that gender differences arise through the differences in the conditions of burden. In essence, stress-appraisal models have been developed to explain the relationships between carer stressors, appraisal, protective factors/coping strategies and carer outcomes (Goldsworthy & Knowles, 2008). For example, stressors may be the care recipient's deteriorating health, appraisal may be feeling out of control, protective factors could be perceived support and outcomes – the level of burden. In addition, the stress-appraisal approach separates overall subjective feelings of burden from secondary stressors – which are problems arising from the caring situation.

Subsequently, Swinkel et al (2019) found that female carers reported higher burden and more secondary stressors than men. These secondary stressors, which included financial problems and problems juggling different tasks, were associated with the increased burden in women. Hours spent caring increased burden in men but not in women. However, of note was that the carers had an average age of 73 years. It would be useful to replicate this study with middle-aged carers referred to (in policy and literature) as the 'sandwich generation', who balance care with work and/or caring for children and elderly parents. Furthermore, hours spent caring were used as a proxy measure for appraisal. However, as discussed (Olson et al. 2014) perceptions of time (or a lack of) can impact on emotional expression. An alternative, as used by Fitzell and Pakenham (2010) in their study on positive and negative adjustment in colorectal cancer caregiving, would have been to measure appraisal through a measure of stress, challenge and control.

Nevertheless, the study by Swinkel et al. (2019) makes an important contribution as it considers that men and women respond *differently* to caring circumstances, with men feeling more burden due to the intensity of the situation (their appraisal) and women due to the combination of primary and secondary stressors. These findings support the work of Savundranayagam and Montgomery (2010), who concluded that it is the subjective evaluation of the 'workload', as well as the subjective evaluation of its effects, that cause caregiver burden. Therefore, there is value in exploring justifications for male and female burden from different theoretical perspectives, as it mirrors the multifaceted and complex nature of both gender and caring. Male and female carers will face similar and different stressors. These stressors will elicit different appraisals and coping strategies. Yet, these appraisals (at a cognitive and behavioural level) are context specific – as amplified in the discussion on social roles and responsibilities.

Consequently, quantitative cross-sectional studies do not acknowledge how people engage in making emotional and cognitive sense of their family and caring circumstances. Without evidence on the mechanisms involved in creating these gender differences (or similarities), and insight into contextual factors such as specific work, family and household responsibilities, I am cautious of research that claims that either gender may be more severely impacted by their caring situation. That is because the *process* by which distress may be experienced, or not, has been disregarded. There is evidence to suggest that, rather than internalising distress as sadness, men may 'externalise' it through other outlets, such as aggression, over-working and substance abuse (Lomas, 2013; Mahalik & Rochlen, 2006) – that is, not in ways that are always measured in outcome-based studies.

And so, turning to the small field of qualitative research[12] on gender there are some valuable insights. Locher et al. (2010) explored the gendered organisation of care in relation

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[12] A search in September 2020 in EBSCO using the terms 'gender', 'carer', 'cancer', 'qualitative/interview' (separated by AND) only produced five relevant articles. I acknowledge other scholars have made reference to gender issues in their work but there are very few qualitative articles where gender (both sexes) is the primary focus.

to food and eating activities amongst 21 American carers, all of whom were over 68 years old. Male spousal carers expressed a lack of experience and felt helpless when they could not meet their wife's demands. By their own admission, none of the men in this study had engaged in meal preparation before their wife's diagnosis. However, both genders were distressed when the patient rejected the meal they had made as they saw it as a rejection of their care. This study draws attention to how something so routine as meal preparation can be associated with emotional content and thus become a source of distress.

The scholar who has made a notable contribution in this area is Jane Ussher. Drawing across her three qualitative publications (Ussher et al., 2008; Ussher et al., 2010; Ussher et al. 2013) that specifically focus on gender in carers of someone with cancer in Australia, she has raised some critical issues. Underpinned by a social constructionist analysis of gender roles and positioning theory, Ussher and her colleagues have explored gender differences in samples of Australian carers looking after family members with a range of cancers. However, two of these studies (2013; 2010) use the same sample of participants. Through semi-structured interviews and thematic analysis, Ussher and her colleagues have considered the way that men and women position themselves within the carer role. They also offer explanations for why men and women may perceive negative emotions such as depression and anxiety.

In their 2008 study, men (n=6) positioned caring as a competency task which they had mastered. This provided satisfaction but the emotions of the person with cancer, and their own emotions, were negative aspects of their caring experiences. For example, physical tasks were positioned as being unproblematic in comparison to emotional labour. Women (n=7) described being positioned as all-encompassing expert carers who were expected to be competent across a range of tasks, as well as providing emotional support. This, the authors interpreted, was related to the women's feelings of anxiety, isolation and 'self-policing' practices, where women internalise the notion of the 'caring self' as the normative feminine ideal. Subsequently, any feelings or behaviours that contradict this ideal may be silenced.

This idea was developed in their 2010 publication, where they identified that both men (n= 19) and women (n=34) 'self-silence' to put on a front and prioritise the needs of the care receiver. This was also recognised in the qualitative study by Emslie et al. (2009) of gender and spousal support after a colorectal cancer diagnosis. However, as identified from the quantitative component of the study by Ussher et al. (2010), men actually scored higher than women on the global rating of the 'Silencing the Self Scale' and on the sub-scale 'Care as Self Sacrifice', which relates to putting the care receivers' needs before their own. The authors considered that women self-silence to avoid external judgement that they are not a naturally 'good' carer, emulating an idealised version of femininity (Ussher, 2004), whereas men self-silence in response to hegemonic masculine norms that position emotional expression as a weakness (Ussher et al., 2010). Guided by this interpretation, both sexes were acting in order to live up to culturally constructed versions of masculinity and femininity.

Collectively, these studies provide a further rationale for acknowledging that there is a gendered component to caring experiences. There are similarities between men and women but there are some significant differences, with consequences for the carer's health. However, across Ussher et al's studies, the depth of discussion on male experiences did not match the detail and consideration given to the positioning of female carers. For example, there was not a great deal of discussion around the finding that men had higher scores on the 'Silencing the Self Scale'. Methods and findings are linked to the researcher's philosophical position, experience and perspective (Noble & Smith, 2015). Therefore, looking at their position they state 'women carers report higher rates of depression and anxiety, lower life satisfaction, experience greater personal loss and activity restriction, more unmet needs and greater burden' (Ussher et al. 2008:946). This was their starting point for their exploration into caring and so, understandably, it will have shaped their interpretation. While I value the insights from these studies, particularly around positioning theory, which I take forward in the next chapter, I am starting from a different perspective. This evidence is all part of the 'bigger picture', but I want to understand male experiences before seeking justifications as to why either gender may have more or fewer challenges.

2.6 Male Caring

There is a paucity of research on male caring. Early research (in the 1980s) into informal caring focused on the care of elderly parents and a large majority of these studies were from the perspective of women. In 1989, Arber and Gilbert, with a sociological lens, described men as ‘forgotten carers’. Drawing on data from the UK 1980 General Household Survey, they suggested that men make a bigger contribution to the care of the ‘infirm elderly’ than was recognised. Their explanations for why men are invisible to researchers and policy makers are that it has been assumed (but not demonstrated) that men who care receive support, and as women are more likely to care, gender norms relating to obligations and duty frame female caring as more ‘natural’. Therefore, men are ‘forgotten’ about.

Consequently, in the 1980s male carers were positioned as being atypical. The National Alliance for Caregiving (a US-based organisation) identified through a national survey that in 1987, 25% of carers (caring for a range of circumstances) were male. However, by 2016 this had risen to 40% (NAC, 2020). In Scotland, this is estimated at 41% (Scottish Government, 2019). With this shift, male carers have been represented more in the literature (for example, Russell, 2001; Calasanti & King, 2007; Willis et al., 2020) but predominantly in the context of dementia, Alzheimer’s disease and frailty (Robinson et al., 2014). A higher proportion of women are affected by dementia which may, to some extent, explain this focus, particularly within research where the participants are heterosexual spousal carers. It is encouraging to see a greater focus on caring in older age, as a higher proportion (59%) of carers who are over 85 years old are actually male (Slack & Fraser, 2014).

In terms of approaching caring as a gendered role, there have been some useful insights made in relation to older men’s experiences. For example, Milligan and Morbey (2016) explored how the feminisation of care impacts on men’s identity. They gathered written stories (n=15) and interviewed older men (n=9) who were caring for their wives due to a range of health conditions, including cancer, stroke, depression, Alzheimer’s and multiple sclerosis. In the main, the men in this study did not identify as a carer as they ‘were just looking after their wife’ (Milligan & Morbey, 2016:109). This manifested in a stoic approach, a reluctance to seek help and, in some, feelings of isolation. This latter issue was starker in this demographic as, unlike younger men, they did not have as many social opportunities that can arise through employment. The authors also noted examples of where the men drew on their practical skills to try and find solutions to their problems and there were also instances where the men ‘crossed gender boundaries’ and took on gender atypical tasks to provide both practical and emotional care.

Turning to the psycho-oncology literature, the evidence base on male caring is small. In the last ten years there has been a slight increase, with researchers predominantly seeking men who have a partner with breast or gynaecological cancer. Table 2 below summarises this literature[13].

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[13] Aligning to the main search strategy, the articles retrieved were from 1995 onwards and only focused on male family carers caring for an adult with cancer. End of life/palliative studies were excluded.

Design	Author & Date	Setting	Aims	Main findings	Relevance
Quantitative	Segrin et al. (2009)	USA	To evaluate interpersonal predictors of mental health in male partners (n=63) of women who have been recently diagnosed with breast cancer.	Quarter of the sample were considered to be depressed as measured by the CES-D[14]. Distress was worse if treatment had involved a mastectomy. Relationship satisfaction was associated with lower levels of distress.	Recognition of the dual impact of a mastectomy on the man and woman. Importance of the pre-established dynamics in the caring relationship in acting as a buffer against distress.
Quantitative	Bigatti et al. (2011)	USA	To examine depression, social support and coping in husbands (n=81) of women with breast cancer and husbands of women without chronic illness.	Husbands of patients scored higher on depression, lower on use of problem focused coping and equivalent low levels of support across the two groups.	These findings contradict studies that report little to no distress in male carers. Further, there was a relationship between perceived lack of support, inappropriate coping and depression with implications for improving men's access to support.
Quantitative	Cairo-Notari et al. (2017)	Switzerland	To examine subjective burden and couple satisfaction over time in	Burden decreased over time and those who were dissatisfied with their	Underpinned by the stress process model the findings indicated that the quality of the relationship had a bigger

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[14] Centre for Epidemiologic Studies Depression Scale (Radloff, 1977).

			men (n=47) caring for a spouse with breast cancer.	relationship were particularly vulnerable to burden.	impact on the negative impact of caring than the patient's condition.
Quantitative	Mazanec et al. (2018)	USA	To describe the perceived needs, preparedness, and emotional distress of male caregivers (n=50) of postsurgical patients with gynaecologic cancer.	Male caregivers' greatest needs were interaction with the healthcare staff and information. Perceived preparedness was not associated with emotional distress.	Assessing carers for their needs is an important step in identifying appropriate support. This study was conducted in America but carer assessment and identification is not routinely done in the UK. That the men had greatest needs around information links with evidence that men approach caring in a more practical manner.
Quantitative	Yeung et al. (2019)	China	To investigate the correlates of guilt in Chinese husbands (n=176) of women with breast cancer.	Higher burden was associated with guilt. For those who endorsed the 'masculine strength' gender norm 'seeking support from spouse' was associated with higher levels of guilt.	Masculine norms may provide the motivation to be strong and protect. However, support seeking is not always preferred, particularly from family members and within an Asian population.

Qualitative					
Qualitative	Samms, (1999)	USA	To identify husbands (n=9) perceived needs relating to their wives' breast cancer	Husbands' concerns relating to their wives' breast cancer changed across the illness trajectory. Husbands' misunderstandings about their own emotions hindered their ability to support their wives.	Expectations stemming from the male gender role guided their behaviours.
Qualitative	Hilton et al. (2000)	Canada	To explore men's (n=11) perspectives on how their wives breast cancer and chemotherapy impacted upon them and their families.	Men needed assistance with household tasks. The healthcare system was viewed as being patient focused and some did not feel acknowledged. Strategies used to buffer the challenges included being positive, adapting their work lives and putting their needs on hold.	Feeling unsure how to support their wife and not feeling acknowledged in the healthcare setting led to feelings of helplessness. The men felt a responsibility to keep 'family life going' by being positive and putting their needs second to their families.

Qualitative	Maughan et al. (2002)	UK	To investigate attitudes to illness with particular focus on coping and risk management among men (n=6) with a partner with gynaecological cancer.	Men viewed themselves as problem solvers and wanted to try and 'fix' their partners cancer diagnosis. The couples encountered sexual difficulties and problems with communication leading to strain. Men felt their needs had been overlooked.	Issues around acknowledgement and value- from family and health professionals. Men's coping styles are likely to be shaped by masculine norms – such as those promoting control and autonomy.
Qualitative	Fitch & Allard (2007)	Canada	To explore the impact of breast cancer on husbands (n=15).	Challenges were work-related demands and feeling uncertain how to support their wife. A positive was feeling closer bond.	A desire to be supportive may not translate into feeling effective. Issues around confidence and expected roles for men.
Qualitative	Harrow et al. (2008)	UK	To explore the experiences of male partners (n=26) of women who had completed treatment for breast cancer.	While negotiating a role in their wives' breast cancer experience the men attempted to find a balance between the ambiguity and uncertainty they experienced and their need to maintain normality.	Highlights the expectations embedded in this experience (such as to move on and find 'normality') and feelings of being 'in-limbo'. Ambiguity and uncertainty also discussed by Frank (1995) in the patient literature.

Qualitative	Zahlis et al. (2010)	USA	To describe male spouse's (n=48) experiences of their wives newly diagnosed breast cancer.	Men found providing emotional support difficult and dealt with their own emotions on their own. They reported a lack of support and did not want to burden their wife and they devised strategies to try and feel in control.	The 'work' involved in providing emotional support was challenging particularly when there was little to no outlet for their own emotions.
Qualitative	Lopez et al. (2012)	UK	To explore male spouses (n=15) experiences caring for partner breast/gynaecological cancer over one year.	Male carers dealt with problems that arose in the caregiving congruent with their masculinity, such as difficulty expressing emotions, focusing on tasks, and keeping their own stress to themselves. Overall, their distress and the challenges reduced over time.	Coping strategies driven by traditional masculinities may have positive value. Also, counter to the claim that men as less distressed than women this qualitative study has highlighted that men have difficulty expressing their emotions so may not report the distress.
Qualitative	Gilbert et al. (2014)	Australia	How does the male carer (n=1 case study) use narrative to make sense	Complex negotiation of masculinities including	Masculinity is a plural concept. In the context of cancer caring men may construct and perform different versions

			of his role caring for a partner with breast cancer.	strength, powerlessness, distress and 'heroic' strength.	of their masculinity. Use of metaphors to convey oneself in a particular way.
Qualitative	Chen et al. (2014)	Canada	To assess the perceived needs and preferred services of male partners (n=27) of women newly diagnosed with breast cancer.	All men reported emotional distress (in the interview) and wanted information, including practical advice on how to cope and what they can do to support their wife. Yet, little attention was given to their wellbeing. They did not want to join a support group preferring instead to use informal support networks.	Health care professionals are not recognising men's needs but also men are not articulating their needs.
Qualitative	Montford et al. (2016)	Canada	To explore the transition experiences of male spousal carers (n=91) of someone with breast cancer.	Analysis from an open-ended survey identified changes to roles and relationships, mental health and housework responsibilities. Fostering a positive approach and 'being involved' were critical processes in their transitions.	Change in various forms was a critical part of the carer experience. Transitions were facilitated by communication with partners and access to information and support.

Qualitative	Oldertroen et al (2019)	Norway	To develop knowledge on the experiences of male partners (n=6) of women with breast cancer.	Three main findings were related to loneliness, vulnerability and an altered sexual relationship.	Under hegemonic expectations the men wanted to protect and hide vulnerability. However, care is relational so by theorizing masculinity in this way too, highlights the way the men expressed an interdependence in their relationships with the women and others. They wanted to be acknowledged, valued and cared for.
Review					
Review	Petrie et al. (2001)	N/A	To conduct an integrative review to describe the needs of spouses of women with breast cancer.	Synthesis of 16 articles (published 1976 to 2000) found spouses have emotional, information, practical and spiritual needs.	Spouses had similar needs to the patient but they were overlooked by the health professionals.

Table 2: Male caring for someone with cancer – literature summary

2.6.1 Synthesis – male caring

This literature aligns to the general literature on caring for someone with cancer. Similar challenges include a need for information and support (Petrie et al., 2001), being 'seen' and recognised within the healthcare setting (Hilton et al., 2000; Maughan et al., 2002; Chen et al., 2014), putting the needs of the care receiver before their own (Mazanec et al., 2018; Hilton et al., 2000) and the importance of pre-established relationship dynamics, such as relationship satisfaction, which can act as a buffer against distress (Sergin et al., 2009; Cairo-Notari et al., 2017). In relation to that, a positive aspect of caring for men (and women) is feeling a closer bond with the care receiver (Fitch & Allard, 2007). However, some scholars have argued (not solely in the cancer literature) that men are more likely to feel a deepening of the bond or a greater sense of purpose than women (Calasanti & King, 2007). Nevertheless, as identified through these studies, men's perspectives have some unique elements. These relate to their task-oriented approach to caring (Mazanec et al., 2018), different and difficult levels of emotional expression (Zahlis et al., 2010; Lopez et al., 2012), low levels of social support (Bigatti et al., 2011), coping styles (Maughan et al., 2002; Bigatti et al., 2011) and the impact of male gender discourses on attitudes and behaviour (Gilbert et al., 2014; Oldertroen et al., 2019; Yeung et al., 2019).

There is a societal expectation for women to take on caring roles. Men have traditionally been defined as protectors and providers (Addis & Mahalik, 2003) so when they find themselves in a caring role, often suddenly and in state of shock, they need to adapt. Gilbert et al. (2014), in the most relevant study to mine, highlighted the complexity of gender identity through the idea that a man may not simply conform to or resist traditional forms of masculinity but rather there is a more complex negotiation of subjectivity depending on context. Gilbert et al. (2014) identified in their case study that the male carer positioned himself as a 'strong hero' but also as someone who was vulnerable and victimised.

There are three points I wish to emphasise from the study by Gilbert et al. (2014) that have implications for my interpretation of male carer experiences. Firstly, the conceptualisation of masculinity as something that is plural and fluid. This rejects the view of a single or a universal masculinity and embraces the idea of 'multiple masculinities', arguing that masculinity exists in diverse forms that change as a function of cultural and historical factors (Connell, 2005). This was also considered by Oldertroen et al. (2019), who noted a duality in men who wanted to protect and also feel cared for. Secondly, the performative nature of masculinity that can occur within caring circumstances, i.e. the way that men construct and present themselves in a particular way. For instance, Zahlis et al. (2010) found that the men in their study devised strategies to feel and appear in control but at the same time they 'built a wall' to shut down their own emotions. There was a clear pattern across a number of these studies to report on men's difficulties in expressing and providing emotional support. Yet, there is an evidence gap as, theoretically, emotion management within males caring for someone with cancer is largely unexplored. The third issue is that the endorsement of masculine norms can be associated with negative behaviours, such as aggression, or risky behaviours such as substance abuse (Cohn & Zeichner, 2006). But as Gilbert et al. (2014) found through the participants who positioned themselves and benefited from being a 'strong hero', these norms can have a protective function. This links with wider research that considers the way in which masculinity can function to both constrain and facilitate health behaviours among men (Gough, 2013).

Fourteen of these studies focused on caring for someone with breast cancer and the remainder for gynaecological cancer. Therefore, there is a need for research that explores male caring experiences within the context of different cancers because, as identified at the beginning of this chapter, the tasks and responsibilities that carers engage in, and perceptions around the perceived difficulty of these tasks, may vary depending on different clinical circumstances. The sample sizes within the quantitative studies were fairly small. While this alone is not always problematic, is does impact on the generalisability and validity.

Finally, only two studies (Lopez et al., 2012 and Cairo-Notari et al., 2017) investigated caring experiences over time. Caring begins at diagnosis but can last for years, or in some cases, if the individual has permanent side effects or emotional difficulties, for the rest of that person's life (Shaffer et al., 2017). For instance, Harrow et al., (2008) noted, in their qualitative study on men with a partner with breast cancer, that changes to roles and relationships required continual assessment of the impact of breast cancer on life expectations. Plans for the present and the future were continually questioned and refocussed. Furthermore, fear of reoccurrence is a major concern for patients and carers, years after diagnosis (Kim et al., 2012). In a systematic review on the effects of caring for a patient with cancer, Seal et al. (2015) made a recommendation that more research is needed to understand the variations in carer experiences over time.

Chapter Conclusion

This review, based on primary research, policy and reports produced in the third sector from 1995-2020, provides an overview of the support carers provide. It synthesises common carer experiences and documents positive aspects of caring, as well as the challenges. These challenges exist at an individual and societal level. Carers have peripheral status, therefore organisations have campaigned for carers to have more rights and greater status. Despite policy identifying the obligation to identify carers and assess their needs, the evidence demonstrates that this is not happening in the majority of cases. Consequently, carers are experiencing adverse impacts to their health and wellbeing while feeling ignored and undervalued.

This review has identified important knowledge gaps. Firstly, the overreliance on quantitative correlational studies, largely driven by the psycho-oncology field, means that there is less understanding of how carers make sense and construct meaning from their caring experiences. Secondly, there is a lack of research that explores the process of caring over time. Thirdly, I have challenged the view that female carers are *more* emotionally distressed than men, with evidence that sample sizes are biased towards women and evidence from studies that capture high levels of distress in men. Furthermore, it has been considered that men may feel distressed but they may be more prone to hide their distress than women.

The influence of masculine norms and their associated standards and expectations, to provide, to be stoical and self-reliant, can overshadow the fact that men who are faced with caring responsibilities may feel powerless, scared and vulnerable. When men care, their task-based, problem solving approach can be interpreted as them being less distressed or less emotionally giving than women. However, an alternative idea is that a man's approach to caring reflects a way of redefining the carer role (positioned by society as female) in *masculine terms*. The next chapter will take these ideas forward and ground them in theor

CHAPTER 3: THEORETICAL APPROACHES

Structure of chapter:

- *Social constructionism*
- *Social identity*
- *Carer identity*
- *Discourse*
- *Gender identity*

Overview

The purpose of this chapter is to arrive at a theoretical understanding of male carer identity. This will be done by discussing identity through three broad categories – social identity, carer identity and male carer identity. By moving through the wider features and qualities of social identity to the specifics of male carer identity, I will present a multi-layered theoretical understanding of identity that considers how individuals acquire and develop a sense of self under caring circumstances. In order to navigate through these approaches, I will apply a number of 'lenses' drawing on work from psychology, sociology and discourse-based theories of identity that provide the vocabulary to articulate the factors that I consider to be important in this study on male carers. Central to this approach is a focus on identity as *socially constructed*. Constructionist theories treat the term 'identity' itself as a socially constructed category – it is whatever people agree it to be in a given historical and cultural context. Constructionist approaches explore how people perform, ascribe and resist identity and how identity is produced in talk and text. Consequently, the question that guides this chapter is: *How do individuals construct and interpret their male carer identity?*

To answer this question the chapter is divided into five sections. The first introduces **social constructionism**, discussing the origins and core assumptions that underpin this approach. These assumptions are that our reality is socially constructed and that this reality is mediated by the particular social and historical context we are in. Subsequently, in order to unpack these assumptions, I will reflect on the proposition that our knowledge of the world is constructed between people. That is, how our social reality is made possible through social processes. This is intended to be a window to enable the reader to view the variety of approaches to identity that follow.

In the next section I discuss **social identity** by introducing the concept of collective identity and contrasting constructionist approaches to essentialist beliefs about identity construction. The purpose of this is to demonstrate how different interpretations of identity can permeate into wider and non-academic beliefs about sex and gender. Situated within this broader debate on social identity is a discussion on **carer identity** in the third section, specifically discussing how an individual may acquire their carer role by drawing on 'positioning theory', and also considering how men's positioning in society has meant that their emotion management in response to caring is overlooked. In essence, this section brings into focus and emphasises the construction of identity through language and social relationships.

This focus on language brings me to the penultimate section of the chapter which explores **discourse**. An exploration of language in its social context requires an examination of discourse. The overarching point in this discussion is that discourse is more than language – it is what we say, how we say it, who we are and what we are doing while we say it.

Consequently, this section provides a bridge to the final section which explores **gender identity**. In this section I bring the former discussions together and draw attention to how gendered discourses can influence how men and women are presumed and expected to behave and feel. Moreover, these discourses make available particular subject positions that, when taken up, have implications for caring experiences. In this section I focus specifically on masculinity, discussing the role of hegemonic masculinity and the idea that men may 'perform' different versions of themselves depending on the audience and the social interaction.

By moving through theoretical approaches the aim is to offer a multidimensional approach to identity that is underpinned by reference to particular historical periods, thinkers, debates and empirical research. The end point is an understanding of identity as dynamic, fluid and specific to a particular historical and cultural context.

3.1 Social Constructionism

Social constructionism is referred to as an approach, a movement, a theoretical orientation and a position (Stam, 2001). While scholars do not seem to agree on a label or status, at a general level the fundamental assumption underpinning social constructionism is that reality is socially constructed (Burr, 2006). As explained by Gubrium & Holstein:

> '*The leading idea of social constructionism has been that the world we live in and our place in it are not simply 'there', rather participants actively construct the world of everyday life and its constituent elements.'* (Gubrium & Holstein, 2009:3).

3.1.1 Origins

Following the publication of the sociologists Berger and Luckmann's (1966) seminal text 'The Social Construction of Reality', social constructionism began to emerge and take shape. Berger and Luckmann's core premise was that the sociology of knowledge should be concerned with the relationship between human thought and the social context in which it arises. In their own words:

> '*A sociology of knowledge will have to deal not only with the empirical variety of 'knowledge' in human societies, but also with the processes by which any body of 'knowledge' comes to be socially established as 'reality'.'* (Berger & Luckmann, 1966:15).

In turn, Berger and Luckmann derived their perspective from the thinking of George Mead, amongst others. Mead was an American philosopher and social theorist who placed emphasis on the social self, suggesting that each of us develops a sense of self through engagement with other selves (Mead, 1934). Mead has been considered by some to be one of the 'founding fathers' of the school of Symbolic Interactionism – a body of social theory which focuses upon the process of interpersonal interaction based on the use of symbols (Bilton et al., 1996; Andrews, 2012). Hence, social constructionism has various multidisciplinary roots emerging from the combined influence of American, British and continental writers from across social sciences, humanities and literary studies.

As a result, there is no single social constructionist 'position'. Burr (2006) offers an analogy to the many writers who adopt social constructionist ideas as having 'family resemblance' –

that is, there is no one feature that identifies a social constructionist position but there are key assumptions and defining features. Before introducing these main features, I will offer a definition of social constructionism whilst acknowledging the complexities attached to this multidimensional concept.

3.1.2 Defining social constructionism

The array of disciplines and approaches that underpin social constructionism creates a challenge when trying to locate a definition. Therefore, I am guided by Hibberd (2006), as she has produced in her text 'Unfolding Social Constructionism' a general statement on social constructionism that provides a useful starting point:

> *'In general, social constructionism emphasises the historicity, the context-dependence, and the socio-linguistically constituted character of all matters involving human activity.'* (Hibberd, 2006:8).

This statement provides insight into how social constructionists view the world, namely that they focus on the interaction between people within a particular historical and sociocultural context. The emphasis on 'linguistically constituted character of all matters' emphasises the idea that knowledge and reality are constructed through language. I will now elaborate on these points – *the construction of reality* and the importance of *sociocultural context* as they are defining features of the social constructionism approach.

3.1.3 The social construction of reality using language

A fundamental assumption within social constructionism is that reality is socially constructed. The process of reality construction is deemed to be *social* as it involves a process of social interaction. In other words, social constructionists propose that our knowledge of the world is constructed between people. This is why language is of particular interest to social constructionists. Spoken language is one system which enables people to communicate understanding and experiences to one another and it allows people to share a common reality. However, social interaction of all kinds including influences from art, literature and media are also significant.

John Searle, an American philosopher noted for his contributions to the philosophy of language, mind, and social philosophy framed his writing in The Construction of Social Reality around the question 'how is a socially constructed reality possible?' (Searle, 1995). This question seems particularly complex as our social reality is not something we can hold or point to – it is invisible and perhaps taken for granted. Therefore, to answer this question it is helpful to consider how reality becomes intelligible, that is how individuals are aware of it.

In crude terms, consciousness is a biological, physical and cognitive feature of human beings that makes us aware of internal and external happenings (Gennaro, 2011). The complexity of debates on consciousness is considerable, covering extensive terrain across philosophy, psychology, cognitive science and neuroscience. For that reason, it is beyond the scope of this discussion to delve into these debates. However, I will draw from these debates an admittedly condensed point as it acts as the foundation for subsequent discussions on the construction of a social reality.

Searle (1995) states that with consciousness comes 'intentionality', a term referring to the capacity of the mind to represent objects and beliefs. Note that intentionality here does not mean intended or deliberate as it is taken from the Latin word 'to point' (Gennaro, 2011). This is perhaps clearer if I refer instead to representations – representations are things that are about something else. For example, the words we speak are representations. If I was to say that my favourite colour is red I have said something about my favourite colour – the words carry information. The sound 'red' means the listener will know that I am talking about a particular colour that is the same colour as, for example, a ripe tomato. Therefore, individuals have mental states that have agreed and shared representations. This is logical to a point, but it becomes harder to conceive when considering how more abstract entities such as power or freedom are represented.

The feature of language that is crucial for the establishment of complex abstract thoughts is the existence of symbolic devices that mean or represent something beyond themselves (Searle, 1995). For example, if I was to verbally state 'Boris Johnson is the Prime Minister of the United Kingdom', these words symbolise something beyond themselves relating to power, competency, responsibilities and political institutions. These symbols represent a reality that 'we' (society) collectively accept and recognise. Hence, some facts, such as[15] 'Boris Johnson is Prime Minister', depend on human institutions. The central point is that if consciousness is the medium by which reality becomes intelligible, and if there are 'collective realities' (Burns & Engdahl, 1998), it helps to understand the processes by which a *social reality* is constructed and ascribed meaning.

Building from this, social constructionism suggests that our ways of understanding the world come from a reality shared with other people. This means that knowledge and beliefs are shaped by social processes. For example, taking the statement again that 'Boris Johnson is Prime Minister', social constructionists suggest that this knowledge is constructed between people. What individuals understand as 'Prime Minister' is not a product of an objective observation but a product of the social practices that are bound up in that statement relating to political institutions. In other words – things that people believe can be derived from, and maintained through, social constructionism. They are created by human beings who share meanings as they are members of the same society or culture. Accordingly, social constructionism places importance on the fact that the ways in which people commonly understand the world is situated within a particular historical, social and cultural context – the next core assumption to be addressed in this chapter.

3.1.4 The importance of historical, social and cultural context

A core tenet of social constructionism is that reality is a product of the particular social and historical context that individuals are situated in. For example, there are historical and cultural variations surrounding the concept of gender (Beall, 1993). These variations are shaped by historical and cultural expectations, norms and laws (Lorber, 2001). From a social constructionist perspective, gender is defined and shaped by interactions between people, by language and by cultural discourses. Under this assumption there is no universal characteristic of masculinity or femininity that is the same for all men or women across time and cultures. A case in point is how some beliefs about gender roles have changed over time.

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[15] Boris Johnson is Prime Minister – a fact at the time of writing (October 2020) (unfortunately).

Brewster and Padavic (2000) have explored beliefs about women's work and family roles in the United States over the past two decades. Using data from the General Social Surveys (1977 to 1996), they found that in 1977 most respondents (approximately 60%) from a sample size of 13,963, who were a representative sample of the US population, disapproved of women combining work and family roles. A majority (approximately 70%) believed that pre-school children suffer if the mother works and just under 60% of the respondents agreed that it is more important for a wife to help her husband's career than to have one of her own. Exploring these beliefs again in 1996, the authors found a considerable shift in view. One of the biggest changes was in the statement 'It is more important for a wife to help their husband's career'. This moved from just under 60% in agreement in 1977 to 20% in 1996. The authors of this study suggested that a range of factors played a role in the formation and change in these attitudes at the two time points. Examples include changes in age and education level of the study sample and broader societal factors such as expanding labour market opportunities for women, meaning that by 1996 a much higher proportion of women were in the labour force than in 1977.

Therefore, this research highlights that the way that someone may understand the world is culturally and historically situated (Haraway, 1988). The views expressed in Brewster and Padavic's (2000) study may be interpreted as being specific to that time and they can also be considered as products of that time. Over the years public beliefs about women's roles were seen to become more liberal due to changes in the labour force (and vice versa – it is arguable that the expansion of women in the labour force was only possible due to changing social attitudes) and general exposure to different sources of information in, for example, the media (Jaumotte, 2003). Collectively, this knowledge shapes and constructs an individual's reality. Acknowledging that this is just one example situated within a Western context, this study highlights that the gendered reality of being a woman is historically and socially situated because belief systems operate within a system of norms and expectations that are relative to a particular culture at a particular point in time.

3.1.5 Social constructionism – summary

Social constructionism places emphasis on social interactions and the meanings that are generated through these interactions. This is because a core assumption of social constructionism is that our understanding of the world – our reality – is socially constructed. Accordingly, language plays a key role in this approach as it provides the basis on which we make sense of the world. Language provides us with the categories that we use to classify and order concepts, events and persons, and this understanding is contextual. Knowledge is specific to particular cultures and periods in history. Focusing on these broad assumptions of social constructionism highlights the features that will have implications for how I approach and conceptualise identity – not as something that is located 'inside' someone as a product of their mind or cognition, but as something that is constructed through social processes.

3.2 Social Identity

Guided by these assumptions I will now turn to the idea of a socially constructed identity. 'Identity' has a long history as a term in Western philosophy, from the Ancient Greeks to contemporary analytical philosophy and modern sociological thought. The introduction of identity in the social sciences was developed by the works of theorists such as Cooley and Mead (Cerulo, 1997). Mead (1913; 1934) in particular, placed emphasis on the *social self*, suggesting that each of us develops a sense of self through engagement with other selves. However, there was also a significant body of theorising and research that moved away from this focus to issues of group agency and political action (Schwartz, 2011). As a result, identity studies were largely relocated to *collective* identity – with gender/sexuality, race/ethnicity and class forming the main focus of this field (Appiah & Gates, 1995).

Collective identity addresses the 'we' of a group, stressing the similarities or shared attributes around which group members unite (Melucci, 1995). It is the shared definition of a group that derives from members' common interests and experiences. Defining the self in relation to relationships with others creates solidarity and can give presence to marginalised and oppressed groups. For instance, in the USA during the 1970s and 80s it was common to see protests representing groups such as animal rights activists, gays and lesbians, feminists and the disabled as they demanded new laws and practices and sought recognition for their identities and lifestyles. Hence, this collective action meant identity took on a new meaning as it was constructed and projected to society through protest and associated with social and political action (Polletta, 2001).

However, it was also argued that collective identity can fail to address conceptualisations of individuals as occupying multiple statuses or multiple social positions across numerous groups (Taylor, 1992). For example, some feminist scholars in the early 1990s began to challenge essentialist definitions of femininity that had developed in the 1970s, which over-emphasised the experiences of middle-class white women (Stone, 2004). Black feminists challenged the use of women and gender as a homogenous category that reflected the essence of all women (Collins & Bilge, 2020). Consequently, race theorists went on to develop the term 'intersectionality' to describe the connections between race and categories such as gender and class as they rejected the idea that race, class and gender were separate and essentialist categories (Valentine, 2007). Social constructionism opposes essentialism because essentialist theories suggest that the social world, including identity, is fixed and therefore not subject to any change. This can be limiting or worse, damaging, if it is used to suggest what people can and cannot do.

3.2.1 Questioning essentialism

Essentialist theorisations approach collective attributes as 'natural' or 'essential' characteristics – qualities that are universal and biologically driven (Barrett, 2001). Members of a collective group are believed to internalise these qualities, suggesting a unified, singular social experience – a 'single canvas against which social actors constructed a sense of self' (Cerulo, 1997:387).

For example, essentialist theories of sex and gender, and the relationship between these, assume an essence of sex and gender that is reproduced genetically. Such theories may evoke Charles Darwin's idea of the evolution of the species to claim that our collective past as human beings is hardwired into our bodies. For instance, aggressive or violent male behaviour under this approach has been explained by bodily factors such as the larger, more muscular male physique and the effects of testosterone, or men's function in protecting territory from intruders (McCaughey, 2012). This seems quite a narrow view (although historically relevant when food was not plentiful) as it ignores diversity, resting its assumptions on a particular view of human history. Yet, the same could be said for much of everyday language which is influenced by explicit and implicit gender interpretations. For example, words such as 'aggressive', 'passive' and 'emotional' can be interpreted within dualistic understandings of what it means to be a man or woman (Miller & Swift, 2000). Thus, certain explanations relating to sex and gender can easily permeate widespread assumptions and values. While I may reject the idea that gender is fixed and unchangeable, these perspectives can play a part in wider societal explanations for understanding gender.

Not too surprisingly, essentialist theories have been challenged and critiqued with anti-essentialist studies promoting the social construction of identity as a more viable basis of the collective self than the idea of an internally located self (Burr, 2006). Further criticism stems from the use of essentialist views as political devices or weapons. Essentialist notions of masculinity and femininity have been used to suggest that qualities such as relationality and autonomy are fixed and can be used to justify behaviours (Crompton & Lyonette, 2005). As Whitehead and Barrett (2001:12) state, 'it serves to lock human beings into political categories'. Therefore, under this theory there is little hope of social change as identity is unchanging and universal. Consequently, many scholars now dismiss any articulation of group-based identity as essentialist (Fischer, 1999).

Returning to the example of male aggression, rather than accepting that it is an inevitable hard-wired characteristic, constructionist theories ask questions such as what sociocultural norms and values in this culture, and at this time, contribute to such aggression. Thus, rather than identity being an *internal* project of the self, social constructionism focuses on the process by which an individual inhabits and embodies a social identity and how this is initiated and sustained. This internal/external divide highlights an important dualism in identity theory representing two ontologically distinct perspectives. My focus is on the latter – the acquisition and negotiation of identity through interaction and experience. Caring is an interaction and an experience. Therefore, the discussion now moves to understanding how the self exists in relation to the other by drawing on positioning theory to consider how an individual transitions into and acquires a carer identity.

3.3 Carer Identity

Caring, like other social behaviours, is governed by cultural norms. 'Cultural norms' are the rules and structures that operate within a society that deem what is appropriate and inappropriate in terms of values and behaviours (Lapinski et al., 2005). These norms may dictate who acquires the role. For example, surveys carried out across the world in countries such as Australia, the UK, Canada, Japan and the USA have found that about 70-75% of the home-based care of ill, frail or disabled family members is carried out by women (Eriksson et al., 2013; Suguira, 2004). The prominence of female carers suggests that there are shared social norms that expect females to carry out the caring role.

Relationship to the cared-for is also important. Cantor (1979), in writing about the informal support used by older people in America, explained shared cultural understandings of caring responsibility in what she has called the 'hierarchical compensatory theory of social supports'. This means that there is an order as to who will assume the caregiver role. This is first fulfilled by a spouse, if one is available. Children are next in line, followed by more distant family members, friends and neighbours. Furthermore, a person's ethnic and cultural background influences expectations as each culture has its own norms relating to caregiving responsibility (Scharlach & Kellam, 2006). Finally, each family may also have their own 'family ethos'. This determines which members in the family are responsible for caring, the types of care that can be expected, and the conditions under which it might be appropriate to seek help from outside the family from formal service providers (Montgomery & Kosloski, 2009).

The point here is that the determination of who becomes a carer may be bound up in wider social norms beyond who is physically available or capable. This prominence of female carers has led scholars to suggest that, globally, caring is positioned as a feminine practice within society (Gilbert et al., 2014; Haberkern et al., 2015; Stimpson et al., 1992). However, demographic trends are changing. There is evidence to suggest that more men are adopting caring roles. Therefore, these variations *should* alter the conceptualisation of care being a feminised activity. Yet, as raised in chapter two, there is evidence to suggest that men are sometimes less likely to relate to the term 'carer' (Arber & Gilbert, 1989; Baker et al., 2010). Therefore, understanding how men understand themselves as carers – how they transition into and self-identify with the carer role – is an important consideration in my study.

3.3.1 Positioning theory

Davies and Harré (1990) use the concept of position to refer to personal, historical, social, and cultural attributes of a person that can be ascribed by discursive acts. Positioning theory refers to the study of the discursive processes by which people are ascribed, take up, refuse and contest the rights and duties they find themselves with in their social world (Harré, 2012). In the social sciences the concepts of 'positioning' and 'position' were first introduced by feminist writers. For example, Hollway (1984), in her analysis of the construction of subjectivity in heterosexual relations, has spoken of 'positioning oneself' and 'taking up positions'. While Hollway focused on the location of persons as men and women, positioning theory expands the idea to a whole set of rights, duties and obligations that speakers have. Adopting a 'position' involves the use of linguistic devices by which an individual and other speakers stand in various kinds of relations. These include, for example, relations of power, relations of competence and relations of trustworthiness. Hence, positioning theory has been applied to settings such as education and the health setting (Harré et al., 2009).

Applying the theory to an informal caring context, O'Connor (2007) carried out interviews with 33 carers (family members) who had attended a family support group in Canada. As these carers already defined themselves as 'carers', this data was supplemented with transcripts from a secondary data set. In this second study, 14 spouses (six females and eight men) caring for a memory-impaired partner were interviewed up to three times in order to explore the experience of living with a memory-impaired spouse and the use of formal support services. Across both datasets the authors found that most of the participants did not see themselves initially as a carer. This was not a conscious decision, but they felt that they were not doing anything more than they would normally in their relationship with the care recipient.

This is consistent with the sociologists Montgomery and Kosloski's (2013) extensive research on caring experiences. According to these scholars, if the care needs of the care recipient increase beyond the normal boundaries of that existing relationship (for example, a spousal one), then an individual may alter their behaviour to respond to this change. At this point they may also change the way in which they see their role in relation to the care recipient. Therefore, this may be the point of self-identification as a 'carer'. Based on this reasoning, there may be a conscious moment when someone acquires the role. However, positioning theory offers an alternative way of understanding this transition. O'Connor (2007) found that the participants in her study did not assume the role of carer through care-focused activities but most commonly through interactions with others, such as health and social care professionals or other carers.

For example, the participants (carers) in this study spoke about health professionals, referring to them as 'carers' – before they had consciously identified themselves as a 'carer'. This labelling, transmitted through language within the context of a hospital setting, then contributed to the formation of their carer identity. This interaction facilitated their positioning from family member/spouse to carer. Therefore, this use of language has wider significance; it has created a new connection between two people (care receiver and carer rather than husband and wife) which is likely to bring feelings of wider responsibility. However, identity is not constructed and enacted through language alone.

Who we are and what we are doing is more than language – it is associations among ways of using language, of thinking, valuing, acting and interacting in the right place at the right time and with the right objects. This is what the sociolinguist James Paul Gee refers to as 'discourse with a big D' (Gee, 2004). The notion of 'Big D Discourse' captures the ways in which people enact and recognise socially and historically significant identities through language, interactions, objects, tools, technologies, beliefs and values. There are numerous Discourses in society, such as doctor, patient, student, carer and each are connected to 'social goods' (Gee, 2004). Social goods are anything that a group of people believe to be a source of power and status, such as knowledge, intelligence, money or age. What is relevant within this discussion is that in O'Connor's (2007) study, the health professional recognised the participant as a carer (a particular identity) as they were carrying out a particular task (caring) while interacting with a person with a particular identity (the patient). In other words, situating these individuals within the 'carer' Discourse led to these individuals shifting from being partners or family members to carers which, in turn, is bound up with particular values, assumptions and expectations. Thus, the concepts of 'position' and 'positioning' are used to suggest how people are 'located' within conversations or situated within networks of power.

A position is similar to a role in that it supplies someone with meaning when they engage in an act, but it differs in that it is dynamic, shifts within conversations, and can be renegotiated (Harré, 2009). Using the concept of 'position' to conceptualise the carer role suggests that there is a fluid, interactional and discursive nature to how someone may self-identify as a carer. Therefore, in order to make sense of the relationship that exists between the assumption of the carer role and self-identity, O'Connor (2007) considers that caring should be conceptualised as a 'position' rather than a role. This takes the view that identity arises through social interaction and is discursively constructed. Consequently, through this theory we can understand how individuals, through others, may construct their carer identity.

This theory draws attention to how language can position someone, highlighting how a social and interactional environment can contribute to the development of the carer identity. Hence, individuals do not just assume the role, rather it is constructed through an interaction with others. However, the transition to carer usually occurs within a pre-existing relationship. This raises the question – do people position themselves as carers *and* spouses? Some individuals resist the 'carer' label. These individuals do not see themselves as a 'carer' and only wish to be defined by the pre-existing relationship they are in (Knowles et al., 2016: Molyneaux et al., 2010). Actively rejecting the carer label suggests an unwillingness to position oneself within the carer role. Therefore, as highlighted by Heaton (1999), an understanding of the discourse of informal care is not just an issue of semantics but something that has significant social consequences. If some people are reluctant to use the term 'carer', this suggests that there are complex processes involved in positioning oneself, or being positioned, as a carer.

In summary, positioning theory proposes that someone may self-identify as a carer through *social interactions*. This theory focuses on language and relations and emphasises a dynamic and movement-oriented approach to identity construction. These are not necessarily smooth or unidirectional movements and while there may be common elements to the carer experience for each individual, the adoption and then experience of the role is guided by unique cultural, relational and demographic factors. Moving towards the next section of this chapter – identity and discourse – this is an important point. I have focused on the process by which an *individual* may adopt (or not) their carer identity. I have also touched upon cultural norms that may dictate who acquires the role. To add to this understanding, I wish to consider the *wider* mechanisms and structures that underpin an individual's transition to carer. These mechanisms and structures are discourses, with the implication being that discourses make positions available for people to take up. Positioning theory in particular is a useful bridge to these wider processes as it considers that social interaction is changing, fragmented and contextual (Tirado & Galvez, 2008). This is an important starting point from which to move into a more focused discussion on discourse and identity.

3.4 Discourse and Gendered Identity

There is no unitary definition of discourse. The term is used in a variety of disciplines such as critical theory, sociology, linguistics, psychology and philosophy with each discipline offering different definitions of the term (Mills, 1997). Nevertheless, broadly speaking, discourse has linguistic and philosophical meaning. Discourse refers to language use – such as spoken interaction and written texts that can be analysed to understand how language is used to construct or represent individuals or events (Burr, 2006). Alternatively, non-linguistic definitions of discourse that bring assumptions about its philosophical and theoretical meanings diverge from this. For example, Foucault stated that discourses are 'practices which form the objects of which they speak' (Foucault, 1972:49). Through this definition of discourse it is suggested that engagement with the world is shaped by the meaning provided by discourse. Hall (2001) expands on this:

> *'Discourse defines and produces the objects of our knowledge. It governs the way that a topic can be meaningfully talked about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others.'* (Hall, 2001:72).

Subsequently, the term is used in different ways by different theorists depending on their disciplinary context and research focus (Mills, 1997). I am seeking theoretical approaches to explain how individuals construct their identity. Therefore, as I further this discussion on discourse, my starting point is that an understanding of who we are, in whatever capacity and context that may be, is *established* and *shaped* by discourse.

To unpack this proposition I am going to turn again to James Paul Gee's (2004) thinking, as he offers an accessible description of discourse that isolates an important distinction between the use and function of language that has relevance for identity research. Specifically, I will explore his emphasis on enacting and performing identity through a consideration of how individuals may enact their gender. Additionally, if discourses regulate the knowledge of the world, as emphasised in Hall's (2001) understanding of discourse, then the application of discourse to topics of identity and gender bring theoretical assumptions about the interrelationship between discourse, identity and power. Foucault (1972) was centrally concerned with this relationship – therefore this section also considers his theory on discourse. I will focus specifically on the central tenets of discourse and power and reflect on the relevance of Foucault's thinking for gender identity. In turn, this integrated discussion does not rely on a single approach to discourse but highlights a number of key themes and areas of convergence.

3.4.1. Discourse and identity

In the previous section on 'positioning theory' I considered, through O'Connor's (2007) work, how individuals may resist or be 'positioned' in carer discourses. To continue this discussion, I will take a step back and consider *how* and *why* the discursive production of the self may occur. James Paul Gee's theory, developed through a long period of scholarly work, proposes that language allows us to say things but also to *be* things (Gee, 2005). Therefore, discourses involve language, but they also encompass features such as thoughts, values, gestures, appearance and actions which allow individuals to be recognised as enacting a particular identity and engaging in certain activities (Gee, 2005). Consequently, it is the *socially agreed* nature of discourse that make us recognisable as enacting a particular identity. In other words, discourses do not tell individuals *how* to act but enable individuals and groups to develop shared representations for issues of social and cultural importance, such as health and illness.

To expand on this further, Gee (2005) makes a useful distinction between discourse with a 'little d' and discourse with a 'big D'. 'Little d' discourse refers to language in use – how language is used to enact identities and activities. 'Big D' discourse suggests that speakers use language and context to enact particular social identities. Those around us pay attention (or not) to these identities and recognise them as a particular identity. In Gee's words d/Discourse theory is concerned with,

> *'…enacting and recognizing socially significant identities. It is about recognition of 'certain kinds of people' in performances and context. Discourses can be big or little (for example, politicians, athletes, gang members). They come and go in history. They are*

> *rooted in conventions that allow us for a time and place to enact and recognize being certain socio-historical types of people'* (Gee, 2005:26).

Thus, Gee emphasises *enacting* and *performing* identity. The main point is that language is not just about conveying information through words and sentences but the collection of sentences or utterances that are enacted and determined by the social context. Social context therefore plays an important defining role in the development, maintenance and circulation of discourses (Mills, 1997). Subsequently, discourses provide structure and influence how people may think, feel and act (Benwell & Stokoe, 2010). Gee (2005) suggests that each discourse has a theory on the 'right' way to act and feel which then becomes accepted as instances of a particular identity. The implication is that these shared understandings allow members of a group to act in similar ways as they share values and group identity – for example, 'groups' such as males, females, patients and carers. I will now consider this proposition in relation to discourses of masculinity and femininity.

3.4.2 The construction and enactment of gender

Gender is one aspect of identity that is constructed through culturally available discourses of masculinity and femininity. Social constructionists propose that gender is a cultural, historical and social construct. Gender, therefore, is approached as a phenomenon that is *constructed* rather than biologically driven (Lorber, 1994). Within a constructionist framework, gender is said to be 'done' or 'performed' (West & Zimmerman, 1987). Conceptualising gender as a 'performance' or an 'enactment' implies that men and women are actively engaged in a process of doing, creating and recreating gender identities as they occupy different discourses of masculinity and/or femininity.

The idea of a 'performance' is influenced by the sociologist Erving Goffman, who used a theatrical performance metaphor to suggest that speakers (actors), when they come into contact with other people, guide the impression that others make of them (Goffman, 1959). His dramaturgical metaphor involves two elements; a 'front' and concealment – which are sometimes referred to as 'front stage' and 'backstage' to highlight situations where the impression created is different to an underlying 'reality' (Goffman, 1959). The implication of this for the study of masculinity is the idea that there may be tensions between 'front stage' and 'backstage' due to the norms and values (or in Goffman's words 'culturally acceptable plots') that operate within a society.

For Goffman, women and men 'read' images of femininity and masculinity (as Gee said, recognition of certain kinds of people) and then attempt to mimic them when giving a gender performance. Whilst feminine and masculine images and discourses may come from a number of sources of socialisation, Goffman's analysis (1979) of advertisements highlighted the importance of popular culture in the construction of gender. As a result, if subjective experiences are influenced by discourses, then it is important to reflect on the idea that different discourses can have different identity and power implications.

3.4.3 Dominant discourses of masculinity

The concept of gender is an example of how some discourses are dominant as they are linked to positions of greater power and some are marginalised as they are linked to minimal or no power (Litosseliti & Sunderland, 2002). Dominant discourses of masculinity in Western culture include 'hegemonic masculinity'. The term hegemonic masculinity was first proposed by the Australian sociologist and gender theorist Raewyn Connell. This form of masculinity is characterised by traits such as stoicism, heterosexism, control and authority (Connell, 1995). Within this discourse, to be a man is to be strong and invulnerable (Kiesling, 2005). This form of masculinity subordinates femininities and other masculinities and shapes relationships between men and men, and men and women (Courtenay, 2000). Connell's theory of masculinity is therefore relational (Gough, 2018). Men who occupy or are influenced by discourses of hegemonic masculinity will inhabit a particular sense of self that shapes what they do, how they talk, think and interact with others.

The concept of hegemonic masculinity has been applied across many academic fields such as employment, education, criminology and health. Gray et al. (2000), exploring the relationship between hegemonic masculinity and the experience of prostate cancer, found that while men's experiences of cancer were different, hegemonic masculinity played a central part in shaping these experiences. Analysis of three individual narratives identified challenges related to seeking support, sexual function, work and lifestyle choices. The men renegotiated aspects of their masculine performance but that was mainly done within the parameters of hegemonic masculinity. However, the concept of intersectionality is again important. In Gray's (2000) study, the men were identified as being white, middle-aged, well-educated and fairly affluent – all of which will have shaped their movement towards and resistance to hegemonic values. Therefore, Gough (2018) suggests that intersectionality should act as a reminder not to homogenise groups such as 'white men'.

It is useful at this point to return to positioning theory. To recall, positioning theory suggests that identity is constructed and negotiated in relation to the positions taken up by an individual or by being positioned by others. Selves are located in, for example, conversations but also through 'reflexive positioning' where an individual takes a position (Davies & Harré, 1990). Therefore, the way men self-position and are positioned by others (spouse, health professional, friends and so on) is a key feature of my study. To consider this further, gendered constructions of being a husband or wife (or co-habiting partners) in a heterosexual relationship can shape and reproduce dominant gender ideologies. The division of household responsibilities and childcare, parenting roles, emotion work, employment arrangements and earnings are just some elements within a relationship where gender identity may be constructed and maintained.

It has been suggested that in heterosexual marriage, masculinities and femininities are seen as being oppositional (Thomeer et al., 2015). Men may position themselves, or be positioned by their partner, to be the breadwinner who provides for the family due to earning a higher salary. A further example is through parenting style. Hunter et al. (2020) analysed how fathers and masculinity are constructed in 'popular' parenting texts. They found that the men emphasised physical and rough play and contrasted their masculine approach to that of 'dainty' mothers (Hunter et al., 2020:12). Thus, their positioning adhered to a masculine ideal (strength and the avoidance of femininity) and allowed them to reframe their caring behaviour in masculine terms (Gough, 2018).

However, it can be problematic when men are positioned by others, who may expect them to enact and embody dominant masculine characteristics and values, when they do not want to or find it difficult to do so. There is a wealth of literature on the negative consequences associated with the standards and expectations embedded in hegemonic masculinity (Parent et al., 2019; Baugher & Gazmararian, 2015; Smith et al., 2015; Gallagher & Parrott, 2011). Furthermore, a stark statistic is that in the UK (and most European countries) men form three-quarters of the number of people who die by suicide (ONS, 2019;

Platt, 2017). A further case in point is the term 'toxic masculinity, which has gained prominence in both academic and non-academic texts to describe the effects of harmful ideals about masculinity. However, Harrington (2020) noted that most scholars who use the concept usually do not define it or embed the concept into wider masculinity frameworks.

Since 2016, in the media, the term 'toxic masculinity' has notably been used to describe prominent figures such as Harvey Weinstein in discussions about the #metoo movement. In January 2019, the razor blade company Gillette sparked debate by airing an advert asking men to stop 'toxic masculinity' in behaviours such as harassment and bullying (BBC News, 2019). However, the term has been critiqued for branding *men* as toxic rather than the behaviours associated with the term (Waling, 2019). In part, the discussion over toxic masculinity reflects a conceptual debate in studies about men and masculinities as to whether masculinity is a series of traits, a psychological correlate, a sociocultural construct, or all of these things (de Boise, 2019). Harrington (2020) suggests part of the reason why the term has become so widespread is that it describes an easily recognisable character type. This makes sense – but it is concerning as 'ease' should not be the driver in scholarly debate.

Accordingly, dominant ideals may limit the recognition of different and more nuanced masculine performances. As such, the extent to which the men in this research study may understand, identify with, or resist dominant forms of masculinity, is a key consideration. In the main, men are not positioned as being emotionally nurturing. Yet, from surveys (of men and women) on what tasks carers engage in, it is known that carers provide a great deal of emotional support. However, for men particularly, this can be a difficult and demanding part of the role but there has been little discussion of this in the carer literature beyond the idea that this may be because of men ascribing to hegemonic values.

An alternative idea is that the process involved in managing emotions can be viewed through the lens of Hochschild's (1985) conceptualisation of 'emotion management[16]'. Hochschild described two types of emotion management – emotion work and emotional labour. Emotion work is the process of managing and presenting emotions in the private sphere with friends and family. Emotional labour is the management of feelings to generate

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[16] Hochschild states that she uses emotion work and emotion management synonymously to refer to acts done in a private context. Whereas, emotional labour refers to public displays (Hochschild, 2012).

a performance that displays *expected feelings* in the public sphere, such as a work setting (Kelly et al. 2000). A key difference for Hochschild was that, in the private sphere, individuals offer their emotions freely but in an organisational sphere they can be commodified – as workers are expected to act in ways that meet organisational demands.

Hochschild explained that emotional labour requires one to,

'…induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others' (Hochschild, 2012:7).

Therefore, according to Hochschild, when someone generates a performance it is an *insincere* performance as it is an act governed by the rules and norms of that particular interaction. Hochschild's theory is underpinned by feminist theory as it shines a light on the often underappreciated and hidden elements of work (in the public and private sphere) which are usually done by women (Hochschild, 1985). Therefore, emotion management in *men* has largely been overlooked. However, using this lens encourages reflection on the hidden elements of 'work' associated with the role. It considers that men are not just simply suppressing their emotions and it encourages focus on more nuanced elements of masculinity.

Nevertheless, Connell has emphasised that hegemonic masculinity should not be assumed to be 'normal' – only a minority of men might enact it. All the same, it is symbolic and 'normative' as it legitimises behaviours, expectations and attitudes (Connell, 2005). Furthermore, some men may embody the features of hegemonic masculinity in some contexts, perhaps unknowingly, without consciously subscribing to hegemonic values (Connell, 1995). Consequently, moving into the next section, understanding more about the mechanisms of power will provide further clarity on the way discourses shape and establish identity. Power is a key element in discussions of discourse and an influential theorist to help guide this discussion is the French historian and philosopher Michel Foucault.

3.4.4 Discourse and power

Foucault's work broadly spans three interlinked concepts: discourse, power/knowledge and subjectivity (Motion & Leitch, 2007). Foucault first discussed the concept of discourse within his work The Archaeology of Knowledge (1972). In this text he promotes 'archaeology' as an analytical method underpinned by the idea that systems of thought and knowledge are governed by rules, beyond those of grammar and logic, which operate beneath the consciousness of individual subjects. In turn, these 'rules' define and determine the boundaries of thought in a given social and historical context (Brenner, 1994). For example, when Foucault used the archaeological method in his work History of Madness (1961), he believed it should be read as an exploration into the different discursive formations that govern talk and thought about madness from the 17th through to the 19th centuries (Gutting, 2005).

The social theorist Michele Barrett summarises her understanding of The Archaeology of Knowledge as 'the production of 'things' by 'words' ' (Barrett, 1991). This is a useful summation as it succinctly captures Foucault's thinking[17] on this topic, which is that 'things' acquire social and historical meaning through discourses ('words'). Therefore, led by this understanding, and considering Foucault's 'archaeology' approach to knowledge production, this implies that discourse is something which produces or structures something else. Consequently, in terms of thinking about the relationship between discourse and identity, this paves the way for understanding discourse in terms of its structural and rule-bound properties, specifically, by considering how discourses shape what may be said, by whom and in what context. Crucially, however, what sits at the crux of these assumptions is power. Foucault argued that all forms of knowledge are associated with power. This is certainly a rather broad statement so I will begin by unpacking this assertion and focusing on what Foucault believed when he referred to the concept of power.

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[17] Foucault's (1966) book 'The Order of Things' was originally published in French ('Les mots et les choses') which translates as 'words and things'. So, while this is Barrett's summation it will be influenced by Foucault's original understanding.

3.4.5 Power

Foucault has been instrumental in 'rethinking' the concept of power (McHoul & Grace 1993). That is, he challenged scholars to think differently about the range of practices that can be associated with the term. Power, for Foucault (1972) is omnipresent, produced through social interaction. Power circulates in social life, structuring experiences and sense of self. That power 'circulates' implies that it is not fixed but something that changes, spreads and flows. Therefore, power is produced in *discursive relation* rather than an entity that is held or exerted from the actions of particular individuals or groups. Furthermore, rather than being associated with negative connotations, Foucault suggested that power can be positive and productive (Nealon, 2007).

Foucault (1972) suggested that it is through the ubiquitous and dynamic properties of power that:

> *'Certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals.'* (Foucault, 1972:98).

For example, prevailing discourses of femininity construct women as nurturing, emotional, and likely to engage in domestic behaviours. Discourses of masculinity construct men as being stoical, emotionally closed and aggressive (Connell, 1995). Discourses are 'political' meaning they are associated with power, status and valued knowledge (Gee, 2005). Of course, not every man or woman acts this way but these discourses are widespread, raising the question as to *why* they dominate.

Pierre Bourdieu, an influential French sociologist, philosopher and social capital theorist, focused on the diverse and subtle ways that power is transferred and social order maintained within families. Bourdieu argued that people derive their 'social capital' from their membership of a group, such as a family or spousal relationship (Bourdieu, 1986). Social capital broadly refers to the resources – such as shared values, trust and norms that are obtained from the interactions between individuals or networks of individuals (Lin, 2002). However, more recent thought on social capital extends the concept from an individual asset to a feature of communities and nations (Portes, 1998).

Nevertheless, the main point is that material or symbolic exchanges within these interactions and relationships produce obligations and mutual recognition of group membership. This 'group' (family/marriage) is then the place through which capital assets are transmitted over time and through generations, and dominant discourses prevail. Hence, Bourdieu's concept of capital is useful within this discussion on discourse as it highlights that the possession of 'valued capital' can determine the status of individuals and groups (Coles, 2009). As raised in relation to Gee's (2005) point about 'social capital', there are therefore effects and consequences arising from the discourses to which an individual may belong.

Discussions about dominant discourses across, for example, race, gender, class, ability and sexual orientation suggest that identities are 'statused' and therefore have particular meanings (Robinson, 1999). Robinson's model on discourses advances that, in Western society, dominant discourses maintain – in both subtle and explicit ways – how those who hold membership in one group are more valued than others and therefore have increased access to social goods and power (Robinson, 1999). Within this model, Robinson suggests that white is valued over being a person of colour, males have higher status than females, and being middle class has higher status than being working class. Therefore, by virtue of certain group membership, individuals are positioned by discourses in relation to others. However, as raised previously, the notion of intersectionality brings to the fore that the same person may occupy multiple identities. Subsequently, there are consequences for experiencing notions of power, privilege or vulnerability.

In summary, the power to act in particular ways and claim resources depends upon the knowledge currently prevailing in a society (Benwell & Stokoe, 2010). Individuals can exercise power by drawing upon discourses that frame their actions within an 'acceptable' light. People can be 'married', 'divorced', 'single', 'mothers', 'fathers' or 'patients' and so on. These structures (and the intersection between them) then act as a frame of reference and are associated with the practices that individuals engage in within their lives. However, there are alternative discourses. Not all discourses are dominant and widespread. Moreover, not all dominant discourses remain dominant. An example of this is that the demographic structure of families has changed. The 'nuclear' family is no longer the predominant family structure in Western society due to increased rates of divorce and single parenting (Popenoe, 1993). When social change produces situations that disrupt established norms, individuals can no longer rely on shared understandings of how to act. Therefore, individuals must negotiate new ways of acting – a process that can be a potential source of conflict and/or opportunity.

3.4.6 Shifting discourses in the field of masculinity

There is much discussion and debate across the Western world about the social and cultural shifts that have generated multiple understandings of masculinity (Mac an Ghaill & Haywood, 2006). Connell has also been significant in theorising the notion of *multiple* masculinities, particularly differences within and between men on the basis of class, ethnicity, and sexual orientation (Connell, 2005). Connell states that 'at any one time, one form of masculinity rather than others is culturally exalted' (Connell, 1995:12). The idea of multiple masculinities thus raises the idea of hierarchies and status amongst the different forms of masculinity. In some settings men will be privileged by adhering to hegemonic norms and some will be subordinated. Gay and/or disabled men, for example, may be discriminated against and marginalised as they do not fit hegemonic standards or have access to valued resources (Gough, 2018). Connell's work brings into focus the power relations that exist between men (and women) that can then drive inequalities. However, it downplays the nuances and contradictions. In turn, the theorists who have moved away from Connell's theory did so because they wanted to emphasise the flexibility of contemporary masculinity (Anderson, 2009).

For that reason, discourses on masculinity are becoming more nuanced. Authors such as McQueen (2017) and Schwab et al. (2016), by using language such as 'navigate' and 'transition', propose that men may move or 'flow' from performances of hegemonic masculinity to contrasting forms of masculinity characterised by traits such as emotional openness and expressivity. However, this negotiation between different forms of masculinity can be complex, particularly within the context of a major life disruption such as illness that can radically alter one's sense of self (Bury, 1982; Frank, 1995). As discussed in chapter two, research with men caring for someone due to illness has found that their position as a carer can involve a struggle around the negotiation of masculinities, particularly emotional expression (Oldertroen et al., 2019; Gilbert et al., 2014). This is compounded by the fact that society frames caring as a feminine practice. As a result, a male taking on a caring role may feel that caring threatens his sense of masculinity, so will act in ways to counter or reframe his masculine expressions (Gilbert et al., 2014). This may be the case even with a more nuanced 'softer' and dynamic discourse of masculinity.

To that end, to understand why certain discourses dominate, it was useful to reflect on certain social and demographic conditions that provide the impetus for the development and impact of particular discourses. Discourses produce knowledge of the world – they influence, manage and regulate who we are and how we are recognised. Importantly, however, discourse is a *social construction*. It is shared and negotiated across people, media and other social practices (Gee, 2000). Identity is unstable, multiple and dependent on social and historical context. This understanding is possible within a social constructionist framework as social constructionism proposes that knowledge is not objective but socially constructed through language and social interaction (Robinson, 1999).

Chapter Conclusion – Implications for Male Carer Identity

I am interested in capturing how the men in this study narrated their views on becoming a carer, as triggered by their partner's cancer diagnosis. The way they respond will be related to many things (social resources, relationship satisfaction, confidence and more – as detailed in chapter two) but also to their sense of masculine self. I focused on identity, as analytically identity is a useful concept to explore during a time of disruption or uncertainty. Therefore, the frameworks presented here, that draw attention to how men may construct their identity, are positioning theory, hegemonic masculinity, performative masculinity (including Goffman's work of impression management) and Hochschild's focus on emotion management. Collectively, they explain how and why men may feel and act in certain ways and they offer new lenses for understanding male carer experiences. Masculinity is a plural concept. It is fluid, contextually dependent and it intersects with other variables such as age and socioeconomic status. Individuals who occupy, or who are influenced by carer discourses, will inhabit a particular sense of self that shapes what they do and how they interact with others. Together this makes *male caring* a complex phenomenon that warrants an appropriately detailed method to understand it.

CHAPTER FOUR: METHODOLOGY

Structure of chapter:

- *Historical context*
- *The narrative turn*
- *Experience centred narratives*
- *Performative approaches*
- *Holistic analysis – presenting the data*

Overview

This chapter sets out the justification for why a narrative methodology is appropriate for this study. The next chapter (Chapter 5) will detail *how* - through longitudinal interviews - a narrative approach was applied to understand the intertwinement between masculinity and accounts of caring experiences.

In chapter three I positioned my study within a social constructionist ontology. Therefore, I chose a methodology that was congruent with this position and allowed me to interpret the identities, perceptions and relationships of my participants within a caring context. A narrative approach is applied when the aim of the research is to explore an experience or a particular phenomenon in depth as it provides a detailed understanding of that issue (Riessman, 2014). One way this can be achieved is by talking to people and asking them to tell their stories. Narrative researchers collect stories from individuals about lived and told experiences. Stories are told by someone *for* someone making this process an inherently social act.

Before discussing how narratives relate to experience (and therefore are appropriate for this study) I will provide an overview of the key historical antecedents to contemporary narrative research, including the structural approach. In the 1980s the rising popularity of narrative research led to the ‘narrative turn’. This ‘turn’ towards narrative reflected the way different disciplines embraced narrative as a way of understanding identity, experiences, actions and meaning within particular social and cultural contexts. Therefore, the next section of this chapter focuses on four assumptions that underpin experience centred narratives considering the implications for research, such as mine, that uses narrative to understand perceptions of experience.

In the final section of this chapter, acknowledging there are limitations to the structural approach, I present the performative approach to narrative analysis. I made the decision to layer the structural and performative approach together in my analysis as it provided the mechanisms for a detailed exploration of masculinity and caring. I conclude with a section that details the theory behind my decision to represent the findings as individual stories and scenes.

4.1 Historical context

Vladimir Propp was a Russian folklorist and scholar. In his work '*Morphology of the Fairy-tale*' he identified 31 functions[18] that help to classify and structure the narratives of over 102 Russian folktales (1968; 1928). Propp's analysis of folklore tales was regarded as being pioneering as it considered the organization of stories. He noticed similarities and differences in diverse stories and recognised that folktales had a narrative form that was common to all storytelling (Landau 1993). For example, Propp observed common functions related to different characters, such as villains and heroes that help to develop the plot and make it recognizable as a fairy tale. These functions do not necessarily appear in every tale or in the same order but can be found in many folk tales, such as 'Cinderella' and 'Snow White' and also in more modern works like 'Labyrinth' and 'The Lord of the Rings'. Subsequently, Propp's analysis has gone on to be applied to various types of narratives such as film theory, news reports and advertisements (Dogra, 2016).

I began here as it is important to recognise historical lineage but also to lay the groundwork for understanding *structure* in narrative research. Propp's analysis recognises that there are common elements to stories that are replicated. However, his work has been critiqued for failing to recognise the 'deep structures' of narrative and for not contextualising his work within Russian culture (Dundes, 1997). Nevertheless, the significance and reach of his work extend beyond folktales (Steenivas, 2010). Indeed, what prevails are his ideas about structural functions within narrative. Therefore, acknowledging these criticisms, Dundes

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[18] See Appendix 3 for a full list of the 31 functions

(1997) suggests that structural analysis is a beginning not an end - as will be revealed this is a consideration that I applied to my own analytical approach.

4.1.1 Structural approach

Propp's concepts continued to stimulate interest in scholars across different disciplines. Subsequently, it paved the way for sociolinguists William Labov and Joshua Waletsky's structural analysis of narratives (1967). Leading with the idea that narratives have clearly defined properties or internal structures, Labov & Waletzky developed an approach to the study of narrative from research into language and personal experience narratives, primarily with black youths in south-central Harlem, USA (Labov, 1972). Signifying a move away from literature and folklore to the analysis of everyday conversation, their method identifies structural parts of the narrative that recur across stories about experiences. Narrative 'segments' are kept intact and analysis focuses on component parts of the story and their relationship to one another.

4.1.2. Defining narrative

There are ranges of positions scholars take with regards to how narrative is defined. Therefore, determining the boundaries of narrative is essential. Labov's (1972) description of the personal experience narrative is:

> *'One method of recapitalising past experience by matching a verbal sequence of clauses to the sequence of events which (it is inferred) actually occurred'* (Labov, 1972)

The Labovian approach defines narrative as the representation of events – specifically past events. Therefore, events that did not happen directly to the speaker, events that will happen in the future or events that might have happened are not defined as narrative following these criteria.

4.1.3 Narrative construction

In general, Labov suggests that a narrative is a sequence of past events and this sequence is referred to as the plot. Moreover, this sequence does not begin or end by chance but has a beginning, middle and end so the listener knows when a narrative has begun and ended. For that reason, a narrative is not a typical turn of talk of a sentence or less, but an extended account (Labov, 2013). Further, according to Labov (2006) a narrative must contain at least one reportable event - recognising that what is deemed to be reportable is relative to time and social context. In other words, the narrative must be about something - whether sparked by a question in an interview or to make a point in a conversation. Successively, once the narrator has identified a reportable event and the decision to tell a story has been made, particular structures hold the story together and enable the listener to follow and determine what is important.

Labov & Waletzky (1967) devised a 6 part model to describe a fully developed narrative:

- Abstract (AB) - Summary, the point of the story
- Orientation (OR) - to time, place, characters, situation
- Complicating action (CA) - the event sequence, or plot, usually with a crisis or turning point
- Evaluation (EV) - where the narrator steps back to comment on meaning or communicate emotions
- Resolution (R) - the outcome of the plot
- Coda (C) - ending the story/making a statement

A fully developed narrative by Labov & Waletzky's standards is internally structured with these six parts. Each part corresponds to a question about how the event is connected. For example, in the orientation the narrator orients the listener to who, where, when and what. Labov (1972) went on to acknowledge that not all narratives contain all six elements, for instance, the coda is not always present and they can occur in varying sequences. Nonetheless, this model highlights how content is organised by the speaker. Analysis can then focus on how individuals may use structures such as 'complicating action' and 'evaluation' for effect and how in interviews participants may use these structures to transform the interpretation of events.

While all elements contribute to the interpretation of the event the evaluation is central as it indicates why the narrative was told. The evaluative function:

> ‘*reveals the attitude of the narrator toward the narrative by emphasizing the relative importance of some narrative units as compared to others*’ (Labov & Waletzky 1967: 37).

Returning to the point about a narrative being reportable, the evaluation demonstrates why the narrative has been remarkable in some way, whether that be because, for example, it was unusual, funny or challenging. Consequently, narrators may use evaluative devices to present themselves in the best possible light (Langellier, 1989). Goffman (1959) termed this an act of ‘self-presentation’ which in essence is the process by which individuals construct roles and portray them to an audience (the listener). Acknowledging that self-presentation may be an individual variable and a function of social situations scholars have explored the concept of self-presentation in research interviews across a range of diverse groups such as; crime victims (Jagervi, 2014), people who are homeless (Boydell et al. 2000), and internet forum users (Jensen et al. 2003) to develop understanding on the strategies that people may use to construct and negotiate their identities.

Illness narratives, which may be constructed by the person that is ill, by their family member or by a medical professional align to Labov & Waletzky’s definition of a personal experience narrative as the narrative may depict events that have occurred in the past that have posed a challenge to that individual. The narrative is then a way of evaluating the challenge and making a statement. For example, Riessman (1990) discusses, from a study on divorce, how one of her research participants who also had advanced MS used different techniques, such as using structural features of different story genres, to present himself in a positive manner. He spoke about being a devoted husband, a good father and someone who was resilient despite his deteriorating health and upsetting social situation (his wife left him and his son then left home). Accordingly, focusing on the structure of an illness narrative can provide insight into the relationship between structure, identity, meaning and action.

Accordingly, applying a structural focus allows the researcher to examine how different individuals or groups (ages, ethnicities, genders and so on) may compare in their narrative structuring of the same or similar events. Therefore, focusing on structure highlights *how* participants compose their narratives. Analysis can then explore in what manner individuals may combine and use structural elements differently when they have different points or evaluations to make.

4.1.4 Limitations

However, while there were clear merits to this approach for my study of caring experiences there is a key limitation; there is no consideration of context. This creates some disconnect with my theoretical framework. I have proposed that gender and identity are fluid, dynamic, socially constructed concepts. Therefore, as an analyst, interaction between researcher and participant and wider sociocultural context are important. Contextual elements such as the purpose of the interview, the interview setting, the dynamics between the interviewer and the interviewee, the interviewee's life history, the performative elements of storytelling and the position of the narrative within different discourses are just some factors that will shape articulation and interpretation. Therefore, given this rather major limitation and Labov & Waletzky's focus on 'past events', thereby excluding present and future orientations to time and narratives that are not deemed to be about an event, I made the decision to layer structural analysis with a performance approach to narrative.

As I will detail later in the chapter, a performance approach explores how talk among speakers is dialogically produced and performed. This approach focuses on context, including the influence of the researcher, setting and social circumstances. By connecting the performative approach to the structural approach my aim was to weave together an analysis of text and context or the 'what's' and 'how's' of storytelling to understand male caring experiences from a range of different dimensions. However, before moving on to outline the performative approach, I have detailed how the increasing focus on narratives of personal experience lead to what was termed the 'narrative turn'. This provides a useful backdrop for understanding why narratives of personal experience can play a part in understanding the construction of identity.

4.2 The Narrative turn

Since the 1980s the study of narrative has grown extensively (Murray 2000). This growth is considered to be related to a rise in humanistic approaches within sociology and psychology which focused on person centred approaches, individual case studies and biographies in reaction against positivist empiricism, the approach that prevailed after the Second World War (Andrews et al, 2013). Narratives were seen as providing 'windows on inner life' (Gubrium & Holstein, 2009) providing researchers with a portal to delve into, understand

and interpret human expression where quantitative methods could not (Clandinin & Connelly, 2004). This contrast in approach towards the idea of there being no fixed truth has been described as a movement towards deeper meaning:

> "*Narrative moves [us] away from a singular, monolithic conception of social science toward a pluralism that promotes multiple forms of representation and research; away from facts and toward meanings*" (Bochner, 2001: 134-135)

Accordingly, narrative methods have appeal, as it is a very personal approach to data collection. The rising popularity of narrative research in the Western world was also influenced by postmodern, psychoanalytic and deconstructionist movements and the corresponding work of theorists such as Foucault, Lacan, and Derrida (Andrews et al. 2013). Such theory, focused on features such as: conscious and unconscious meaning, story structures and as discussed in chapter three the power/knowledge relations that produce and shape narratives. Consequently, while there are debates within these approaches as to what a narrative signifies, in combination, these developments in theory and the need for methods to understand the complexities of social life, set the stage for what has been called the 'narrative turn' (Riessman, 1993). This 'turn' towards narrative reflected the way different disciplines such as psychology, sociology and anthropology embraced narrative as a way of understanding the intertwinement between identity, experiences, actions and meaning within a particular social and cultural context.

Therefore, the study of narrative is not confined to one particular scholarly field. It has interdisciplinary appeal within the human sciences, as narratives are '*a basic and universal mode of human expression*' (Herman, 2009 pg 9). In other words, storytelling is an inherently human way of articulating experience. Hardy's (1987) observation describes the ubiquitous nature of narrative well:

> *"We dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, construct, gossip, learn, hate and love by narrative"* (Hardy 1987: 1).

Yet, telling a story is not just about articulating an account of an experience. Narratives according to Bruner can '*segment and purpose-build the very events of life*' (Bruner, 1987 p10). By this, Bruner is stating that they are also a way for individuals to *make sense* of experiences (Bruner 1990; Mischler, 1986). This is particularly relevant in life transitions and challenging situations such as illness (Bury, 1982). Recall Riessman's case study about the man with advanced MS – through narrative retelling he created a social self that was confident and in control, despite the array of challenges he was facing. Subsequently, in order to understand people's lives, it is the role of the researcher within a narrative study to 'attend' to this experience and analyse how meaning is accomplished (Riessman, 1993; Holloway & Freshwater 2007). In the next section I will discuss what 'attending' to perceptions of experience entails and what implications arise for the narrative researcher.

4.3 Experience centred narratives

Clandinin & Connelly (2004) consider experience as the starting point and core of narrative research. The experience centred narrative is therefore the dominant conceptual framework within current social science narrative research (Andrews et al. 2013). Researchers who focus on individualised accounts of experience are led by the view that individuals make sense of experiences through storytelling (Riessman, 2014; Polkinghorne, 1991).

Guided by this, there are important implications for this study. Caring is an experience. However, crucially, it takes place in relation to others. For example, in the context of a romantic relationship, with other family members, with health professionals, in a home, in a community and so on. Therefore, there are individual and social elements to this experience. From an individual (carer/participant) perspective, narrative is a way of accessing, understanding and representing that experience. Researchers can then use narratives to access and analyse the recall and reconstruction of an experience with consideration of the social and cultural context within which this occurs. Consequently, Clandinin & Connolly (2004) suggest that narrative is both the *phenomenon* and the *method*. By this, they mean that narrative is an experience and a way of accessing experience.

4.3.1 Narrating experience- four key assumptions

Considering what it means to experience something carries a range of assumptions that have relevance for the narrative researcher. Andrews et al. (2013) proposes that, in general, the experience-centered approach assumes that narratives are:

- Sequential and meaningful
- They are an essential part of human existence
- They represent, reconstruct and express experience
- They represent personal transformation or change

- *Sequential and meaningful*

Working through these assumptions, experience narratives are sequential as they involve movement or succession usually as sequences of talk that articulate and develop meaning. For example, the narrative can follow an aspect of someone's life. In my research, I asked my participants to tell me their caring story. For most participants this was articulated as a life turning point told chronologically from the day of their partner's cancer diagnosis to present day with sequence and meaning developing through this theme. However, experience narratives do not need to be chronological. They can include past, present and future stories. They can address particular defining events such like this or more general experiences (Denzin, 1989). They may also be imagined events and these events and experiences may appear more than once in the same interview and in different interviews in similar or contradictory ways (Riessman, 1993).

This has particular relevance to my study as each participant was interviewed three times over a year. Linear time therefore provided an organizational framework to examine sequence. For some, time provided coherence to a disrupted life course helping the participant to reflect, find new meanings and understand who they are. For example, by the third interview, knowing our time together was ending, constructing possible futures provided hope – it allowed carers to imagine positive outcomes in relation to their partner's health, their wellbeing and their relationship. Hence, by attending to sequence both within and across interviews, by preserving longer and larger sequences of talk, both respects the individual's history and gives insight into their way of organizing and making sense of experience (Riessman, 1990).

To understand the meaning the researcher can focus on spoken words but also features such as metaphors, contradictions, repetition, laughter, pauses and tone and the relationship between language and wider discourses around, for example, masculinity and informal caring. Meaning is also derived from the interaction between the researcher and the participant because narration is a social process with consequences for, as will be discussed later in the chapter, how these stories are used to interpret experience.

- *Essential part of human existence*

Narrative has been described as the 'very fabric of human existence' (Robert & Shenhav, 2014). In fact, the psychologist Jerome Bruner considers humans to be '*homo narrans*' (Bruner, 1990). The idea that humans have a natural tendency to tell and understand stories is a significant assumption of experience centred narrative researchers (Labov, 1972; Ricoeur, 1980). Taking this a step further is the belief that narratives are not just characteristic of humans but *make* us human (Andrews et al. 2013).

Bruner (1991) in 'The Narrative Construction of Reality' supports this position suggesting narratives actually structure perceptual experience and organize memory. The belief that human knowledge is structured and organized sits within the field of cognitive psychology (Schank & Abelson, 2013). Applied to narrative '*narrative structuring'* it is argued, allows separate and unrelated life events to appear as a meaningful whole (Polkinhorne 1991). This enters into the somewhat vast and complex debate about the relationship between narrative and human existence. In essence, when human existence is understood as a process of narrative construction it assumes that humans have an innate capacity to generate narratives. It is language that provides the human capacity to organize and communicate experience in narrative form. Subsequently, these narratives shape reality. Bruner, and other scholars such as Mishler and Gee are therefore proposing a distinctive relationship between narrative and self.

Similarly, David Polkinghorne, a counselling psychologist, in his book 'Narrative Knowing and the Human Sciences' (1988) outlines how the 'realms of human experience' are constructed and made meaningful through narrative expression. Polkinghorne points out that there are stories of nations, biographical and autobiographical stories of individuals, and fictional stories in the form of novels and fairy tales. In addition to these public stories, individuals construct private and personal stories linking various events of their lives into unified and understandable wholes. It is these latter stories about the self that Polkinghorne (1991) suggests form the basis of personal identity.

Generally, Bruner and Polkinghorne and scholars with a psychological interest in narrative approach narrative accounts as the unfolding and articulation of an inner self (Gubrium & Holstein 2009). Therefore, from an analytical perspective if an individual's sense of who they are is bound together with narrative then what and how something is narrated becomes points of analytical interest. Yet, returning to my earlier point, stories are told to someone. Therefore, Gubrium & Holstein (2009) propose that the concept of a 'narrative reality' also flags the socially situated practice of storytelling and the context which the stories are told are as much a part of their reality as the stories themselves. For example, stories are not only told in research interviews - they are part of the fabric of the storyteller's life. Narratives about illness, for example, are prompted and told in various circumstances such as clinical consultations, support groups and amongst friends and family. Consequently, asking someone to tell their story within the interview may elicit the retelling of an already told tale.

Conceptualizing narrative this way adds significance to the role and purpose of narrative with implications for research that uses narrative to understand experience. For instance, Squire (2007) reflected on her research with individuals who spoke about being HIV positive. Squire believes that these personal narratives of HIV represent crucial aspects of living with the condition. Squire's argument is further supported by the large amount of autobiographical writing and art about HIV and AIDS. This can be extended to illness narratives in general (Hyden, 1997). Articulating an illness or caring experiences from a first-person perspective generates a framework in which a speaker can weave together illness experiences, such as symptoms (or monitoring symptoms) into their personal life. Thus, the illness narrative takes on meaning and provides coherence amongst the disruption of illness.

Scholars such as Labov who focus on event narratives are less persuaded by the relationship between narrative and identity. Labov does assert there is a meaningful association between people and stories but his focus is text and event centred. Labov has stated that before such narratives are constructed they are 'pre-constructed by a cognitive process that deems these narrative to be reportable' (Labov, 2006: 37) but he does not elaborate much further than that (Labov, 2006). From this it would be reasonable to infer that Labov is stating humans have an internal capacity to narrate but he does not go as far as saying these narratives *make* us human. Therefore, while there is agreement within the bounds of narratives of experience that narrative is an important part of human meaning making, there are points of philosophical divergence concerning assumptions about the nature and status of narrative.

- *Narratives represent, reconstruct and express experiences*

The next consideration of the experience centred perspective is the manner in which narratives 'represent' experience. When someone tells a story, the expression of that experience may not be the direct translation of that experience. That is because individuals may 'perform' stories depending on the context - an assumption which drives the performative analytical approach. The idea of a 'performance' is influenced by Goffman who went on to suggest that 'culturally acceptable plots' are the norms and values that operate within a society that shape individual self-stories.

Somers (1994: 606) writes:

> *"We come to be who we are by being located or locating ourselves (usually unconsciously) in social narratives rarely of our own making."*

That is to say, people are shaped and sometimes constrained by the range of available stories (plots) that they can use to interpret their experience. This view has been applied by contemporary narrative researchers as a way of recognising that stories are social entities that are shaped by both speaker and listener (Somers, 1992). Ricoeur describes narratives as jointly 'told' between writer and reader, speaker and hearer. This, once again, brings into focus the importance of *context* within narrative research. For example, in my research there are several layers of context. The participants are all male, white, Scottish or Irish, had different socioeconomic backgrounds and they were mainly, with the exception of one participant, aged over 50 years old. Speaking to a white, female, mid 30's, English researcher, these layers of context will intersect and impact on the way the narratives are expressed and analysed.

- *Narrative as transformation*

The fourth and final assumption of experience centred narratives is that narratives represent personal change or transformation. Longitudinal interviews are particularly well suited for capturing and examining change. However, 'change' is multifaceted so attempts to capture it within research can be difficult. Bruner (1990) suggests that change can be interpreted when stories involve the violation of normality and an attempt at its restoration. Consequently, through narrative, an individual may seek restoration to makes sense of the complexities and this will become a significant point of analytical investigation. This chimes with the sociologist Arthur Frank's (1995; 2013) work on illness typologies. In particular, he suggested that the restitution narrative is the return to health and the ultimate victory over illness. There were moments when the participants in this study seemed to find comfort in this story arc but 'restoration' was complicated as it required adjusting to altered relationship dynamics and routines.

Squire (2007) suggests that this interest in narrative change can often compel experience-centred researchers to look for improvement in stories. Yet, that is just one way of understanding change. Saldana (2003) reflecting on change in longitudinal interviews suggests that within the analysis the researcher should be sensitive to the many possible types of change and analysis should also focus on how and why these changes occurred. The implication for my own work is that the participant's life story is taken as a whole and sections of text are interpreted in the context of other parts of the narrative rather than dissecting the story into smaller sections.

4.3.2 Experience centred narratives - summary

Scholars differ in their views as to what constitutes a narrative. Yet most agree on the ubiquity of narrative in Western societies (Josselson & Lieblich, 1995). It has been proposed by scholars such as Bruner that narratives are not just descriptions of events or experiences they actually create order and generate meaningful connections. Whereas, scholars such as Labov approach narrative through structure and form isolating the key features of narrative that connect in order to generate a comprehensible whole. Accordingly, in my analysis (the process detailed in the next chapter) I layered readings of the text on personal experiences from a structural perspective with the acknowledgement that meaning making is specific to a particular social, cultural and historical context. Gubrium & Holstein (2009) add that it is important in narrative analysis that questions about *why* a story was told in a certain way are asked in relation to questions about plot and content as both are significant in understanding someone's life experiences. It is from this starting point that I will now outline the performative approach.

4.4 The performance approach

The performance approach explores how talk among speakers is dialogically produced and performed. This approach focuses on context, including the influence of the researcher, setting and social circumstances. Riessman states;

> *'Stories don't just emerge they are composed and received in context. Context being historical, cultural, discursive'* (Riessman, 2008: 12).

As discussed in chapter three it is primarily through discourse that 'selves' are represented and enter the social world through networks of power such as the family, medicine and gender. Conceptualising gender as a 'performance' or an 'enactment' implies that men and women are actively engaged in a process of doing, creating and recreating gender identities as they take up different discourses of masculinity and/or femininity. In an interview context performances are expressive attempts to involve an audience - they are 'performances-for others' (Riessman, 2008). A performative approach therefore asks the following kinds of questions about identity and positioning: Why was the narrative developed that way, and told in that order? In what kinds of stories does the narrator place himself? How does he[19] strategically make preferred identity claims? What other identities are performed or suggested? What was the response of the listener/ audience, and how did it influence the development of the narrative and interpretation of it? I return to these questions in the next chapter.

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[19] Choice of pronoun 'he' to reflect my research sample.

4.4.1 Defining narrative

Riessman (1993: 8) defines narrative as:

> *'A bounded segment of talk that is temporally ordered and recapitulates a sequence of events'*

This is a broader approach to narrative than was offered by Labov & Waletzky. Rather than limiting narrative to past events, Riessman proposes that temporality and sequence are the two defining elements. This sits within the assumptions of experience centred narratives that usually, although not always, evolve in a temporal sequence with the consequential linking of events. However, temporality is not just the linear progression of time. Temporality can also be examined in relation to perceptions of time. Riessman (2015) has noted that often narratives do not move neatly through a beginning, middle and end and that it is common for storytellers to jump between the past, future and present. Writing a first person account of her own cancer diagnosis, Riessman (2015) found that temporality can be at odds with 'clock time'. For example, within her account she found herself shaping the incidents that were reported and the characters mentioned (and omitted) for the benefit of the audience. This left chronological gaps in the story that trouble the notion that well-formed stories have beginnings, middles and endings. For that reason, Riessman encourages analysts to look beyond these temporal divisions and embrace the idea that lives are 'messy' so we should expect the stories we collect about them to be messy in turn (Riessman, 2014).

While I agree with this observation, longitudinal interviewing imposes a structure on the articulation of experiences. For instance, aware that they were in a *process* of interviewing, there was a sense that the participants in this study were trying to connect their end (the final interview) to their beginning (the first interview). In turn, this helped them to create order as they used boundaries of time to establish something meaningful from the unfamiliar. In particular, for some, the final interview was used to conclude their story and talk about their imagined future. My point being, it is recognised that temporal ordering is not always chronological, especially within the context of illness, as individuals (patients/carers) are trying to make sense of the disruption to their life. However, when we invite someone to 'tell a story' it is, to use Bruner's words, an 'invitation to a particular style of epistemology' (Bruner, 1990). This means that elements such as; temporal order, sequence and plot are used as they align with cultural preferences and expectations for well-formed conclusive stories (Mischler, 1999).

This leads me to return to Riessman's (2008) point that stories are composed and received in context. Storytelling is a way of speaking to someone – it is a performance. Approaching narrative analysis this way focuses analytic attention on how the story is told and the dynamics of the storytelling environment. Adding to this, my focus is on storytelling by male carers. Therefore, analysis focuses specifically on how gender is performativity constructed and established through language - with narrative being a way for these men to make claims about their gendered positioning. As raised in chapter three, the role of language in creating a shared reality is of central importance in narrative research. Language and discourse are the ways by which individual's co-construct knowledge and meaning (Stoudt, 2009).

4.4.2 Holistic analysis - presenting the data

Temporality and sequence are two defining features of experience centred narratives. I interviewed the participants three times over a year and so regular contact allowed me to explore perceptions of temporality, process and change. Therefore, from an analytical perspective, I wanted to keep the participants stories intact in order to preserve the caring 'journey'. In holistic approaches an individual's story is viewed as a whole so parts within it, are viewed in relation to other parts (Lieblich et al., 1998). While Lieblich et al., (1998) offered a four part schema[20] for the holistic analysis of narrative data they acknowledged that, in line with Holloway & Freshwater's (2007) view, creativity can be applied in order to understand narratives from different perspectives. I embraced this view and combined analytical approaches. Consequently, this influenced my decision to present the findings as individual stories and as scenes.

In chapter six I have written eight individual stories. The process of constructing these stories aligns theoretically with holistic analysis and was adapted from Polkinghorne (1995). In summary, Labov (1972) has described the plot as the 'skeleton' of the narrative. Therefore, the first step was to identify the plot – this established the beginning and end and created temporal boundaries. This also helped me to decide what was pertinent. For

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[20] They are - Holistic - Content, Holistic - Form, Categorical -Content and Categorical - Form.

example, in one participant's (Angus') story the plot (in terms of temporally linked events and actions) was the interweaving of two caring stories. He moved backwards and forwards in time and used 'events' such as his wife's treatment, to compare his current experiences to those twenty years ago when he was caring for his previous wife. According to Polkinghorne (1995) associating a current experience with a past experience is a cognitive process that enables an individual to understand events in terms of the 'bigger picture'. Angus described his response to his current partner's diagnosis and related this to how he felt when his first wife was diagnosed. He concluded that he was grateful for the advances in cancer care (both medical and wider support) and so this narrative link helped Angus, and me, to understand his responses within the context of his entire life. I noted the actions, events and context that formed the plot in order to consider the meaning of the story. I have detailed this process in appendix 4.

Every story was a construction. I took each individuals interpretation of their experience and I produced my version of that interpretation (Beal, 2013). Each story was then titled with a representational quote to capture the essence of each man's account of their experience. Angus' quote *'If you're not positive you give up'* reflected the expectations he felt to remain positive, a feeling which at times he seemed to struggle with. In summary, I adopted the position of 'story analyst' and approached the narratives as 'data'. I used analytical strategies to explore features (content and form) of the narratives in order to present each person's 'story' (Smith & Sparkes, 2006). By going through this process I have represented the differences and diversity of individuals (Kelly & Howie, 2007).

However, in order to construct a more general and transferable understanding of male caring, I pulled out five narrative threads from the individual stories in order to provide a framework for writing the findings into scenes - as detailed in chapter seven. McAdams (1993) refers to 'narrative threads' as providing coherence and meaning. A structure to organise the scenes was required because the men's accounts described such an array of experiences with shifts in time describing events covering days to several years. A critical starting point was the men's reactions to their partner's diagnosis. Then as time went on and their partner's health improved or deteriorated the men responded by engaging in different (often new) tasks and responsibilities. This brought different concerns, emotional reactions and challenges – such as fear that the cancer may return. Contextual factors such as the type of cancer, a history of cancer in the family, the men's employment status, pre-existing relationship dynamics and crucially their negotiation of masculine discourses all impacted on differences between the men's accounts. Yet, the pre-identified threads centred their experiences within an organisational framework. Previous research and theory was used to understand how this data supported or diverged from the literature.

Quotations were used in the individual stories and in the scenes so that the men's words (and mine where relevant) were an integral part of the interpretation. Furthermore, one of my aims with this research was to provide the men with voice and authority as male carers are an underrepresented group. Therefore, the scenes were symbolic. Not only did they reflect the performative nature of identity, they represented the men's perspectives taking centre stage. Bogdan & Biklen (1998) describe 'giving voice' as 'empowering people who may remain silent' and feminist researchers have discussed the idea of using research to 'empower the researched' (Lather, 1991; DeVault, 1999). Thus, in this research, by attending to whole stories in order to preserve the detail and complexity of each person's life and by constructing and representing the data into scenes, my aim was to play an active role in putting their perspectives under the spotlight.

Chapter summary

The aim of this chapter was to lay the groundwork for understanding narrative and provide rationale for why I chose to use a narrative approach. This took the discussion in three directions. Beginning with Propp's analysis of folktales drew attention to the organization of stories noting that stories contain common elements that make them recognisable as stories. Within the field of structural analysis, scholars Labov & Waletzky produced a seminal six part model on the elements of narrative. This model influenced the preliminary stages of my analysis. Recognising the limitations of the structural approach I felt that it was important to recognise that how a story is told is as important as what is conveyed. That is why *content* and *structure* are accepted as being significant points of analytic investigation within narratives. Performative approaches recognise that stories are not told in vacuums they are told for someone. Content *and* form need 'attending to' so my analytic framework layered the two approaches to enable a multidimensional interrogation of male caring experiences. The depth of insight that can be gathered from this methodology was certainly a factor in my decision to use a narrative approach to answer my research questions. However, for me, the biggest appeal and also I feel one of the strengths of this study is the way that inviting someone to ‘tell their story’ creates a platform in which a participant can fuse illness and accounts of their carer experiences into their personal life and circumstances. As a result, these stories take on meaning. Obviously this is important for analysis and interpretation - but also for the individual who is articulating their perspective.

CHAPTER FIVE: METHOD

Structure of chapter:

- *Research design*
- *Participants*
- *Recruitment*
- *Interviews*
- *Transcription*
- *Identifying narratives*
- *Applying the analytical framework*

Overview

This chapter details how the study was conducted. It will move through all aspects of the study process beginning with the selection of the study sample and ending with a discussion on analysis. Ethical considerations are weaved throughout.

After presenting my research design, including study aims, I will begin by detailing the range of strategies that were used to recruit my male participants. I will reflect on the challenges I faced and how I overcame them. Next, I will provide a summary of the participants included in this study – however, a more detailed description of the participants can be found in the next chapter.

The interview process is then described, including the settings that the interviews were conducted in, the strategies used to elicit a narrative interview and a consideration of the process behind longitudinal interviews. Each interview was transcribed and I discuss how the transcription process carries particular implications for interpretation of the data. The chapter closes by detailing the decisions I made in regard to identifying narratives and how I applied a structural and performative analytical approach to the interview data.

5.1 Research Design

Ethical approval for this study was granted by Edinburgh Napier University in February 2017 and can be found in appendix five.

5.1.1. Research question

This study was designed to explore participants' narratives in relation to the overarching research question:

- *How do men narrate their experiences of caring for a partner with a cancer diagnosis?*

This overarching research question is supported by the following sub-questions:

- What is the relationship between caring and masculinity?

- What are the challenging and positive aspects of this caring role?

- What is it like to care for a partner over one year?

The focus of this research was to allow the participants to talk about what is important to them. As discussed in chapter four, I approached this research with the view that individuals make sense of experiences through storytelling, so narrative is a way of accessing, understanding and representing their experiences.

Given the underrepresentation of male carers within carer samples a further objective is:

- To provide an opportunity for male carers to articulate their perspectives and for these perspectives (following my interpretation) to be the outcomes of this research.

As also discussed in chapter four, this objective then informed my decision to represent my findings as individual stories and scenes. As the narrator (the interpreter of experience), it was my responsibility to reflect on the data, my chosen theoretical framework, current literature and then select the most important events in order to craft something that was reportable. In doing so, I gave voice and authority to the male participants.

5.2 Participants

My target study population was men who were currently caring for their partner/spouse due to a diagnosis of cancer. I made no exclusions based on relationship type (married, cohabiting, living apart) or length of time in the relationship. The decision was made to focus on spousal caring as this is often one of the most intense caring relationships, with carers providing support and care 24 hours a day (Cheung & Hocking, 2004). I only included men from Scotland due to the logistics of travelling and interviewing someone on three occasions within a year.

As discussed previously, views differ around the term 'carer'. Some people dislike the term as they do not feel it relates to their role and relationship – which is first and foremost that of a husband/wife or partner. I became aware of this through the literature (Molyneaux et al., 2010) and through discussion with a male carer, who I met with on two occasions before I began this study, to talk about matters such as the wording in my information sheet and potential topics of conversation within the interview. Following his advice I used the word 'supporting' rather than caring, stating that I was looking to recruit 'men who are supporting their partner due to their cancer diagnosis'. I felt this was a more inclusive term and hoped this shift in language would open up the study to a larger pool of participants who did not view themselves as a 'carer' (see appendix 6 for participant information sheet).

In the first six months of my study I focused on care receivers with breast cancer, as it is the most common cancer in women in the UK (Cancer Research UK, 2019). I hoped that due to the number of women diagnosed with breast cancer there potentially would be more opportunity to recruit their male partners. It is acknowledged this assumes a heterosexual partnership between the carer and care receiver. However, same-sex relationships (where the male has breast cancer) were also open for inclusion in the study. A further factor in my decision-making process was that breast cancer has a higher survival rate than other cancers (Cancer Research UK, 2019) which was taken into consideration due to the longitudinal design in this study.

I set the time from diagnosis between three and 12 months as I wanted to capture current caring experiences, including reaction to the diagnosis, adjustment to their partner's illness and significant clinical moments such as their partner receiving treatment. As this was a longitudinal study, I wanted to ensure that the participants felt willing to talk about their caring role one year from the first interview. I reasoned that where participants were beyond 12 months post-diagnosis, say, two or three years from diagnosis, their experiences may differ from someone in the earlier phases of diagnosis. Research suggests cancer 'survivors[21]' who are ten years from diagnosis may have unique needs, such as increased existential issues (Hodgkinson, 2007) and this is likely to impact on the carer.

However, as recruitment was slow, I decided to broaden my criteria to any type of cancer. As my aims were rooted in understanding masculinity and caring, irrespective of cancer type, it seemed reasonable to broaden my pool of potential participants this way. This amendment was approved by the university ethics committee in May 2018. In my final sample, cancer types included breast, oesophageal and gynaecological.

5.2.1 Inclusion and exclusion criteria

The broad aim when deciding upon my inclusion and exclusion criteria was to ensure my sample had the desired characteristics to meet my study aims. The sample therefore needed to be male and supporting a spouse/partner with cancer. The exclusions were set as these were factors that would influence the study in ways that would move the findings away from my original aims. Adults who lacked consent to participate were excluded because of the legal and ethical implications of conducting research with such participants.

Inclusion	**Exclusion**
Males, over 18 years old who reside in Scotland	Professional carer (paid to provide care)
Supporting a spouse/partner with a cancer diagnosis	Person deemed incapable of consenting to participate as defined by the Adults with Incapacity Act (2000)
The care receiver will be diagnosed with cancer within the last 3-12 months at the point of recruitment. This may be a primary or secondary diagnosis.	Bereaved carers

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[21] The term 'survivor' is contested due to a lack of consensus over the definition and meaning. See, for example: Berry, L. L., Davis, S. W., Godfrey Flynn, A., Landercasper, J., & Deming, K. A. (2019). Is it time to reconsider the term "cancer survivor"? *Journal of Psychosocial Oncology, 37*(4), 413-426.

Table 3: Inclusion and exclusion criteria

5.3 Recruitment

Participants were recruited in a variety of ways between February 2017 and August 2018. In compliance with standard ethical procedures (NHS, Health Research Authority), the first approach was made by someone other than me. This was done to avoid participants feeling coerced into participation and to avoid a situation where someone may wish to decline but find it difficult to say no to the researcher. Three Scottish organisations/charities promoted my study. They were:

1. Improving the Cancer Journey[22], a community-based cancer service located in Glasgow and Dundee[23], posted 80 letters (appendix 7) on my behalf to their clients (individuals with a cancer diagnosis) who were invited to pass on details of my study to their male partner. I have established contacts with the employees of this service so this recruitment method was used first. I recruited four participants using this method.

2. Cancer Support Scotland[24], a Scottish cancer charity, advertised my study through a poster (appendix 8) in their main centre in Glasgow. They also posted details about my study on their Facebook page and tweeted details about the study twice. The post asked those people interested to contact me for more information. This strategy was used 12 months into recruitment and I recruited one participant using this method.

3. Macmillan Cancer Support[25], a major UK cancer charity, posted details about my study on their Scottish Facebook page and tweeted details twice. Study details were also included in the Macmillan library newsletter and my recruitment poster was put up in five Glasgow libraries. I recruited one participant through Macmillan.

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[22] https://www.glasgow.gov.uk/index.aspx?articleid=17159

[23] The service has now (Oct 2020) rolled out to 5 areas across Scotland.

[24] https://www.cancersupportscotland.org/

[25] https://www.macmillan.org.uk/

Further strategies were:

- A recruitment poster (appendix 8) was placed around Edinburgh Napier University Sighthill campus in mail and photocopier rooms and spaces where staff meet for lunch. The poster provided my email address and invited people to get in touch if they were interested or required more information. I recruited one participant using this method.

- An 'all student' email was sent to the PhD students in the School of Health and Social Care at Edinburgh Napier University providing study details and contact details should they be interested or know anyone who may be interested. This method did not generate any participants.

- Finally, through 'snowballing', the last participant recruited into the study had found out about the research through his friend, who was also a participant.

5.3.1 Recruitment challenges

These different strategies reflect a 20-month recruitment period. I had hoped to recruit all participants through letters sent by Improving the Cancer Journey. However, after 12 months, I had only recruited four in total. It is acknowledged that in qualitative research small sample sizes are optimal (Denzin & Lincoln, 2008). However, sample size is influenced by theoretical and practical implications. At the initial design stage my preferred sample size was ten, erring on the slightly higher side to account for attrition. However, I realised that rather than focusing on recruiting a fixed number of participants, it was acceptable to have a sample size range considering a minimum and maximum number of participants against the time I had to recruit. I drew on the literature to support this decision making (Vasileiou et al., 2018; Crouch & McKenzie, 2006). I set my maximum at ten and my minimum at six. I felt this range provided scope for individual and cross-sample analysis without being overwhelmed by the amount of data. All decisions were also discussed with my supervisory team and we were all in agreement that this was a sensible strategy.

In order to meet my recruitment target I decided to rethink my strategy. I considered that the letter approach was not very effective for two reasons. Firstly, a cancer diagnosis can leave individuals feeling overwhelmed and they may, particularly at the diagnosis stage, receive a lot of information. Consequently, the letter may be forgotten about amongst other priorities. Secondly, the letter relied on the person diagnosed handing this information to their partner/spouse. This adds a layer of 'gatekeeping' into the process that may have affected recruitment (Sutton et al., 2003). Indeed, I actually received a letter from an individual who had decided her partner would not be suitable for the study, which illustrates my point well.

Therefore, I decided to broaden the way that potential participants could access my study information. I approached Cancer Support Scotland and Macmillan Cancer Support and asked if they would promote my study through their social media (Facebook and Twitter) and place information in their centres and in their newsletters. This method was chosen due to the large number of online followers that these two charities have (in combination approximately 9,500).

Recognising that social media is not used by everyone, I also decided to make a recruitment poster. My decision to put these posters up in university spaces (as well as cancer sites) was due to the prevalence of cancer in society. I considered it may be likely that someone would either be in that situation themselves or know someone who may be willing to participate.

In summary, through this range of methods I recruited eight participants. Upon reflection, I feel that using different ways to advertise the study increased the range of participants in terms of their age, socioeconomic background, profession and relationship status (married/cohabiting). While the individuals who use the community cancer service (the first recruitment method) are varied, the majority fall within one age band and have either breast or lung cancer. Indeed, it was the other methods (social media and snowballing) that attracted the youngest and oldest participants to the study. Accordingly, the benefit in gaining a more heterogeneous sample was that any commonalities found amongst these individuals can be related to the wider phenomenon under investigation – masculinity and caring – rather than being specific to a particular group.

5.3.2 Recruitment challenges – male carers

Beyond these general challenges associated with recruitment, I have considered whether there was anything particular about the target sample (male carers) that made recruitment difficult. Scholars have considered the difficulties recruiting men. Brown (2001); Oliffe & Mroz (2005); Pini (2005) and Walby (2010) have all discussed men's reluctance to talk about their health within research. Emotions play a significant role in the discussion of health (and illness) as these conditions can evoke feelings of fear, shame, sadness and guilt (Bowman, 2001). Consequently, Affleck et al., (2013), discussing qualitative interviews and different theories of emotional inexpression, believe it is likely that the level of emotional discussion required within a long interview on a 'sensitive' topic such as illness may be uncomfortable and perhaps off-putting for some men. For that reason, some men may have been reluctant to talk about their caring experiences within the research interview, so did not volunteer to take part.

In tandem with this, evidence suggests that carers often neglect their own self-care as they are preoccupied with the care of their family member/partner (Knowles et al., 2016). Consequently, they may not feel that they have the time to take part in research or believe it would be inappropriate to devote time to their experiences when it is their partner who is ill. I believe this probably played a part in who participated in this study. While all the men were actively caring, in terms of providing support and attending hospital appointments and so on, they were past the more intense stage of care of when their partner was first diagnosed. For example, one of my participants (David) spoke about a time when he was unable to leave the house because his wife was so ill. It is unlikely that he would have volunteered for this study at that point. However, when he did see the study information things were less intense and he actually suggested meeting in Maggie's Centre[26] (hereafter referred to as Maggie's) rather than at home.

In light of this, I recommend that researchers are flexible with their recruitment approach, that they emphasise to carers that *their* experiences are important and valuable to the research community, and where appropriate consider media such as Skype and the telephone if a face-to-face conversation may prove to be difficult. Nevertheless, men do take part in research and are comfortable talking about sensitive or difficult issues. My study is clearly the case in point here but also within my review (Young, Kyle, & Sun, 2020) I found that there was a higher proportion overall of male participants (45.7%) in the qualitative

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[26] Maggie's Centres are drop in centres across the UK. They offer free support and information to people affected by cancer. They are usually located within hospital premises.

studies than in the quantitative studies (34.6%). Moreover, it indicates that male participants are willing to share these experiences, when asked.

5.4 Interviews

5.4.1 The interview setting

Each participant was invited to take part in an interview at a location of their choice and on a day and time of their choice. Most (n=5) wanted to meet in their home. Other settings included a café, a library, an office in the Beatson West of Scotland Cancer Centre[27] (hereafter referred to as The Beatson) and a private room in Maggie's.

The advantage of interviewing in someone's home included convenience, privacy and comfort (Borbasi et al., 2002). The participants looked relaxed and often made themselves a hot drink before beginning the interview. For two participants this also meant that they did not need to leave their partner, as their normal routine involved spending the day together. For one participant, interviewing in the home meant that he could also look after his teenage daughter.

It is unclear exactly how much the setting contributed to the participants' candour but it is reasonable to assume that in the situations where no one else was present, apart from the participant and I, being in the privacy of their home provided the opportunity to talk about sensitive subjects such as sexual intimacy and display emotional reactions, such as crying. However, the disadvantage of the home setting was that there were uncontrolled interruptions, such as the telephone ringing and a lack of privacy from other family members. On one occasion the participant got up and closed the door to the room we were in so his partner would not overhear our conversation. On another occasion, the participant started arguing with his daughter during the interview and asked her to leave the room, but she would not.

The interviews conducted in the public spaces were not noticeably different. They were of similar length and we covered similar topics. I believe this is partly related to the fact that, despite them being 'public' settings, I tried to create privacy within these settings. For

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[27] A specialised cancer care centre – the largest in Scotland.

instance, before meeting a participant in a café I phoned ahead and asked if I could book a booth to avoid being seated in a busy and noisy part of the café. Likewise, in the library I was able to ask if I could use a private room – again to avoid a situation where the participant may feel uncomfortable and not wish to talk openly. Personally, my least favourite location for interviewing was the Beatson. There was an overwhelming sense of formality about the space, an office belonging to a consultant oncologist. This felt at odds with my research, which aimed to understand personal experiences rather than clinical outcomes. The participant who was interviewed there seemed relaxed but notably he was more open about his feelings on sexual intimacy in our second interview, which was in his home. Also, when we returned to the Beatson for our third interview, he mentioned that he did not like being back on hospital premises as it brought back unpleasant memories. He reassured me that he was happy to be interviewed but, taking this forward, I think where possible I would like to avoid such formal settings.

Nevertheless, a point to note is that the participant always chose the location. While I am making the assumption that public spaces are not always ideal when conducting an interview that may delve into private and sensitive topics, this may not be the participant's view.

5.4.2 Consent

The consent forms used for this study are in appendix 8. Upon arrival at the interview setting I would (and particularly in the first interview) spend a few minutes developing rapport with the participant. This would usually involve a chat about how I travelled there and in the home settings I was offered a cup of coffee or tea. Once we were both comfortable, I would begin by thanking the participant for their time and I would then summarise the content of the participant information sheet (appendix 6). All participants had received by post or email a copy of the information sheet in advance of the interview, but I wanted to verbally go through the information and then ask if there were any questions or concerns. I highlighted that there would be three interviews, if they wished, and that they could withdraw from the study at any point. I assured participants that all identifiable information would be removed from the interview transcripts and that in publications and the thesis their identity would remain anonymous. On every occasion the participant was happy to proceed with no questions. We then went through the consent form together and we both signed it. I did not receive written consent for each subsequent interview and consent for these interviews was taken over the telephone, usually in the two to three weeks before the interview. The day before I would then telephone, text or email the participant again (depending on preference) to ask if they were still happy to continue. On the day, I also took informal verbal consent.

5.4.3 Beginning the interview – tell me your story

Riessman (2008) describes interviews as 'narrative occasions'. A narrative interview allows for an in-depth sustained account of events and experiences. The usual rules of conversation apply, such as entrance and exit talk and turn taking, but participants were encouraged to lead and tell their story in their own words, rather than replying to a set of questions as is typically the case in a semi-structured interview.

I was aware of the sensitivity of the topic and wanted to provide the participants with the time and space to talk. A short topic guide was developed that covered the following broad themes; relationship dynamics, social/practical/psychological needs, roles and responsibilities, and support requirements. The purpose of this guide was to provide structure and to keep the interview focused if conversation became stilted. However, the overall aim was to allow the participants to speak freely and have control over the direction of the interview (McAdams, 1993). The guide was only really used in the first interview as subsequent interviews were tailored to the participant's individual circumstances.

After clarifying once more that the participant was happy to proceed, I turned on the audio recorder and began every interview with the question:

> *'I would like you to tell me your story of what it's like to care for your partner who has a cancer diagnosis.'*

Most participants, without hesitation, then began to talk. One participant asked where he should start, to which I answered, 'anywhere you feel comfortable'. One participant asked if he should start from the diagnosis, to which I also answered that it was up to him where he would like to start. In most cases the conversation flowed with minimal input from me.

5.4.4 Closing the conversation

In order to bring the interview to a close I thanked the participants for sharing their views and asked them if there was anything else that they would like to talk about. Participants tended to then say no and state that they hoped what they had said was useful. Some were worried that they had just been 'rambling on' to which I reassured them that they had not and that this style of research is all about capturing longer, extended accounts. Once I turned the audio recorder off I then carried out a debrief. This involved asking the participant how they felt. I was prepared to offer support from Macmillan Cancer Support if anyone had needed it but everyone stated that they felt fine and most then expressed their thanks to me for being given the opportunity to talk. Finally, if this was the first or second interview, I then made tentative arrangements for our next interview, stating the month that I would next be in touch. In the third and last interview, I asked if participants still consented to me using quotes in the dissemination of this study as long as I removed any identifiable information and protected their anonymity with a pseudonym. I also asked if they would like me to send them feedback from the study and then I wished them well for the future.

5.4.5 Anonymisation

Protecting the participants' anonymity was essentially about removing identifiable information such as their name, references to geographical locations, and the names of other family members or friends. The purpose was to protect their privacy, to build trust and to maintain ethical standards, so that if and when the data was presented to external audiences, the reader or listener would not know who was being quoted (Baez, 2002). Corti et al. (2000) suggest that by using pseudonyms 'the data remaining after anonymization tells us a story without saying whose story it is' (Corti et al., 2000:21). I decided to use pseudonyms, rather than participant numbers, as this felt more personal and respectful. I spent some time thinking about the names and tried to match names to the person's age band. This was not just a 'mundane' task – I was trying to both respect the participant and create a connection for the reader of this research (Edwards, 2019).

I took responsibility (after discussions with my supervisors) for deciding what aspects of the participants' life and circumstances were removed, or not. For example, I used the participants' exact wording when they referred to the individuals who work in a hospital ('nurse' or 'oncologist') rather than use a generic title such as 'health professional' (an issue which was debated by Thomson et al. (2005). However, I did remove the clinicians' names. I gave the participants' partners a pseudonym and I removed any reference to friends, other family members or reference to information such as street names or the hospital their partner was attending. However, some scholars claim that removing data can distort the data or change the context of the text because it removes or alters the connections between people, places and events (Heaton, 2004; Nespor, 2000). I acknowledge this position and have reflected on the decisions we made. My supervisors and I came to the conclusion that the information I removed did not alter the essence of the data as, in the main, the changes were in relation to objects and names, not data carrying meaning about experiences. Yet, this was not a straightforward process and there were more grey areas than I had first realised at the beginning of the PhD process.

Kaiser (2009) reflects on this in her paper 'Protecting Respondent Confidentiality'. She suggests that there are alternative steps that researchers can take to give them a wider range of options when considering anonymisation. The researcher can make the participants aware that confidentiality may be an issue that is returned to throughout the research process. This would enable the researcher to contact the participant again if, for example, they wanted to discuss the possibility of the research being disseminated amongst new audiences. There is also the view that not all participants may want complete confidentiality, either from the outset, or that they may change their mind during the course of the study. However, I made the decision that they would have pseudonyms, something which may be considered paternalistic (Giordano et al., 2007). Kaiser (2009) suggests that a post-interview confidentiality form would enable further discussions about identifying information and may lead to participants expressing a desire to publish data that researchers may have deemed too sensitive. This suggestion is corroborated by the idea that individuals can feel empowered or useful knowing that they are helping others with their data (Beck, 2005; Carter et al., 2008). Consequently, while I know that my decisions were based on established ethical standards that aim to protect participants from harm or discomfort, I do acknowledge that the steps I followed are not the only ways to maintain anonymisation and confidentiality.

5.4.6 Field notes

After each interview I wrote field notes covering first impressions, conversational tone, setting, body language, reflection on interview relationship and any significant points of interest. This helped with reflexivity as I considered my influence on the interview dynamics. It also helped to reread my field notes when I was returning to interview someone again (appendix 9). This was also a useful way for me to debrief, providing me with the opportunity to reflect on my feelings and views. I spent some time thinking about the way the conversation had unfolded and the co-constructed nature of the interview experience, particularly after first interviews. I tried to reflect on why some interviews felt more relaxed and informal and some were 'harder'. By that I mean interviews where the conversation did not flow as easily or occasions where I have asked a question which, upon reflection, I wish I had phrased differently. For example, taken from my second interview with Mark:

> *'So there's that fine balance between what I'm doing myself and what she can help with and when I'm doing it wrong, she tells me I'm doing it wrong.'*
>
> [both laugh]
>
> *'So there's always that balance. And obviously trying to fit the kids in and get them all sorted.'*
>
> Interviewer (me): *'Do you think you've adjusted a bit more to those kinds of things?'*
>
> [Pause]
>
> Interviewer: '*Maybe, maybe not?'*
>
> *'There's been quite a lot of tension and, er, adjusting to the work. I've changed a lot of things I do. I've taken more hours in my work to get more money. So, adjusting no. Because to me everything is ongoing. You adjust to a certain situation then another situation comes along.'*

Reading this back, my question about 'adjusting' changed the dynamic of this interaction. I read his pause as an indication that he had not adjusted (so retracted my question) and he went on to confirm that, actually no, he had not adjusted and why. I wish I had asked the question differently as it now feels a little insensitive, although I took his laughter as a sign that he was 'adjusting'. For context, in our first interview he spoke a lot about doing things around the house in the way that his wife wanted them done and this made him frustrated and angry. Therefore, hearing him laugh about this was the first time he had conveyed a different emotion to me. Nevertheless, this was also quite a closed question, leaving little scope for him to describe his experiences to me. In combination, interactions like these will have created a particular tone and reflecting on this in my field notes helped me to understand my position and influence within the interview setting.

I also wrote an interview summary in which I condensed what was said in my own words. This formed the basis of a summary document that I emailed to each participant after our interviews. The purpose of this was twofold; to provide the participant with a typed copy of our discussion for their own records (if they wished) and to ascertain if my summary of our conversation was consistent with theirs. There was no attempt at analysis in this document, it was just a description of the topics covered in our interview. I chose to do this rather than send transcripts as these contained features such as pauses, false starts and grammatical inconsistencies. Participants can become embarrassed or self-conscious when they see their thoughts represented like this and worry that they were 'rambling' or that they were being inarticulate (Carlson, 2010). None of the participants had any comments after receiving their interview summary.

5.4.7 Longitudinal interviews

Qualitative longitudinal interviewing captures the interplay between time and the cultural dimensions of social life (Neale & Flowerdew, 2003). Saldana (2003), writing in a highly cited text on longitudinal research, states that longitudinal qualitative research is not just about researching from A to B, it is about researching from A to B *through* time – which implies a process rather than focusing on isolated events.

Seven participants were interviewed three times in this study over one year. Each interview was approximately four months apart. This timeframe was chosen to capture any change that may occur coinciding with the clinical trajectory that the person diagnosed with cancer was following and to capture any change or variation in relation to reactions, emotions, behaviours, relationship dynamics and plans. Ultimately, the decision to interview over one year was based on both evidence and time constraints. There is a lack of research on the long-term experiences of carers so I had a clear rationale to explore caring over time. I did not have an infinite amount of time to complete the PhD, so I decided that a one-year interviewing timeframe would be practical. I was also conscious that it may be harder to keep a participant engaged in a study the longer time passes. Reflecting now on the 12-month time period, I feel reassured that this was an optimal period of time as, by the third interview, which for some people was 18 months from diagnosis, they wanted to ‘move on’ as they viewed their caring role as something that was now in the past.

Follow up was made after approximately two weeks between interviews. I either emailed, texted or telephoned the participant (depending on preference) and invited them to set a date and time for the next interview. One participant (my eighth) was only interviewed once. I sent him two email requests asking if he would like to participate in his next interview but he did not reply. In our first interview he spoke about his wife needing to return to hospital for tests as they were concerned that her cancer had returned. I do not know why I did not hear from him again, but I wondered if this may have been the reason.

5.4.8 Longitudinal interview dynamics

Longitudinal interviewing is a process that creates a particular dynamic between the researcher and the participant. When returning to interview someone for the second time a relationship had already been established. This meant that I spent less time establishing rapport and generally just moved straight into the interview. I began second and third interviews with a request to ‘tell me how things have been since we last met’. My intention was to focus the conversation on anything that may have happened between interviews so as to explore change. I also wanted to set a relaxed tone that was more characteristic of a chat than a formal interview to help put the participant at ease end encourage longer accounts.

As discussed in chapter four, from an analytical perspective regular contact with participants allowed me to explore perceptions of temporality, process and change. I could return to topics that I wanted to know more about and get to know that person and their wider circumstances in greater detail. Over one year I heard about job loss, relationship breakdown, ill health in the carer, house moves and other family members receiving a cancer diagnosis. All of these situations had a significant impact on the participants' narratives and would not have been captured in a study that only interviewed the carer on one occasion.

Sadly, given the longitudinal time frame, on two occasions when I returned to carry out the final interview the participant's partner had died. One participant told me in advance and with the other I only found out just before the interview. In both situations I emphatically suggested that we did not need to carry out the interview but both men were happy to continue. James (Participant 3) actually stated that his wife would have wanted him to continue as she 'was academic like me'. This was a touching reflection on how he perceived me and how he felt he was respecting his wife's wishes after she had passed away. I excluded bereaved carers from my initial sample population due to the distinct experiences that they would face. But, given the nature of the illness, I did anticipate that over one year some of the men may become bereaved. I think this is another strength of the longitudinal approach and while the interview itself needs to be managed sensitively it is important that, if willing, the participant's voice is heard during this time.

However, I feel one of the biggest strengths to regular interviewing is the relationship formed between the researcher and participant. It was this connection that allowed these men to share experiences that, for some, had remained unspoken. As I approached the final interview of this entire process I reflected on how these participants had shared hours of their time with me, covering such a breadth of topics and emotions. I felt humbled but in some ways saddened, knowing that I would not get the chance to interact with these people again. There is a literature base on 'exiting' the field that draws on the fact that, for many researchers, becoming emotionally attached to the research and the lives of their participants is an unavoidable but – importantly – not a detrimental part of the process (Benbow & Hall, 2018).

I can relate to this – so much happened in these men's lives and their stories continue, a year after my last interview, to feature in my life as an academic researcher. Moreover, due to my own personal circumstances I can sympathise with a statement that one of the participants made about always feeling 'on call' to describe feeling constantly worried about the health of a loved one. To some extent, I now have a new level of appreciation for the emotional impact of caring. This is not a troubling thing, nor has it made the 'exit' from the field any harder. Nevertheless, the emotional balance between striving for closeness and rapport while maintaining appropriate boundaries has required reflection and discussion with my supervisors (Watts, 2008).

5.5 Reliability and Validity

Concepts such as reliability and validity are typically associated with quantitative research and there is debate about whether the terms are appropriate to evaluate qualitative research (Rolfe, 2006). My position is that qualitative research cannot be judged according to the same criteria as quantitative research. However, while each qualitative study will be unique (and that is a strength), there are a number of practical steps and considerations that the qualitative researcher can go through in order to enhance the quality and transparency of their study. For example, reliability in qualitative studies can refer to a number of practical issues within the interview process such as the wording of interview questions, establishing rapport, and a consideration of the power dynamics between the researcher and the participants (Breakwell, 2000; Silverman, 2013). In summary, it is about the 'soundness' of the study.

Guba & Lincoln (1994) have suggested four different criteria that are more appropriate to the qualitative paradigm. They are credibility, transferability, dependability and confirmability. Credibility establishes whether the research findings present plausible information drawn from the participants' data. Transferability refers to the extent that the results can be transferred to different contexts. Dependability is about the stability of the findings over time and confirmability is the degree to which the results may be corroborated by other researchers (Cope, 2014). Strategies to embed these criteria include reflexivity (including a consideration of the researcher's personal experiences and viewpoints), keeping field notes, and discussions with peers/supervisors about my interpretation[28] of the data. To be clear, I am not claiming these processes are about making my research more accurate or

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[28] During the course of my PhD I have also presented (orally and through poster) at many (around 15) academic conferences and symposiums. The feedback from these events has helped to increase the confirmability and transferability of my findings.

rigorous, it is about recognising researcher involvement. I will now bring all of these ideas together under a wider discussion on reflexivity.

5.5.1 Reflexivity

Interviewers and interviewees both bring their own identities, experiences, assumptions and expectations into the interview encounter. Reflexivity encourages exploration into the way in which these identities and assumptions may influence and inform the research process. Researchers approach reflexivity in a number of different ways but common to all is the idea of reflection on action. This may include a focus on assumptions about knowledge, critical self-reflection and/or an examination of the social and political constructions that inform the research process (Dowling, 2006). As such, Gough (2003) actually argues for the plural term 'reflexivities' to encapsulate the idea that it is a multifaceted concept which can mean many things.

In terms of my role as a researcher, my values and my positioning, I have used commentary throughout the findings and the discussion chapter that considers my position (including age and gender), my presence in the interview, my responses and the co-constructed nature of narrative data. However, before beginning this discussion, it is important to acknowledge that there will be assumptions and biases at play within the interview dynamic that no amount of introspection will reveal. My presence (as a woman, a researcher and so on) will have affected the participants' narrative constructions in ways that I will not have considered. Likewise, there will be factors about the participants that will have escaped my attention. That is because there are forces that lie 'beyond the researcher's grasp' (Bishop & Shepard, 2011:1285). I embrace the fact that a range of factors will have shaped my data collection and interpretation – thereby setting up this discussion with the view that a reflective account is *not* an objective account.

Given the focus on gender in this study, I have spent some time thinking about the dynamic of a female researcher interviewing men. Taking these ideas forward, in 2018 I gave a presentation at the University of Bath as part of their annual qualitative seminar. My full paper on this presentation, 'Moving Masculinities: Exploring Gender Identity through a

Female Interviewer/Male Interviewee Dynamic', can be accessed here[29]. In summary, there is a focus in the literature on problematic gender dynamics in a female interviewer/male interviewee dynamic (Pini, 2005), for example men behaving provocatively by flirting, making comments about the researcher's sexuality, propositioning and touching. However, there is very little said about the dynamics of men interviewing women. The experiences highlighted in the literature by other female researchers reflect the power dynamics that may operate within interviews where men exert a dominant status. However, the dynamics between female researchers and male participants are multifaceted. Further, there has not been the same scholarly focus on the problematic influence of gender within a clinical/cancer research area. Equally, from a personal standpoint I have never encountered an occasion during my seven years of working in cancer care when the men I have interviewed have acted provocatively or tried to exert a dominant status.

Gender interacts with factors such as class, age, the psychological state of the participant, the research environment and the sociocultural context of the interview topic (Broom et al., 2009). Therefore, while male and female experiences can be 'gendered', no two individual experiences will be the same (Reinharz et al., 2002). In my paper 'Moving Masculinities' I discuss how my presence as a female researcher and the process of a research interview may have enabled different versions of the interviewee's masculine self to be revealed and brought into tension. I listened carefully, conveyed understanding, and encouraged the expression of their feelings through verbal prompts and visual cues, such as nods. This, I believe, opened up space for men to challenge their own masculine identities because it contrasted sharply with 'traditional' settings for supportive conversations. The men displayed vulnerability, through crying and discussing personal matters to do with their relationships. On two occasions I was told that they had not shared that information with anyone else.

Layered with this, I was also performing an academic identity. I was dressed relatively smartly, I asked for consent, and I audio-recorded our conversation. This signalled formality and that, while I asked for a 'story', it was a story for the purposes of research. To the participants, this may have sounded strange and out of context. It may have disrupted their

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[29] Clift, B., Hatchard, J., & Gore, J. (2018) (Eds). How Do We Belong? Researcher Positionality Within Qualitative Inquiry: *Proceedings of 4th Annual Qualitative Research Symposium*. University of Bath.

perception of the way that academics collect data. It may also have made them feel nervous, or on the spot, by asking them to begin the interview in such a directed way. However, in our final interviews, most of the men thanked *me* for giving them the opportunity to talk. This restored my confidence that any nerves or feelings of uncertainty that the men may have initially felt had subsided. Most participants launched into their accounts, without hesitation. Consequently, in chapter six, within the individual stories, I discuss the idea of rehearsed stories and reflect how, structurally, there was a common starting point for most of these men when they began constructing their narratives.

I stated on the participant information sheet that this research would provide much-needed understanding on caring experiences from the perspective of men. Therefore, I had set up a dynamic where the participants had something that I (and the wider academic community) required. The main issue here is the circulation of power and status. As the academic, I held the power as this was my study and it was being carried out as part of a PhD, putting me on track to obtain an esteemed qualification. Yet, my hope was to destabilise my power by emphasising the men's much-required insights. It is possible that this may have increased their willingness to take part and commit to being interviewed three times. It may have led to feelings of purpose and doing something for the 'greater good'. Two men stated that they hoped their contributions would go on to help others. One participant in particular spoke about how men may not contribute to this type of research so his motivation for participating was about breaking the silence on men's perspectives. For example:

> *'Not all men like to do it* [talk to others] *because I've spoken to other husbands and their wives have had cancer and they very much clam up, don't want to talk about it, it's a weakness.'* (David)

However, while emphasising that the purpose of the research may have encouraged participation, it may also have created some pressure. Four men, all at some point in their interviews, said something along the lines of, 'Is this OK?' or 'Have I gone off on a tangent?', seeking clarity from me that what they were saying was suitable and fell within the boundaries of a research interview. I worked hard to convince these men it was OK. In one interaction I stated that I had asked for a story and stories are not perfectly linear. I was trying to reassure and, in some sense, take accountability for the choice of method. They were not doing anything wrong or saying anything off topic because I was the one who had asked them to articulate themselves in that way. I return to this point in chapter nine when I consider the limitations of using interviews to capture perceptions of experiences.

5.5.2 Situating reflexivity within the research process

After studying the literature (as covered in chapter two), I identified that male carers are underrepresented. Therefore, my overarching question of '*How do men narrate their experiences of caring*?' was formulated as I did not believe it could be sufficiently answered using the current academic literature. Further questions with regard to understanding positive and challenging experiences and investigating this phenomenon over time using narrative interviews also stemmed from my views on the limitations within the evidence base. However, my motivation for this research was not only about filling an evidence gap. As I explored the literature (including policy and charity reports), I wondered *why* men were underrepresented. I have discussed this in relation to recruitment challenges (this chapter) and in terms of societal attitudes towards men.

My final aim in the research was to provide an opportunity for male carers to articulate their experiences and for these experiences to be the outcomes of this research. This was about providing men with voice and authority (Bodgan & Biklen, 1998). This also reflects my attitude towards men. As considered in the introduction, I think that men face particular challenges due to the existence of constrictive masculine discourses. One consequence of this is that it may limit their willingness to express themselves emotionally. Then again, if willing they may find there are limited opportunities or outlets to be able to express these emotions. Therefore, there are interrelated personal and societal issues at play. These are my beliefs and assumptions based on the views that men have articulated to me, observing men (professionally and personally), reading academic literature and engaging in sources written about men in the media and the arts. This is why I wanted to provide an opportunity for men to speak about their experiences through this research study. When I consider the implications for future research, policy and practice (chapter nine), this ambition to make male carers more visible fed into my plans about what I wanted to do with this research.

Yet, not being male, none of my views, motivations and assumptions are based on personal experience. Therefore, *curiosity* also motivated my research question, or as Gaglio (2006) phrases it, a 'willingness to look into the world of the other'. The lenses I applied in my theoretical framework, to some extent, expressed these curiosities. They provided me with a map to navigate through concepts such as identity and my thoughts about masculine discourses. Curiosity plays an important role in the research process and I think this also helped to sustain my motivation over the last five years. Once I had established that this was a novel area of enquiry (both topic and method), it further sparked my interest. In turn, thinking about the most appropriate method to use, I was drawn to the narrative approach because it enabled someone's personal and illness experiences to fuse together to generate meaning. Furthermore, there is a level of complexity to the narrative method in terms of the volume of data and the depth of analysis. This was not off-putting because I think there was a relationship between my curiosity for this topic and my desire to explore and search for meaning through narratives.

That is not to say that the volume of data did not pose any challenges. Holloway (2007) has reflected that 'the more unstructured it is, the greater the anxiety that it is going to be impossible to analyse rigorously' (Holloway 2007:21). When I began the analysis I was a little overwhelmed. However, I found what helped to reduce any anxiety over the amount of data was to analyse each transcript immediately following (or as close as possible) to the interview. Finally, I made the decision that I was going to have a chapter devoted to the participant's individual stories. This helped to reduce the concerns I had during my analysis that I would omit important elements of the men's individual experiences if I only focused on interpreting across the stories. What 'important' meant to me will have been influenced by a range of personal and external factors. I discuss this further within the two findings chapters.

5.6 Transcription

Riessman (1993) describes transcription as an interpretive process with transcription conventions reflecting the researcher's theoretical position. In other words, transcription is a representational process in which the researcher decides what is represented in the transcript. This process needs to be acknowledged and explained. As Davidson (2009) puts it:

> *'It is impossible to record all features of talk and interaction from recordings, all transcripts are selective in one way or another.'* (Davidson, 2009:38).

Oliver et al. (2005) suggest a continuum to encompass the range of transcription practices. At one end is 'naturalism'. In a naturalised approach to transcription, language represents the 'real world' and every utterance is transcribed in as much detail as possible. Conversational analysis is classed as a naturalised approach (Davidson, 2009). At the other end of the continuum is 'denaturalism', in which elements of speech such as pauses and stutters are removed. Between these two approaches are a variety of methods for transcribing that should reflect the researcher's theoretical stance and research aims.

Contemplating my transcription choices, I knew that I did not want, nor was it necessary to, transcribe to the detail used in conversational analysis as my analytic focus was not on the intricacies of spoken language or features such as turn taking. Leaning towards the 'denaturalism' end of the continuum, my aim was to accurately represent the substance of the interview. My focus in this study was on the 'ideological dimensions' of speech (Cameron, 2001). Therefore, interviews and transcripts provided access to features such as identity positioning and discourse.

In line with my research aims and theoretical framework I made a judgement in terms of what to include in my transcripts. I included features such as pauses, emphasis, laughter, crying, overlapping or interrupted speech, acknowledgments (mmhmm, yeah) and fillers (hmm) as I wanted to capture the context of the interview. Detailing these features helped to convey the emotion behind certain utterances, for example, when someone was hesitant or particularly enthused about something. I did not include non-verbal vocalisations such as smiling or fidgeting in my transcripts, as I reflected on the non-verbal interview dynamics in my field work diary and brought that into the analysis where appropriate. A further important choice I made was to include my voice and anyone else who was present in the interview room in the transcript. In the main this included the participant's partner. I made this choice because, as guided by my theoretical framework, I am focusing on the relational nature of identity – how the self is co-constructed in relation to others and the association between self and social context.

Finally, I needed to decide how to transcribe accents. Six of my participants were Scottish and two were Irish. I decided not to transcribe the words exactly as they sounded but I included common features of their accents such as 'no bad' rather than not bad, 'they two' rather than those two and 'wasnae' rather than was not as it helped to preserve meaning, informality and that person's personality. However, I acknowledge that as I am not Scottish or Irish I heard these interviews through my own cultural filter, which may have impacted on what I considered to be Scottish/Irish words, diction or grammatical structures and what I did not.

In summary, I went through two steps when transcribing:

1. I transcribed everything that was said during the interview in a first draft.
2. I then replayed the audio and edited the transcript adding in the more subtle features such as pauses, emphasis and Scottish/Irish diction. This version had no breaks in the text.

I then reread each transcript and identified narrative segments guided by a structural and performative analytical approaches, as detailed in the next section.

5.7 Identifying Narratives

5.7.1 Story and narrative – a note on terminology

Some scholars use the terms 'narrative' and 'story' interchangeably. Riessman (2003, 2008), for example, does not make an explicit distinction between the two terms. Considering the characteristics of narratives/stories, Denzin (1987) also binds the terms and considers them to be inextricably linked:

> *'A 'narrative' is a story that tells a sequence of events that are significant for the narrator and his or her audience that have happened ... A narrative as a story has a plot, a beginning, a middle and an end. It has an internal logic that makes sense to the narrator.'* (Denzin, 1987:37).

Polkinghorne (1988) reviews possible uses of both terms and concludes by treating them as equivalent. Clandinin and Connelly (1990) claim to have 'in-between usage'. For example, when referring to participant situations (such as interview data), they would use 'story' to talk about particular situations and 'narrative' to refer to longer-term life events. However, in general, they state that they follow Polkinghorne and treat the two expressions as equivalent (Clandinin, 2004).

Scholars who separate the terms suggest that narrative structures form the story. In this view someone may tell the same story but the narratives may change. As discussed in the previous chapter, structuralists like Propp examined the narrative structures that underlie the generation of the story. It is useful to think of this like a hierarchy beginning with a story at the top and going down to narrative and then the internal individual structural elements (Lindley, 2005). Under this assumption, all of the elements are intertwined but each has their own distinct properties rather than being equivalent.

I recognise that everyday speech patterns play a part in the generally interchangeable nature of these terms. Often it may feel more natural or informal to use the word 'story' rather than 'narrative', but the intention is the same. Given that there is no clear consensus as to the differences between the terms, I will, while acknowledging these standpoints, follow in the footsteps of these respected narrative scholars and treat the terms as being equivalent. Ultimately, from an analytical perspective, my motivation is to ensure that the terms encapsulate the articulation of individual experience, which they do.

5.7.2 Defining narrative boundaries

Where there has been more clarity is in how scholars define the boundaries of narrative. In order for me to apply a multidimensional approach to understanding content, form and context within my analysis, I used three approaches to define where narratives began and ended:

1. I listened for and then identified entrance and exit talk

2. I used Labov and Waletzky's (1967) framework

3. Using Riessman's (2008) guidance, I separated the interview data into scenes

5.7.3 Entrance and exit talk

Entrance and exit talk signals the start and then the end of an extended stretch of talk (Jefferson, 1978). There are a range of devices that people can use to begin and end a story.

Entrance talk typically consists of signals to the listener that a story is about to start. It orients the listener by providing information about time or place. For example:

'In our early days Margaret and I used to….'.

'We returned home from hospital.'

'In that moment everything changed.'

Or sometimes people use explicit signals such as:

'I'll tell you a funny story.'

'Here's an example.'

Exit talk then closes the story by taking the listener to where they were when the story began. For example:

'I'm elated now as she's better.'

In this last example a shift to the present (elated *now*) is connected with an evaluation signalling that the story, which was a description of a past event, has finished.

5.7.4 Labov and Waletzky

I also used Labov and Waletzky's (1967) structural framework to identify narratives. As detailed in table 4, in the left hand column is the first draft of some transcription taken from an interview. The middle column is the next stage of editing, where I added in features such as pauses and emphasis and separated the text into clauses that each represent an element from Labov and Waletzky's six part structural framework. The third column details what the letters in brackets and bold refer to.

First draft	***Edited transcription***	***Transcription conventions***
When we were younger I would have a half day on a Friday and I'd be away up to	When we were younger I would have a half day on a Friday. **(OR)**	(p) = pause <u>Underline =</u> emphasis OR =Orient the listener

the supermarket and I'd see old folk going about with their trolley and I used to think, that'll be us one day and not frightened of it. That's fine. But suddenly, I'm 72, Margaret is 69 and I thought, no, this is happening too early, we're still in quite good nick, this is happening too early. This shouldn't be happening yet and it should happen easier than this. There is a sense of injustice which is ridiculous but it is hard to accept. Accepting the inevitable is really, really difficult.	And I'd be away up to the supermarket and I'd see old folk going about with their trolley. (p) And I used to think, that'll be us one day and not frightened of it. That's fine. **(EV)** But suddenly, I'm 72, Margaret is 69 and I thought no, this is happening too early. **(CA)** We're still in quite good nick, this is happening too early. This shouldn't be happening yet and it should happen easier than this. There is a sense of injustice which is ridiculous but it is hard to accept. **(EV)** Interviewer: *Mm..yeah* Accepting the inevitable is really, really difficult. **(R)**	CA = Complicating action EV = Evaluation R = Resolution

Table 4: Stages of transcription

By applying Labov and Waletzky's framework I identified sections which took a narrative form. This provided a structure in which I could compare narrative segments within and across my interviews. For example, in the narrative presented in table 4, I identified that the plot is about ageing and confronting mortality within the context of a life-threatening illness. By breaking down the internal structural elements of this narrative and focusing on this participant's evaluation, it appears that the shock of illness has left him struggling to come to terms with both his wife's and his own sense of mortality.

From the same participant, here is a further example of how I applied Labov and Waletzky's framework to identify the boundaries of a narrative segment. I have chosen a longer account to illustrate how the structural elements can reoccur multiple times in the same narrative:

Transcription	***Transcription conventions***
When she came out of chemo **(OR)** they were showing her how to do it and she said, no, show him how to do it. **(CA)** So I was having to give her a jag in her tummy. (p) I think that was anti-clotting. So I was becoming a bit of an auxiliary nurse **(EV).** Researcher: *How did that feel suddenly taking on that role of medical care?* That's interesting because as much as I hated giving her the jag **(EV)** because sometimes I hurt her **(CA)** no matter how careful I was, sometimes I hurt her.	(p) = pause Underline = emphasis OR =Orient the listener CA = Complicating action EV = Evaluation R = Resolution

And it was always the thing of the day was ‘it’s time for your jag, did it hurt you’ ‘no, that time it was good’ ‘how come it didn’t hurt,’ she was saying. **(OR)** Some of the nurses were hurting her and then when that stopped, it’s interesting. **(EV)** Because as much as I hated doing it that was something less I was doing for her. **(CA)** So that was (p) do you know what I’m saying, that was being taken away from me. **(EV)** That was something less I was doing. **(R)**	

Table 5: Applying Labov and Waletzky’s framework

Focusing on how the narrative was organised brought to attention how this account moves chronologically through time – beginning with the return from hospital and ending at the point when he stops assisting with his wife’s medical care. This story is primarily about loss. However, I did not anticipate this resolution when this participant opened the narrative. His reference to being ‘an auxiliary nurse’ led me to initially think he was going to talk about roles and responsibilities. It was therefore useful to break it down and consider the internal structural elements in this way.

Subsequently, I went through each transcript (corresponding to each interview) and where I identified a narrative that corresponded to Labov and Waletzky’s boundaries of narrative I marked the structural elements in the margin. On a separate document I then began to note down features of these narratives, such as plot and how evaluations were used to convey meaning. This step helped me to visually map the similarities and differences across the participants and it helped me to understand some ‘typical’ caring experiences and story arcs. In table 6 below is a simplified version of this process noting how I focused on different events, evaluations and meanings across two participants.

	Participant 6 (David)	**Participant 3 (Paul)**
Narrative event	Partner loses her hair.	Administering medical care in the home.
Evaluations	Upsetting. Visually punished. Shed a private tear. Pull myself together and get on with it.	Didn't want anyone else to do it. Wanted to 'fix' her.
Meanings	Huge impact on the male partner, in this case David seemed more upset than his wife. He cries privately – major turning point in the narrative where he has let himself cry.	This brought purpose to his carer role. She was 'broken' and he could 'fix' her. Sits within male as protector discourse.

Table 6: Stage one – structural interpretation

As discussed in chapter four, there are limitations to the structural approach. This became even more apparent after going through this process as, while this was a useful first step, I realised how much data could not be bounded by Labov and Waletzky's framework. This led me to the next stage in defining narratives.

5.7.5 Performative narratives

I have chosen an analytical approach that moves between the structure and the content of the text. Under this approach, narratives are situated within a conversational interaction but also with wider social and cultural discourses. A performative approach explores how talk among speakers is dialogically produced and performed. Unlike Labov and Waletzky's definition of narrative, there is no focus on past events. Guided by this, Riessman (2008) advises separating the text into clauses termed 'scenes' to interrogate performance features. Action then unfolds in scenes with a scene representing an extended period of speech detailing a particular event, experience or emotional reaction.

Accordingly, I returned to the transcripts and where possible separated the interview data into scenes (table 7). Any dialogue that did not fit into the scene was kept on the document. Here is an example of a scene I identified and titled 'Shifting roles' to reflect this participant's description of how relationship roles can shift and change and how challenges can arise when other family members are involved. In the right hand column I marked the structural elements to demonstrate how the two approaches (structural and performative) can be combined.

Scene 3- Shifting roles	
I don't really speak to Sarah's brothers or sister as such. I know they've got their own lives and their own families and stuff. Since we moved in with	Entrance
Sarah's mum it's like Sarah's the baby and mum looks after her, and for a couple of months there was (p) Sarah was going to a group, because Sarah	OR
was going there for counselling. And then her mum would go with her instead of me. Oh, okay, and slowly and surely I was like, hang on a second, Sarah's going for a blood test and mum's taking her, I'm not, I was feeling, hang on. I	CA
was thinking like… why aren't I going?	EV
Interviewer: *Well, yeah, that had been your role.* It was something that her mum wants to do, I mean, and I can understand that, because it's her daughter, her first daughter and it's her baby, so (p) but the way I was trying to put into it was, well, you were 73 at the time and we had to look after you as well as trying to recover and stuff like that. We're	Affirmation

living with you, you're doing us a favour by, Sarah used to live there as a baby, now she's back again, so (p) Interviewer: *It all comes back full circle, doesn't it?* Yes, yeah, and it just hasn't really stopped since I last seen you, one thing after the other, it just hasn't stopped.	EV Exit

Table 7: Example of identifying a scene

I decided this was a scene as it contained a coherent, extended stretch of talk that has temporal sequence. It begins in the past – indicated through the use of past tense and reference to time passing – 'for a couple of months there'. Opening the narrative with reference to change (moving in with his mother-in-law) creates 'tellability' (Ochs & Capps, 2009). In other words, it stimulates interest because change sparks curiosity – hinting at something that is about to be revealed (Storr, 2019). He then exits the narrative by moving it forward chronologically and providing an evaluation that that this has been, and continues to be, a difficult situation for him. My responses, while fairly minimal, were intended to reassure him and convey understanding. For that reason, focusing on the way that narratives are co-constructed is important.

5.7.6 Identifying narratives – a summary

Following transcription, a crucial stage in narrative research is identifying the units of analysis. I combined three approaches to help me to identify these units of analysis and determine where the narratives began and ended. I used this combination because my analytic focus was to examine and interpret how identity, events and experiences are storied and performed. Using Labov and Waletzky's framework I identified sequences of past events in order to focus on how narratives are organised and how the same event may hold different meanings for different people. I found that the 'orientation' and 'resolution' elements of their model were similar to the lexical devices used in entrance and exit talk, so these approaches worked well together.

Following this step I then went through each transcript and, where the data allowed, grouped the text into scenes. This felt less restrictive as it allowed me to focus on longer accounts of talk in order to consider the performative and co-constructed nature of storytelling. Moving through the interviews and naming the scenes, as exemplified above, was useful as it focused my attention on the essence of what that person was discussing in that scene. Writing the scene titles down in a list (example in appendix 12) then helped me to understand what was being discussed over time – both during one interview and then across all three.

5.8 Applying the Analytical Framework

After defining the units of analysis, each interview was analysed. At this point, I had begun to think about features such as plot and meaning and had summarised (through the scene titles) what topics and issues were being discussed across the interviews. While these observations were significant, I was aware that they were more descriptive comments than deeper analytical interpretations.

Therefore, aligning with my research aim, the next stage in my analysis was to focus on the participants' positioning (to me and other characters) and to consider the wider context including my influence, setting and social circumstances. To help facilitate this process I worked through a series of questions and considerations, drawing on the guidance of other scholars:

Positioning	How do narrators position themselves? (Bamberg, 2012) How do I (interviewer) position myself to the participant and how do I respond emotionally and intellectually? (McCormack, 2004)

Characterisation	How do participants construct characters and define (or not) their relationship to the character?
Co-construction	How are stories co-constructed?
Context	How does the setting influence the conversation? What sociocultural assumptions/norms influence the participants' storytelling? Murray (2000)
Performative	Why was the narrative developed that way, and told in that order? In what kinds of stories does the narrator place himself? How does the participant strategically make preferred identity claims? What other identities are performed or suggested? What was the response of the listener/ audience, and how did it influence the development of the narrative and interpretation of it? Riessman (2003)

Language construction	Examine words that assume common knowledge or signal a request for understanding. Examine specialised vocabularies (the words that particular groups or communities might use). Examine words that participants use to describe their self-image and talk about relationships. Focus on *how* words are said. For example, active and passive voice. Use of pronouns and metaphors. Internal dialogue – what cultural fictions do participants draw on to construct their view of what counts as being a person. What are some of the natural or 'taken for granted' positions that people draw on? McCormack (2004)

Table 8: Analytical guiding questions

5.8.1 Practical application

In terms of the practical application of these analytic points of investigation, I did not work through these questions like a list but used them as mental 'points of interest' as I read and reread the transcripts, made notes, and produced diagrams, tables and lists which then allowed me to write longer accounts of analysis which I presented to my supervisors for feedback and discussion. This was an iterative process that took about five months but, rather than using a coding process, as would be the case in thematic analysis, this approach allowed me to focus on how participants position themselves to me, themselves and others.

The next two chapters contain my findings. I decided to present my findings on a case by case basis. I wanted to focus on individual detailed stories as this generated a holistic view of the data. Each person has their own life history and therefore has their own story to tell. I wanted to capture these individual perceptions and draw attention to the characteristics, events and so on that were unique to that person. Analysing the interviews in this way allowed for comparison between cases. It helped me to see when particular experiences and emotional descriptions were repeated across the interviews. Theoretical justifications for these decisions are in the previous chapter.

Commonalities between the cases are presented in chapter seven. I have written this analysis as a series of scenes with each scene representing a move forward in time and a significant moment or transition within the carer's experiences. The end point was the third and final interview rather than a particular clinical stage, as time from diagnosis was different between the participants. However, knowing we were meeting for the final time naturally led some of the participants to conclude their stories. Presenting my findings in this way allowed me to highlight the way actions, behaviours and identity positioning change and fluctuate over time. I found Goffman's (1959) dramaturgical metaphors useful in both the analysis and the construction of the scenes in terms of exploring how participants presented their experiences. This involved looking for characters, scenes, roles and positioning.

Chapter summary

In this chapter I have described how I conducted the study and the methods used to generate and analyse the data. My aim was to be as transparent as possible so the reader could understand the decisions I made in relation to processes such as recruitment, transcription and analysis. I have reflected on the challenges, my position as a female researcher interviewing men and the dynamics within longitudinal interviewing. Data were generated from narrative interviews, narratives were identified and then analysed. I concluded this chapter with examples of my application of the structural and performative approach to my data.

CHAPTER SIX: INDIVIDUAL STORIES

Structure of chapter:

- *Sample characteristics*
- *Data selection*
- *Eight caring stories*

Overview

This chapter will examine how the participants positioned themselves in an interview context. The findings are presented in a case study format corresponding to eight individual stories about male caring. Data examples are unpacked and significant moments of researcher/participant interactions are also analysed to understand the co-constructed nature of data generation. Before each story I have provided an overview of the participant's demographic details, how they were recruited into the study, details about their partner and family circumstances; summary information is in table 9 below. All names have been replaced with pseudonyms to provide anonymity.

6.1 Sample characteristics

Participant	***Age***	***Partner's cancer diagnosis***	***Time from diagnosis at interview one***	***Relationship status***
Mark	50	Primary – breast Secondary – lung	One year	Married for 15 years with four children

Stuart	72	Oesophageal	8 months	Married for 50 years with three children
Jack	31	Cervical	7 months	In a relationship for 14 years
David	58	Breast	1 year	Married for 10 years
Brian	62	Breast	8 months	Married for 11 years
Paul	50	Breast	1 year 2 months	Married for 10 years
James	76	Primary skin then spreading to lungs and bones	1 year	Married 20 years
Angus	71	Breast	1 year	Married 20 years

Table 9: Sample characteristics

6.2 Data selection

The following extracts were identified from the interviews to highlight positioning, emotional reactions, performed identities and how the participants used the narrative genre to describe, entertain, inform and ultimately convince me that these were stories that should be listened to. I focused on the structure and content of the narratives and identified the influence of wider social and cultural discourses. In essence, I wanted to bring the participants' unique and shared caring experiences to life (see appendix 4 for an example of this process). The sample was reasonably broad in relation to age range, sociodemographic background and cancer type of the care receiver (their spouse/partner) but there were areas of overlap. Each man had unique experiences that I wanted to share. Finally, the longitudinal nature of this study meant that, for all but one participant, these stories were told over a year. Therefore, I identified change or variation and where the boundaries of time, as imposed by the research process, appeared to impact on the participant's storytelling. This chapter concludes with a summary of five threads that draw across these individual stories to emphasise particular experiences, perceptions and processes that were particularly striking. These threads then informed the development of four scenes that are detailed in chapter seven.

6.3 Mark's Story

'It's never good enough'

Mark is a 50-year-old White Scottish male, married to Gemma for 15 years. They have four children aged 17, 15, 9 and 7. Mark was recruited through a letter of invitation sent to Gemma who had received support from a supportive cancer service in the West of Scotland. I interviewed Mark on three occasions from April 2017 to June 2018 in his home. Gemma was in the house for part of interviews one and two and sat with us on a couple of occasions and joined in the conversation. Their oldest daughter, Lynsey, was also present for two of the interviews. Mark was employed as a delivery driver but in our final interview he told me that he had requested a move to the retail side of the business to secure more family-friendly working hours.

Gemma, aged 40, was diagnosed with breast cancer in early 2016 and by December 2016 it had spread to her lung and her diagnosis became terminal. Gemma passed away in March 2018. Unfortunately, I only found out that Gemma had died when I turned up to Mark's house to interview him. I strongly suggested that we did not need to conduct the interview but he insisted that we carry on. He seemed distracted and tired but happy to talk to me.

Chaos

I found Mark's interviews chaotic in terms of the sequence and structure of his narratives, the topics raised and the interview environment. His wife and daughter were coming in and out of the interview room – during one interview he had an argument with his daughter and we were disturbed by his mobile phone ringing on two occasions. This commotion was reflected in Mark's accounts of anger, violence, frustration and the difficulties he had encountered as he tried to juggle family, work and caring.

Consequently, I found it difficult to identify narratives within Mark's account. He began the interview by describing the lead-up to Gemma's diagnosis, so there was an initial chronological thread. However, in line with Gemma's deteriorating health and his emotional difficulties, there was no obvious movement through time or shaping of events to present a 'good' story. Rather, it felt like a puzzling drama that frantically spiralled up and down in tandem with Mark's, in his words, 'volcanic like' emotions.

Mark generally moved between topics as prompted by my questions. However, he returned on multiple occasions to his main story arc, which was his struggle to carry out domestic tasks in the way Gemma wanted them done:

> *'When I'm at home, I do my best to try and do as I'm told, I need that done, OK I'll do that. But men aren't good at multi-tasking. Going from doing that, to doing that, because she can put on the dinner and hang up clothes. I put on the dinner and I'm standing there waiting for the dinner to finish. And she's going, what about the clothes, well the clothes will need to wait. So everything ended up running behind and there's times where she's getting up and I'm like, I'll get it, but she's, no, I want it done now. So there's that whole must get it done because she's sitting there and stuff has got to be hung up the right way. So she's sitting on the couch going, you've hung that up wrong, and I'm going, oh my god, the stress is starting to get to me.'*

Mark explicitly positioned himself as a *man* who was struggling. He had decided that one of the reasons why things were so difficult was because men and women are fundamentally different. He seemed to associate biological differences with differences in behaviours and values:

> *'Aye, your brains are wired up different and there's admiration of all the things you can do and the way you just plod through. We do something and we go, oof.'*
>
> Interviewer: *'I need a lie down.'*

> *'Aye!' [laughs] It's getting that whole, it's being able to go, right, I've done that now move onto that, move onto that, move onto that and fit in the job in between.'*

By joining in the joke I was encouraging the discourse that 'men can't multitask'. I do not actually agree with this but I wanted to encourage familiarity between us. Due to his belief in these 'hard-wired' differences, Mark stated that he had to teach himself how to run the home. He added that it was like 'teaching an old dog new tricks' – which is also possibly a reference to the fact that he was ten years older than Gemma. By stating that he had to *learn* these behaviours, it suggests that he did not perceive them to be a natural or intrinsic part of his role.

The worker

During interview one, an interview where participants construct and project their 'first impressions', Mark made some preferred identity claims. He was the 'man' and the 'worker'. Consequently, given his association with these roles, he seemed to struggle with the idea of taking up different, predominantly domestic roles:

> '*I was the worker. I always had a minimum of two jobs, always. I had my main job and I always had a job on the side-lines and I done very little in the house, very little. I did the practical DIY stuff but the actual housework was none of my business.'*

He shifted responsibility away from himself by stating it was 'none of his business', rather than perhaps being frank and stating that he felt these tasks were more appropriately carried out by a female. However, later in the interview he was more truthful about his views on gender role expectations:

> *'The looking after the kids, and taking the kids to the club, it's stressful. Because before it was come home, put my feet up, get a cup of tea, watch the telly. I was a man, I was allowed to be a man and now it's come home, get the kids to the club and try and keep their life as normal as possible.'*

Occupying the role of the primary earner or 'breadwinner' within a heterosexual relationship is associated with dominant forms of masculinity and is expressed in this situation through a gendered division of labour. He felt entitled to 'put his feet up' at the end of his working day while his partner, presumably, made his tea and looked after their children.

However, these roles had been disrupted so Mark was struggling. He was trying to occupy both the male and female roles within this household, impacting on his self-identity and emotional wellbeing:

> *'When I think about the illness it hurts, so I try and get everyday life busier. And I try not to cry a lot, it's the macho man in me, don't cry in front of people type of thing. But that's the thing, when I'm hurt, to hide the hurt it comes out as anger, fright, don't show pain type thing.'*
>
> Interviewer: *'And why do you feel you have to be this macho man?'*
>
> *'Because, I don't know if it's down the whole scenario of the bullying thing, but if I show any kind of weakness then people attack me, so any weakness that I feel comes out as anger. I fight the weakness, which means in order for people not to see the weakness I fight and argue and shout and get in people's faces.'*

Mark expressed traits that are associated with hegemonic masculinity – aggression and emotional control. However, he also revealed some vulnerability by declaring that he was bullied, which he then offered as a justification for his alignment to the 'macho male' role. He struggled a little to verbalise it – 'bullying thing' – suggesting that it was maybe a difficult topic to raise. Yet, the distinct boundaries of hegemonic masculinity seemed restrictive as they failed to provide Mark with permission to express his fear and pain. Faced with these new caring circumstances he had to develop an identity that allowed him to retain familiar and valued aspects of his masculinity, such as 'the worker', while also occupying a new role that he had previously deemed to be feminine.

<u>*Searching for a new role*</u>

Accordingly, Gemma's diagnosis forced Mark to take on a greater proportion of domestic care. In order to adapt to this new 'present', Mark reflected back to his past in order to help him construct meaning. He talked about how his dad used to care for his mum. By drawing on this specific memory I felt that Mark wanted to emphasise difference. That is, he knew exactly what type of man he did *not* want to be. He did not speak favourably of his dad:

> *'My dad when my mum was dying was a wee 'yes dear', but he drank and he's still drinking and he's no really got a life and I'm the opposite. I didn't want to be my dad.'*
>
> Interviewer: *'Do you think you're actively trying to not be like him?'*
>
> *'I think so. My mum's been dead since 2011. My dad's on his own and I don't go and visit that often and I don't know if it's because I found it really hard. I meet him at his club and when he's at his club he's a man, whereas in the house he's lonely, he's a broken man. I think I'm scared of the whole am I going to end up like him, so I fight it, but not having a way to express it verbally I go into this whole macho, need I say arsehole, and I know I am, I just can't control it.'*

Husband not carer

This provided another layer of understanding as to why Mark may have such difficulty accepting and adjusting to his new carer role. Mark stated: 'My dad was my mum's carer.' Yet, he never used the word 'carer' to refer to himself. When I asked Mark in interview two what he thought of the term, he replied:

> *'I think a carer is someone who's getting paid [pause] that's a title but I don't feel like a carer, I feel like a husband who's trying to do his best to try and ease her situation. I'm no brilliant, I'm no perfect at it, and I know she does a lot more than she has to do.'*

Mark principally viewed himself as a husband rather than a 'carer', with the latter being something more formal and official as they are paid. This is a common critique of the term – it does not value the relationship from which the care arose. The fact he stated that he was a husband first was a way of valuing his relationship and it also reinforced his masculine spousal identity. This allowed him to detach from the expectations and responsibilities that come with the title 'carer'. He did not feel he was doing a very good job and repeated his perceived failings – 'I'm no brilliant, I'm no perfect' – suggesting that he had not embraced this role with confidence.

However, during interview two something snapped. Recalling a conversation he had had with another carer, he shifted his identity into 'carer' and became more assertive. I then considered that his feelings of inadequacy came from the fact that he did not feel appreciated:

> *'When I spoke to Anne, Anne was quite a nervous wee woman when I spoke to her, her husband kind of controlled the mood in the house and how she felt was mainly down to how he felt. The carer tries to do their best and when the patient is having a hard time the carer is going to have a hard time too. And no matter how much of a saint you are, if you feel you're doing your best and you get criticised, you're going, you are going to resent that, there's no doubt about it and I'm no the most patient. Whatever task, I'll do it to the best of my ability, and if I don't feel appreciated then I feel why the fuck should I, excuse the French, but that's what I feel and why am I even bothering.'*

In this passage he moved between 'the carer', 'the patient', 'you', and 'I'. Using 'the carer' and 'the patient' gave the impression, to begin with, that he was only talking about Anne's experience. This allowed him to talk generally about carer difficulties without disclosing what he thought. However, as soon as he slipped into 'I' he was merging his own experience into Anne's.

Primarily, Mark made his 'traditional' masculinity visible through reference to his aggression, the way he shouted at his daughter, reference to being 'macho' and his increasing use of swearing in our interviews. However, he also wanted me to know that he was bullied at school and that he was frequently 'told what to do' by his wife. For that reason, I considered that there were two conflicting masculine identities underpinning Mark's storytelling.

The bereavement interview

Sadly, it was Gemma's death that brought Mark's caring story to an end. Unprepared for this news, I arrived at his street to interview him and phoned him to check the house number, as I had forgotten to write it down that day. He told me that, actually, they had moved to a new house but as they had just moved around the corner he would drive round to meet me. He stepped out the car and his first words were: 'I'm mum and dad now'. He explained what had happened and we walked round to his house.

We began the interview and I asked him if felt OK in telling me about the last few weeks. My intention was to use this opener to gauge his manner and think about what questions I could ask. Given everything that he had disclosed about their relationship challenges, I wondered if he might talk about feeling under less pressure. He described finding things even harder as Gemma was no longer there to guide him. He was calmer and there was no mention of their difficulties and arguments:

> Interviewer: *'How are things now?'*
>
> *'Worse, because if I was making a mistake I would go in and say I'm not managing, what do I do, and she would explain it to me. If she was fit enough she would give me a hand, if she wasn't she would talk me through it, but now I've got to guess myself. That's the hard thing and even though I was looking after her as well as doing the practical stuff in the bad days, it seemed to be a lot easier as you would just go in and see if she was OK and even the companionship, I think that's the hard thing.'*

Mark was grieving and struggling to find any direction. By positioning himself as 'mum and dad' he seemed committed to taking on this dual role. However, as it was still so close to Gemma's death, I think he was using the words but would need more time to establish a new role for himself that was uniquely his rather than a combination of the two.

6.4 Stuart's Story

'Strong enough not to let anyone see I'm cracking.'

Stuart is a 72-year-old White Scottish male. He met his wife Helen when he was 16. They have been married for more than 50 years and have three children. Stuart is retired and used to work as a telephone engineer. He was recruited through a family member who saw my poster in Edinburgh Napier University. I interviewed him on three occasions in his home, from September 2018 to October 2019.

Helen was diagnosed with oesophageal cancer in early 2018. She received surgery and chemotherapy. Our first interview was about six months after her treatment. When I walked into Stuart's house for the interview Helen was in the kitchen, so we chatted and introduced ourselves while Stuart made some coffee. Helen then said she was going to go upstairs to make a phone call as she appeared to want to give Stuart some privacy.

I just had to deal with it

Stuart initially reacted to the news of his wife's diagnosis in quite a calm manner. Presumably in shock he did not, like some of the other men, describe any immediate emotional reactions such as feeling 'heartbroken'. Instead he recalled listening to and 'assessing' the oncologist's words:

> *'So we're sitting there and they're saying, do you know what we're saying to you, and my wife was the same, we were very calm. You know you're told something and you know what it means, but you don't know what it means. We were assessing, I was assessing, and Helen was probably the same, she was assessing what this means as we had no idea.'*

However, in Stuart's words, when 'the penny dropped' he became 'petrified'. His fear was directly related to the thought of his wife dying. This is a common reaction as, despite medical advances, people can assume that cancer is incurable (Robb et al., 2014). In trying to explain why he felt so fearful he described how close he is to Helen:

> *'We are really, really close, we've got a great relationship and the idea that anything could happen to her terrified me beyond belief.'*

He maintained this position throughout our three interviews. He referred to Helen as his 'best pal' stating that they are 'joined at the hip' and talked about such things as their holidays together and how they enjoy spending their time walking and going to concerts. The loving dynamic in this relationship was distinctive and naturally underpinned his reaction to her diagnosis:

> *'I have to remind myself it is happening to her, not me, but actually we are living this together. We are close and what happens to her happens to me.'*

He acknowledged in this statement how the emotions and behaviours of those in close relationships can be interdependent. Stuart was one of the oldest participants in this study and had been married the longest. The security of marriage can buffer against the stressors associated with the aging process (Fitzpatrick & Vacha-Haase, 2010). Ageing and mortality was a reoccurring topic of conversation in our interviews and something I think Stuart felt forced to confront sooner than he had anticipated as the partnership was under threat.

However, despite feeling so emotionally burdened, he did not seek out any support. Instead, he hid his emotions from his family:

> *'I'm really close to my sister but my sister had breast cancer and I didn't want her to actually see that I'm a wimp. Because that's what I felt like, I thought, why am I not handling this, it was really, really terrifying. So I just had to deal with it and I didn't want my wife to see that I was struggling. Because my wife is quite a strong person and I'm no as strong as I think I am. I probably am in loads of ways but I was probably strong enough to not let anyone see I was cracking. But I had to carry on, I had to face up to it.'*

In this narrative Stuart positioned himself as someone who was struggling to cope but had to just 'deal with it'. The conflict that he described between his feelings of struggle and his performed outward expression of 'facing up to it' highlighted the expectations and pressures that prevail in certain masculine discourses. Dominant discourses of masculinity make available subject positions that claim to be a man is to be strong and resilient. Yet, he did not feel he could live up to such expectations, so he called himself a 'wimp'. His self-deprecation drew attention to his self-doubt. He questioned 'why am I not handling this', seemingly unable to fathom that it was OK *not* to handle it. This suggested that the pressure to enact this form of masculinity was particularly entrenched and not something that he felt he could easily resist. Towards the end of this stretch of talk he positioned his wife as being a 'strong person', thus showing vulnerability by reversing traditional gender roles. However, he then immediately reclaimed his masculinity by presenting his perceived weakness as a strength, bringing to the fore once again how complex and contradictory constructions and performances of masculinity can be.

As the interview progressed Stuart brought in new characters – his children and siblings – making it known that, as well as being a husband, he was also a father and a brother. It is likely that each role will be related in different ways to his masculine identity, sense of self and alignment to particular expectations and responsibilities. I considered that due to his age Stuart may be more likely to align to more traditional male/father roles. Indeed, he placed himself into a protector role in order to shield his family from distress. In turn, he avoided discussing his feelings to prevent his wife and children from perceiving him as being 'weak':

> *'On more than one occasion I went into the further away corner and just screamed. I couldn't handle it. I dropped a hint to my son when we were talking about it and he said, Dad, why didn't you just phone me? And I've got three kids and I couldn't phone any of them because they have to see me as being strong. And there was periods when I didn't feel very strong. And if they are seeing me as strong then they can deal with it. We're a close family and I couldn't let them see that I was the weak link because that would panic them.'*

I felt that Stuart placed double the amount of pressure on himself as he moved between his role as a husband and a father. He wanted to be 'seen' as being strong while maintaining a sense of calm amongst the chaos. He was trying to cope with Helen's diagnosis from a spousal perspective but also felt obliged as a parent to project strength and courage when all he felt was fear and worry.

I sympathised with Stuart's situation, commenting that it must be hard for him to maintain this front. I was interested in delving a little further into how he felt he had coped with these dual role pressures:

> Interviewer: *'I think it sounds really hard, this being strong role in the family, it must make it a bit harder having this extra layer of challenge?'*
>
> *'Yeah, my catchphrase at the time was when people would ask, and how are you Stuart?, and I would just say I'm strong and stable.'*
>
> [laughs]
>
> *'And nobody laughed, I'm trying to be funny here! And people just accepted that and I thought, it doesn't matter. But I did have to keep a veneer, especially in front of Helen. There were times when I had to get up and leave the room and go up and go 'arghh' then go back down again.'*
>
> Interviewer: *'And what was your main reason for hiding that emotion from Helen do you think?'*
>
> *'Because I was aware how much she was dependent on me. She was really dependent on me. I didn't want her to think that I was doing anything out of the ordinary.'*

While presented as a joke by making light of a mocked political catchphrase (strong and stable[30]), his overarching point was that people, presumably friends and family, accepted the response. That is, being 'strong' and 'stable' were accepted as normal reactions to an enquiry about how he was coping. This shines a light on the expectations that are embedded in masculine roles and what 'normal' coping looks like to others. He shared how dependent Helen was on him, offering it as an explanation for why he felt he needed to hide his feelings. This is a significant revelation, as it brings to the fore how emotional concealment in men is not always about hiding vulnerability but, and particularly for carers, it can be related to their perceived responsibility to maintain order and calm.

__Someone to talk to__

A significant source of unmet need for Stuart was his admission that he had no one to talk to, or more specifically he did not 'feel' that there was anyone he could talk to. We had a discussion about this and I asked him how he felt about attending a carer support group:

> *'Going and talking to, say, other guys in my position, I don't know if it would've helped. I don't know, no I really, because it would be their take on it, I don't know.'*
>
> Interviewer: *'So it doesn't sound like you ever felt a need for it.'*
>
> *'No, I didn't. I thought my need was to talk to professionals. I would've been more interested in that. Someone's take on the situation I don't think would help me.'*

While he claimed he did not think a support group would have been helpful, he expressed some uncertainty. He repeated 'I don't know' several times and used the past tense 'I thought' my need was to talk to health professionals, suggesting he now holds an alternative view.

He then went on to talk about his brother and sister. Ultimately his brother was the person he wanted to confide in as he was 'remote enough for me to talk to', but on the day he decided to phone him he could not get hold of him. Of note was his desire to talk to

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[30] At the time of the interview (2017) this was a mocked catchphrase used by the British Prime Minister Theresa May to describe her leadership. The fact that nobody laughs may be because the reference point is already a joke and the people he tells do not know how to cope with this truth from him (that he is not strong and stable).

someone where there was a connection and closeness but also distance. However, his sister, as she had previously had breast cancer, was a valuable source of support:

> *'She [sister] was really good and she was good at putting me in my place, as well in regards to things like wearing the wig and things. It was a smashing wig, it was a great wig, but she was always reminding me about what a big deal it is for a woman to lose her hair.'*

Stuart benefited from her support and advice as he felt he could learn from her lived experiences. He valued her expertise suggesting that caring was something to 'get right':

> *'She wouldn't be frightened to correct me. Because there maybe were times when I wasn't getting it right. So she was great.'*

While I think this reflects a degree of conscientiousness in his personality, or a desire to make sure he provided the best care, it also highlighted another level of burden as he conceptualised caring as a role or task to be done correctly, or not. Considering how he benefited from his sister's support, Stuart then appeared to change his mind about the benefits of a support group. He stated:

> *'But aye, maybe having somebody. I never thought about a situation like that where a group of guys, or maybe women, talking about their experiences. It's no just guys is it.'*

He contemplated that listening to shared experiences, whether they were from men or women, was valuable. Subsequently, when we returned to this topic again in our third interview, he seemed more certain of the need for support:

> *'Sometimes you need someone to talk to but you don't realise it, you know, someone can just open the valve and then you let out all the steam without realising. I think probably there are people because I tend to bottle things up, you know, I let stress build up and probably I should let off steam and I don't. And I think the more you realise, the more you are conscious of it, you need to let off steam.'*

He initially detached from this experience by using 'you' and referring to 'people'. But then he positioned himself back in with 'I bottle things up'. Perhaps being slightly removed to begin with allowed him to build up the confidence to then talk about himself and his support needs; a topic of conversation that can be difficult for carers who are used to prioritising the needs of the care receiver (Nemati et al., 2018). I sensed he had reflected on this as he talked with greater insight into how he should 'let off steam' to help prevent stress from building up. He suggested that sometimes support was required but the individual might not be aware that they need it – which raised a critical point about the form and uptake of support for carers.

After discussing preferences for what form support services should take, we spoke about Stuart's supportive needs. A particular area of difficulty for him, and something he would have liked more support with, was changing his wife's feeding tube. He felt unprepared and under pressure and compared the first night of leaving hospital with Helen to the day they left hospital with their new born son:

> *'Sometimes when you get shown things and I don't always pick them up straight away. Especially when sitting on the ward, my wife is wired to the moon, flashing lights everywhere, and I've got to take in a very, very important thing and you're shown it once then expected to take it in. And you're taking her home and you're taking all these boxes out to your car and you're thinking, ooh. But I'm naturally nervous, I can remember carrying my son in the house the first day and thinking, crikey, he is now our responsibility. You shut the door and you think we have a little monster here and we are responsible for that, terrifying.'*

Beyond highlighting the complexity of the caring situation this is significant, because there were similarities for Stuart in the meaning he associated with being a father and a spousal carer. It seemed his overall sense of being a father and carer was underpinned by responsibility.

<u>*There's things I want to do but my legs are too slow*</u>

An element of need that Stuart identified as being less straightforward to support were his existential concerns. Stuart placed himself into narratives about ageing and subsequently feeling vulnerable. He recognised the inevitability of ageing but felt unprepared:

> *'You know you're going to get old, you know it's going to happen, but it's very hard to relate to it. My dad lived to his late 80s and my mum died in her late 70s. Helen's mother*

> *was late 80s and her dad was late 70s and I've lost friends, but this is very different. This is really, really different.'*

This increased his anxiety, evoking feelings about his own mortality. He blamed himself for not expecting to feel this way:

> *'I thought my wife was keeping good health then suddenly this can happen. Right out of the blue, no warning. And we are two halves of the one person and I'm being cheated here, this feeling of being cheated. Probably I'll go first anyway but it's just a feeling that I've been cheated. I should've been expecting it. Everyone knows that you're going to die but as it approaches, the idea of it.'*

In our third interview he was still grappling with these existential issues but his perspective had changed. He recognised that there was, and actually always had been, an element of hope with Helen's diagnosis:

> *'We were both optimistic. Still terrified, still realising the dire situation that Helen was in, but we were led to believe that it was curative. That was the word that was used.'*

That single word – 'curative' – held a lot of comfort and seemed to help Stuart to cope when the fear, anxiety, and in his words 'his dark days', took over. With the aim to start to bring our final interview to a close, I latched on to his optimism and asked if, despite the challenges he had spoken about, he felt there were any positives that arose from this experience. His response suggested that he was beginning to feel less fearful and constructing a new cognitive reframing of the illness in which the negative experiences were redefined into luck and gratitude:

> *'I wouldn't say anything positive has come out of it, it's been a hiccup and we have survived it and we have to be grateful for that and appreciative of that, really appreciative. And I'm just so grateful that we got through it. Worse things happen to people, much worse things. Really, the things that happen to people. We've been really, really lucky.'*

6.5 Jack's Story

'A problem that is never going away.'

Jack is a 32-year-old White Scottish male. He has been in a relationship with Natalie for 14 years. They are co-habiting and not married. Jack was recruited through a tweet posted by the charity Cancer Support Scotland. His partner Natalie saw the tweet and encouraged him to contact me. I interviewed Jack on three occasions from June 2018 to June 2019. Interviews one and three were conducted in a private office in a hospital and interview two was conducted in his home. Jack is a self-employed plumber.

Natalie, 33 years old, was diagnosed with cervical cancer in 2018. She received chemotherapy and radiotherapy and was still attending hospital appointments at the point of our first interview. In interview two, Jack spoke about some problems he was facing in his relationship and by interview three Jack and Natalie had separated.

Life changes in that second

Natalie's diagnosis had, in Jack's words 'derailed' him. It completely overturned his life leaving him feeling overwhelmed with worry. It also changed the things he valued:

> *'Your life completely changes in that second. I mean, I've always been quite motivated, and motivated by success, and money, and work, and all that kind of stuff. And then, as soon as something like that happens, you're, none of that stuff matters. None of it. So, it's just a weird situation to find yourself in at the age of 30. And she's only 32, it's young, you know. So, aye, she coped with it better than I did. I couldn't believe it, I was sick, I didn't eat for two weeks. I didn't cope well at all.'*

Jack provided me with a glimpse into his life before Natalie's diagnosis by telling me he was 'motivated by success, work and money'. These values align with masculine discourses on work and self-worth. However, he built himself up to then crash down to someone who was vulnerable, sick and struggling. Through these contrasting states he projected a masculine identity that can embrace vulnerability – especially as he compared himself to his female partner 'who coped'.

This ‘stuff’ might not seem important to him anymore but it is likely that it provided him with structure and purpose. Consequently, without these roles and motivations he channelled his energy into trying to give Natalie a ‘winning edge’ before she started her chemotherapy. He spoke about researching healthy diets, watching YouTube videos on positive thinking and practising gratitude. He was seeking control but felt helpless as he knew that elements of their life had permanently changed:

> *‘I just worry she’ll never be the same again. And I worry she’ll never be as bright as she was, and all that kind of thing. But I'm trying to kind of plant the seeds in her mind the now, and anything I do say, just like constant positive reinforcement.’*

Distance

Turning to Jack and Natalie’s relationship, knowing now that they are separated, has changed my perspective on some of the difficulties he described in interview one. For example, as Natalie had cervical cancer, Jack alluded to the fact there had not been any sexual intimacy between them. However, in the 18 months leading up to her diagnosis, as she had a lot of uncomfortable symptoms such as bladder pain and bleeding, this had actually been an issue for quite a long time. This had significant implications for Jack but, at this point (interview one), he did not want to focus on how it had affected him. He made a point of disregarding his feelings and prioritising Natalie’s experience:

> *‘Her gut was telling her something really wasn’t right, and it was very unusual, the symptoms, and they both came at the same time, the bladder symptoms and the bleeding, and all that kind of thing. And that kind of affected things a bit. And then, since the cancer, and the diagnosis was confirmed, it's as if she’s very, not distant in general, but maybe distant towards me. I don't know why that is, just yet, and I've not thought about it too much. But she’s got enough going on, it's not a problem for me. It's just the way things are. Sleeping in different beds, quite a lot of nights, to try and get a good sleep and all that. So a lot of changes in that way, I guess.’*

He tried to normalise the situation by stating ‘it’s just the way things are’ as he probably did not want me to think that he was prioritising his sexual needs over Natalie’s health. We returned to this topic in our second interview (covered later in this section) where Jack was more candid. Perhaps he just needed some more time before going into any further detail.

Everything is fine but it's not good

The overarching tone in interview two was contradiction. Jack felt caught between expectations and reality. Physically, Natalie had improved – she responded well to the treatment and was not due for a check-up for another four months. So 'everything is fine' in that sense but, as is well established in the cancer patient literature (Philip & Merluzzi, 2016), the post-treatment time can be challenging:

> *'Now she's finished her treatment and we are back home it's a wee bit worse, believe it or not. It's good not being at the hospital every day but as far as dealing with it, because at least when you were there you had stuff to do as you had constant appointments and talking to people, but as soon as the treatment was finished you don't hear from anybody. You're just sent home and you don't hear anything from anybody and she had lots of questions, so that was quite frustrating trying to get answers. We had to wait so the waiting was the hardest part about it. The hardest part is dealing with the cancer and it's frustrating for me to watch.'*

When someone is successfully treated for cancer and is seen as 'well' or 'better', norms emerge for acceptable behaviour. Cancer clinics symbolise the end of treatment with rituals where patients 'ring the bell' to celebrate the ending. This can create an expectation to feel positive and happy. However, the absence of disease does not mean the absence of emotional and relationship difficulties.

Jack was caught between a binary of how he felt and how he should feel. While he acknowledged that the treatment outcomes were positive – 'so erm..it's been good that side of things' – he realised that physical outcomes were just one 'side' of this multi-layered experience. Now they were back at home, Jack was solely responsible for Natalie's care. However, Natalie did not need physical care anymore – she needed medical information which he could not provide. This made him feel helpless and frustrated, which directly impacted on their relationship:

> *'You're frustrated and arguing with each other. Aye, but we read about that quite a lot before this happened but even knowing about that in advance didn't stop it. Yeah, we didn't think it would, we thought, ach, we'll be alright, these are older people. Ach, I don't know how to explain It, we thought it would be a different dynamic than a young couple. But no [laughs], it's probably affected us a lot worse. But, yeah, everything is fine but it's just not good'*

This was a significant passage in terms of understanding how Jack's sense of self was closely bound up with his age. Jack brought up his and Natalie's age several times in our interviews in relation to how young they were compared to other couples going through this experience. He hoped that being younger would act as a buffer and help to maintain the bond between him and Natalie. However, realising their age had not protected them was hard to take. He masked his upset with a laugh – it was clearly not 'fine' but he seemed set on trying to convince me that it was.

In conjunction with these relationship difficulties Jack's carer role was changing. Natalie was becoming more independent and was less reliant on his care:

> *'I think before when I was doing more stuff I would maybe use that term carer more, as I was doing stuff that she would normally do so she wasn't having to do anything at all. But as I say, I have always been quite good anyway for doing stuff, I'm not like a typical guy who won't tidy the house, I'm pretty organised and stuff. But I'm not having to drive her about, she's got her licence and stuff. So it's relatively normal apart from she's not at work and she's been keeping herself relatively busy, which has helped.'*

'Normal' was associated with life before cancer. What made this particularly challenging for Jack was that some parts of their life had returned to normality. He was back at work and Natalie was driving again. But the dynamic in their relationship had changed. The 'new' normal was unfamiliar and uncertain and it raised questions about identity, purpose and their future together. Consequently, there was a dawning realisation in Jack that this experience had caused a profound rift in his life and relationship:

> *'In a way, aye, it feels like you're back to doing what you used to do but your life will never be the same again kind of thing, so I can't even imagine what it would be like from her perspective actually dealing with it, as I know for me life is completely different. So I*

> *dunno, it's a very strange set of circumstances. So, your life before cancer and your life after it. Even though it wasn't me.'*

Jack did not want to be seen to be dwelling on his own experiences for too long so brought Natalie into the story to emphasise that she was the one 'actually dealing with it'. Once again, he prioritised her difficulties over his as she had the first-hand experience of living with cancer.

Forgotten carer

A particular point of frustration for Jack was not feeling appreciated or even acknowledged by the medical professionals:

> *'They forget about you, they are focused on the patient, the person suffering from cancer. So, I get that approach in making the cancer sufferer feel like it's under control, they are the one getting attention. But I think probably that's a conversation that needs to happen with people having these talks as to definitely acknowledge the partner. Aye, it was horrible. That was probably one of the most stressful parts. I ended up just walking out the room one time because I was so annoyed and Natalie was annoyed as well, because she was like, I need him. It was embarrassing. We thought maybe it was because we weren't married. And, because we're young as well, as if we had only been together... I think they needed to realise we had been together 14 years.'*

He began with the pronoun 'you' (they forget about you) in order to broaden his comments to other patients and carers rather than focusing on himself. This also allowed him to critique the medical professionals (or one medical professional in particular) but from some distance. That maybe felt less disrespectful given the power and status attached to their role.

Nevertheless, this experience was about him and Natalie and he made this clear by providing a personal evaluation of the situation 'it was horrible'. Despite everything he had done for Natalie, and he made sure I knew just how much by bringing in Natalie's view –'I need him' – he felt ignored and unappreciated. Conversational practices, such as medical consultations like this, call upon people to take on particular roles and positions that provide them with rights, duties and entitlements (Harré & van Langenhove, 1999). In this interaction the power resided with the doctor who had specialist skills, knowledge and experience. Therefore, before anyone spoke there were certain 'rules' set around talking and listening. This in itself was not an issue, as at another point in the interview he stated that 'they [doctors] know their stuff you need to listen to them'. However, when the doctor did not provide Jack with *any* form of positioning, he became invisible. Therefore, he could not take up any rights or entitlements despite being essential to Natalie's care. Adding to this dynamic, Jack felt insecure due to his age and 'boyfriend' status. His powerlessness turned to anger and he left the consultation room.

The 'coital imperative'

In interview two Jack returned to the topic of sexual intimacy. I think, in interview one, he was still trying to figure his situation (and me) out. However, he now seemed clearer on what the challenges were. He was still a little apprehensive about broaching the subject and asked, 'I don't know if other people have mentioned this to you?' He seemed to want some reassurance that it was acceptable to talk about sex and that his experiences sat within the shared and 'normal' experiences of other male carers.

Jack and Natalie could not have penetrative sex and Jack seemed reluctant, or perhaps unsure, how to explore alternative ways to be intimate with her. Gilbert et al. (2010) use the term 'coital imperative' to describe the reluctance to explore alternative ways of being intimate on the part of the 'non-renegotiating' partner carer. Consequently, without sex he felt that they were nothing more than just 'flatmates' now. This drew attention to how closely entwined sex, sexuality, intimacy and relationship status were for Jack and most probably other men too. For that reason, he was sexually frustrated but overcome with guilt:

> *'The way I feel about it I think I'm a good person and all that but there's a physical aspect to being a guy and that starts to become a problem after a couple of days, never mind like a full year. So us not being able to have sex has been a big issue and I feel guilty about that. But at the same time I feel like I can't talk about it because you are physically going insane, but you can't talk about it, and it's bad that she's dealing with cancer so how can I possibly talk about stuff like that. The good thing is Natalie already knows and she's talked about it but that again makes me feel guilty. She shouldn't need to worry*

> *and it physically can't happen, so it's pointless even talking about it as it makes me feel guilty. I know some people have been lucky and they've been able to go back to relative normality in that sense after it, but in our case that won't happen. So I feel the expectation is I need to be here for her even after she gets the all-clear and that's a worry for both of us, because without that side of things you're just flatmates, that's how I feel about it and I feel bad even just saying that. But people from the outside just think she's got cancer, how could you even be thinking about that and I feel bad even thinking about that. So that's probably been one of the biggest pressures.'*

Jack wanted to preserve a positive social identity that he was a 'good person' despite prioritising his sexual needs. He seemed acutely aware that it may seem selfish or uncaring to focus on his needs when Natalie's entire life was under threat. Therefore, he repeated over and over again how guilty he felt. He also suggested that this was a 'guy thing', proposing it was an exclusively male problem. This allowed him to align with discourses on high male sex drive. By making this about male needs he shifted some of his guilt onto the norms and expectations that are created and sustained within certain constructions of masculinity.

Jack's reference to 'people from the outside' added a further layer of context and surveillance to his experience. Through this comment Jack was suggesting that there is a relationship between private thoughts and behaviours and public attitudes – which can prompt a sense of shame if these public and private beliefs are incongruous. Consequently, Jack felt uncomfortable and embarrassed as this was not something that he could openly talk about.

Fear, shame and guilt are extreme emotions to manage and if left to escalate can have a major impact on mental health. However, there was some release in the form of our interview. At the end of the interview he stated:

> *'You're the first person I've spoke to about it [laughs] other than Natalie. It's quite embarrassing as well, I imagine a lot of guys wouldn't want to talk about it or maybe they wouldn't care [laughs].'*

This implied that he trusted me so I was pleased that he felt able to share this. Similar to David (the next story), there was no reference to ever talking to a health professional about this, highlighting the need for professionals to provide couples with the opportunity to talk about sex and intimacy.

6.6 David's Story

'Living between love and loss'

David is a 58-year-old Northern Irish White male. He has been married to Jane for 10 years. David was recruited through a request posted on Facebook by the charity Cancer Support Scotland. I interviewed David three times from November 2018 to October 2019. Each interview was held in a private room at Maggie's. David is a sales manager.

Jane was diagnosed with non-Hodgkin's lymphoma in 2013 which was successfully treated. She was then diagnosed with breast cancer in 2017. She received chemotherapy and had a mastectomy. Jane is employed as a teacher and has a son and a daughter from a previous relationship.

Towards the end of our first interview I asked David if there was anything else he wanted to share with me. He pulled a piece of paper from his pocket with the words 'love, loss, lies and light' written on it. He said before coming to the interview he had reflected on the things that he wanted to talk about. During our last interview he did the same but this time his words were 'family' and 'future'.

Love

Across the narratives, 'love' manifested itself in different ways, for example in terms of feelings of attachment and affection and a desire, rather than an obligation, to care and protect. However, David was actually the only person to directly use the word 'love' and to reflect how love was expressed and intensified through the deepening of his spousal bond:

> *'Well, the love I have spoken about I think it has drawn us together and I think it has made Jane less fearful, believe it or not, rather than more fearful. And in the early days someone said to me, surround yourself with people who are positive. And that wasn't always the easiest thing to do because some people go, cancer, and go, ooh (gasp) death*

> *sentence. And, unfortunately for some people, it is but we are all going to die so it's making each day count.'*

Despite these challenging circumstances love brought David and Jane closer together and generated new perspectives. Cancer can be a 'death sentence' and they have lived through the distress and uncertainty that came with such a sentence for the last year. The psycho-oncology literature refers to a 'search for meaning' to describe the process where the individual (usually the patient) tries to appraise the impact of cancer on their life. During this process the distress can become overwhelming, which may be the point at which an individual accesses support (Krok & Telka, 2018). However, coming through this process individuals can report a greater appreciation for life and better self-awareness – which appeared to be the case for David.

Even so, David placed himself into stories that highlighted his ability to live with the *co-existence* of love and conflict. He appraised the caring experience through categories of contrast – something which became even more recognisable when he concluded the interview with his list of contrasting words. Love in the previous quote was described as the glue that kept their relationship strong and functioning. This 'glue' was important in moments when he struggled to cope with Jane's behaviour:

> *'So there were three weeks when I didn't leave the house. She wouldn't let me go through the front door because she was paranoid. That was really hard.'*

And later in the interview he became more candid about his irritation:

> *'She was tired and crabbit, which women can be, and so can men, but she was just, she was almost like a child that was ready for bed but wouldn't go to bed. 'I'm not tired, don't tell me what to do!' And that was it, and I said, Jane, just go and lie down and 'don't you tell me what to do' [*puts voice on*] And she went up and 'I'll only go up if someone comes with me'. I could've been in bed sometimes at half past five just lying with her. Just with my hand on her shoulder. And if I'd moved my hand thinking she was sleeping, 'don't go' (voice) 'don't go', you know, so I felt very lonely.'*

As David described this situation, I felt sympathy for Jane as my initial reaction was how vulnerable and dependent she was on David. My sympathy increased when he pretended to mimic her voice. His intention was draw attention to her difficult 'childish' behaviour and to emphasise, from his perspective, how challenging things were for him. Yet, given the context of her dependency and Jane's situation (a second cancer diagnosis), it felt unkind to label this as childish. However, as he went on to describe lying with her and touching her shoulder, I was touched by his gentleness and reflected how time-consuming and emotionally intense caring must be. This exemplified how there were instances where my emotional responses changed and fluctuated from the interview to analysis.

Loss

Across David's three interviews he described a loss of two interrelated things – sexual intimacy and an overall perceived loss of 'normality'. David was open and direct about the fact that he could no longer have sex with Jane. He disclosed this to me without any prompt:

> *'Our relationship, it's different. Erm, it's maybe more intimate on an intellectual side but less so on a physical side. Maybe that's an age thing but since her first chemo we've been unable to have sex as much. Or at all in that way, because of where it was, there was a lot of stuff going on there.'*

Once again he created a contrast, this time within the relationship between the 'intellectual side' and the 'physical side'. While he framed this as a gain, seeming to value an increased closeness, the irony was that they were physically more distant. I appreciate this may have been uncomfortable to reveal as there are societal expectations that spouses have sexual intercourse. Therefore, initially, possibly in a bid to preserve some pride or avoid embarrassment, he stated they were unable to have sex 'as much'. But for whatever reason he then changed his mind and stated 'or at all'. Moreover, I was the first person he had told:

> *'We have talked about it and we tried to get round it and that's just the way it is but we both miss it.'*
>
> Interviewer: *'Yeah, it's part of a relationship.'*
>
> *'We both miss it. Another loss and not one that I've spoken to anyone else about, so you're the first [laughs]. But if I was to tell, even today, if I was to tell Jane how much I miss that side she would feel quite hurt and upset because it's not something she can*

> *sort. So I don't tell her, so I just had to say it. This is where we are and this is what we've got.'*

There were some notable similarities and differences between David and Jack's articulation of this issue (Jack being the only other participant who spoke about a loss of sexual intimacy). David was more direct than Jack and seemed comfortable raising this subject about midway through interview one, whereas Jack waited until interview two and after quite a bit of time circling around the issue. David is considerably older than Jack and used his age as a factor in why they were not having sex. This possibly made it easier to discuss as it made it less personal, placing their situation within beliefs about 'normal' sexual behaviour in older age.

David repeated twice '*we* both miss it'. Like Jack, I think he was worried about being perceived as selfish and prioritising his sexual needs when Jane was ill. To try and defuse these negative perceptions he wanted me to know that it was a loss for Jane too. Like Jack, he was entangled in guilt and shame for admitting that he missed sexual intimacy with his partner. He considered that Jane may feel upset by this situation as it's not 'something she can sort'. This positioned Jane as feeling responsible for David's sexual needs. From a wider sociocultural context, this drew attention to the behaviours and expectations within marriages and relationships that create a framework for the caring experience. To avoid conflict and upset, David did not disclose his feelings to Jane. Concealing emotions, particularly from their partner, was a common reaction amongst most of the participants in this study. However, he did seem to benefit from talking to me. He expressed an immediate release after uttering the words 'I just had to say it', bringing to attention the therapeutic benefit in divulging private thoughts and feelings.

David's second perception of loss was what he referred to as 'a loss of normality as I once knew it'. This was particularly difficult as 'normality' was associated with health, security and the familiar. When that was disrupted and replaced with new routines filled with hospital appointments, chemotherapy cycles and altered relationship dynamics, it caused distress.

In particular, David (also like Paul) seemed particularly upset over Jane's hair loss. This loss symbolised the severity of their situation – marking a step away from their 'normal' life towards one affected by illness:

> *'The hair loss was when I realised things were really changing and it was that morning when, because women like their hair, and I liked it a lot as well. And she said, uh oh, I think I'm going to have to do something about this.'*

Further, this reveals the fact that David's attraction to Jane was bound up in her appearance, including her hair. Hair, and particularly long hair, is positioned as a signifier of femininity and sexuality within Western culture, meaning that women who have no hair are positioned outside of 'normal' femininity with implications for their partner's sense of masculine self:

> *'The hair loss was something that really impacted on me.'*
>
> Interviewer: *'Do you know why?'*
>
> *'It was visual. And my wife, who I thought was average, no, I thought was good looking, as men usually should think of their wives. And here she was, reduced to, I suppose, someone like a convict almost, you know. She was being visually punished. It was bad enough what was going on inside but she was being visually punished. It's high impact.'*
>
> Interviewer: *'It is a big moment, isn't it.'*
>
> *'You wouldn't like. No one would and I just really felt. I think what upset me a little bit was that she didn't appear to be upset. She would've been upset for me had she known, so I went up and had a private tear and came back down. I told her later on I had cried, I did say to her. It just hit me as I walked through the door when I left her in the morning, her hair was relatively OK and I came back at night and she looked like I'd never seen her before.'*

David appeared frustrated as the hair loss seemed to upset him more than Jane. This common side effect of treatment can have a substantial impact on relationships and affect men in different ways to their partner (Fitch & Allard, 2007). He referred to a 'private tear', highlighting how much it upset him (the only point when he admitted to crying) and also that he felt he needed to hide his emotion from Jane. Yet, he did tell her at a later point how much this upset him. He possibly hoped she would feel more emotional about the situation and therefore justify his reaction.

His comment that she was being 'visually punished' is noteworthy. Different interpretations of illness impact on coping and adjustment. David stated that Jane was being 'punished' and I think, given his distress, it would be reasonable to suggest that, by association, he may have felt that he was being punished too. I considered that this was related to David's feelings towards control and suffering. Jane has had cancer twice in the last five years – this has left him feeling victimised and powerless:

> *'I thought I was being ganged up on if you like, because second time around, I've missed not being able to, erm [pause], to be in control of the situation as a couple and also not being able to protect her from it. Not only once, but a second time.'*

Cancer has been punitive. It has disrupted his relationship, altered his wife's appearance and taken away their sexual relationship. As a result, he felt that he had failed in his duty to protect – a feeling that was amplified when she was diagnosed for the second time. However, being 'punished' then gave him permission to suffer. This enabled him to use support where others may have been reluctant:

> *'I think the fear is, and maybe especially among men, that I'm going through this myself but I'm not that proud anymore to be honest. If it's there (support) I'll take it'*

Consequently, he drew strength from the fact that he had tolerated the punishment. He wanted to make sense of the suffering and overcome it:

> *'But it's having to realise it… your own vulnerability. And you can't hit every expectation. Not beat yourself up too much about. Which I did a bit last night and yesterday, but I thought… yeah… it's a realisation that you're not as strong as you thought. And then what do you do? I've realised what I've got to do is say it's OK. It's OK to… I can't solve this problem.'*

His suffering became a redemptive character. There was a huge level of responsibility attached to the roles that he was trying, but failing, to occupy within this experience. He wanted to protect and problem solve while remaining stoical and strong. However, this was not always possible as cancer was not a problem to be solved.

Over the course of our interviews I sensed that the burden he was carrying was beginning to lessen. This allowed him to reframe his vulnerability as a strength not a limitation. He stated that he was not going to punish himself, 'beat himself up' anymore, which allowed him to start to look forward. In our final interview, David said that he had started our interview with 'l's' but he wants to end our interview with some 'f's:

> *'One is family. Family is good, our family is expanding with four grandchildren at the moment. So that's good, and future. We have a future and we don't want to dwell too much on the past.'*

The 'future' is a site of hope, orientation towards it came with positive psychological benefits. Love, including the love for his wider family, has triumphed over loss and lies. Symbolically, this process is also related to the 'light' that he referred to in interview one. That is, light represented movement towards hope and health.

6.7 Brian's Story

'The unfinished walk'

Brian is a 62-year-old White Scottish male. He has been married to Karen for 11 years and they have been in a relationship for 20 years. They both have children from previous relationships. Brian was recruited through a letter of invitation sent to Karen who had received support from a cancer service in the West of Scotland. I interviewed Brian on three occasions from June 2017 to July 2018 in his home. Karen was present during all of the interviews, along with their granddaughter for parts of interview three. Brian is employed as a warehouse operative.

Karen, aged 56, was diagnosed with breast cancer in November 2016. She received chemotherapy and radiotherapy. Karen, for the most part, was quiet during the interviews but on a couple of occasions she joined in our conversation when Brian couldn't remember something, such as the timing of an appointment or the name of a doctor.

The Storyteller

Brian was an artful storyteller. His opening narrative was a long and detailed chronological description of the two weeks leading up to Karen's diagnosis. He held my attention by detailing the setting, developing orientation, describing dialogue between him and Karen and using complicating actions to build tension. He weaved together orientation and evaluation to draw me into his account:

> *'Basically, what happened, I came in one Wednesday night after work and Karen says "Feel this, my right breast" and I thought, ya beauty, I don't need to make any moves tonight, and she said "Stop it" and I said, "What is it", and she said "Feel it" and I felt a lump. And right away I kinda got a shock and I thought to myself, no, it canny be. I was convinced in my mind it was nothing more than fat or some woman problem.'*

He began his narrative at the moment where cancer, or the possibility of cancer, entered their lives. His use of humour, 'ya beauty', kept the interaction light-hearted and marked out an early identity claim – he's a bit of a 'joker' and he is in a sexual relationship.

He then used his first complicating action – 'but all of a sudden' – to add suspense and chronologically push the drama forward:

> *'But all of a sudden I get a call at work. Everyone knows I hate calls at work, as I always panic to the extent I always think it's bad news. It was one of the guys, he came out, he said, that's Karen, could you give her a wee phone. The hospital have been on, they have a cancellation tonight, do you want me to take it? I said, aye, by all means, take it I says, don't hesitate, take it.'*

By unravelling his story in these dramatic layers it seemed that Brian not only wanted to describe but he also wanted to entertain. He recalled his feelings – 'I'm thinking she's OK, she's alright' – however, given the context of the interview, I know she's not going to be 'alright':

> *'We found two seats together and we were blethering away to each other, it was a busy place. Someone says to you cancer and you think, bad luck, that's terrible, they've got cancer. And I'm thinking, look at all of these people sitting here but she's OK, she's*

> *alright. We were watching people coming and going and I thought, they're dragging this out a bit and I thought, maybe there's more to this than meets the eye'.*

By describing his denial he took me back to that moment in the waiting room. I asked for a story and Brian was using different techniques to tell me a well-crafted one. He offered some hope – 'she's OK, she's alright' – but I knew we were systematically working through a series of events until he was ready to state the words 'it's cancer':

> *'She said, yes, it is cancerous but it's not that big that we have to give you medication, we'll just cut it out. Now she's obviously broke down at the fact she's been told she has cancer. I've just a bomb going off in my head but trying to be strong and not break down and I thought, why. And I'm trying to justify why, why is this happening. Because in our relationship, we have been together for 20-odd years, we've had to fight for everything, and I'm thinking, I'm going to get it taken away from me, that was the sore part.'*

The emotional aftermath

After disclosing the diagnosis, he described his emotional reaction. Focusing on his language in the above quote revealed a range of emotions and positions. It exposed his stoicism, 'trying to be strong and not break down', and desperation as he pleaded 'why, why is this happening'. Stating he was 'trying to be strong' is an attribute of dominant models of masculinity, suggesting his experiences were shaped by masculine discourses. However, it could be argued that anyone, male or female, would want to seem strong in that moment in an attempt to provide their loved one with strength and comfort after being told they have cancer.

The effect of moving between his internal dialogue – 'why is this happening' – to stating 'we have been together for 20-odd years' added emotion to his situation. He wanted to convey a feeling of injustice and did this by stating 'we've had to fight for everything'. This provided me with some wider context – a nod to the fact that they have not had an easy life. This helped me to understand why he felt such despair.

Building from this, Brian's reaction to Karen's diagnosis reflected his wider views on his social positioning. Brian projected a working-class identity through a combination of factors:

reference to his job (warehouse worker), my perception of his neighbourhood and the way he upheld particular values that he attributed to his upbringing and their economic situation.

He was proud of this identity. Brian wanted to convince me that he was a kind, generous and humble man. He emphasised the positive treatment of others and frequently told moral tales about being kind to others and helping his neighbours and colleagues:

> *'I think it's just been the upbringing, it's the way I've been brought up, to respect people, to care for people. Never to think that I'm any better, or any worse. But to always make sure that people are OK.'*

Yet, returning to his phrase 'fighting for everything', his values and treatment of others sat within feelings of inferiority. This was significant, as someone's understanding of their social world will have profound implications for how they see themselves and others. Consequently, it seemed that his reaction to illness and the medical institution was shaped by deeper feelings of conflict and struggle.

Heroes and villains

Accordingly, Brian's articulation of his caring experience was influenced by underlying feelings of hardship – 'we're both the type where everything we've ever had we've had to work for' – and this seemed to feed into his opinion and portrayal of the medical professionals within his narratives. On the one hand, he was full of praise for the nurses. He told me how he bought them all chocolates and perfume, praising their caring and personable approach:

> *'It's no that we're being flash, but we really appreciate the services that are being done. It must be hard for these women* [nurses] *to treat women all day long.'*

His respect for the nursing staff was bound up with the fact that his sister and sister-in-law are nurses. Therefore, they were relatable and not intimidating. He referred to the nurses by name and gave them personas and roles. However, in contrast, he expressed anger towards the doctors:

> *‘You can talk to the doctors until you’re blue in the face but all you’ll get is medical jargon from them. I don’t take anything away from the doctors, it’s just it’s not the same emotions, they’re not there on the front line.’*

In particular, he recalled one interaction with a doctor that really angered him. In interview two he returned three times to a situation where Karen had gone into the clinic for a follow-up appointment and they were disappointed with the way the doctor communicated with them. He started by describing how the doctor began their consultation:

> *‘We've done chemotherapy and we've done radiotherapy – well, I don't know why you've been sent to see me. And I'm thinking to myself, right, OK. And then she proceeds to go on and talk about how H [name of hospital] is a better hospital than the rest of them, you know, the reason it's all been sort of like sectioned off, you know, the different areas, this, that and the next thing. And, you know, you'd actually be better going and doing yoga. And I was thinking to myself, I'm really not hearing this. I'm not hearing this, why am I hearing this. And I felt like saying, listen, if you think H is that fucking good, what are you doing here. And when we came out, Karen was a bit upset, and the two of us kind of argued, and she went one way and I went another way, and then we kind of, I've went back up and caught up with her. But I could understand why she was upset, because she was looking forward to somebody saying to her, listen, everything's fine.’*

Brian swore a lot more in interviews two and three, possibly reflecting his mood but also his level of comfort. Analysing his recall of this event, he was angry at the doctor – partly because of her communication style but mainly because they were hoping for the all-clear. I imagined them nervously waiting outside the consultation room and how disappointing it must have been to have had such an impersonal interaction.

Fear

Brian expressed more emotion in interview two, which mirrored his story arc. The hospital has now become a traumatic place (unlike in interview one, where he actually used the word ‘party’ to describe the atmosphere on the ward) as it brought back unpleasant memories, making him fearful that Karen’s cancer will return:

> *'I was looking forward to seeing everybody but it made me scared, very scared again sitting there. Because I seen people in the different stages and it kind of took me into a darker place than I wanted to be. I really didn't want to sit there, it brought everything back. And for a few weeks after it, I kind of, I wasn't in the right place, you know. I was still fearful that this is coming back, you know. And what I said to Karen was, I don't think I could ever face this again. I don't think I could go through it. But then again, until I actually maybe got to face it, I don't know.'*

His frustration with the doctor became entangled with fear. Brian, as much as Karen, wanted some reassurance from the doctor that things were going to be OK but they never got it. Disappointment turned to anger which he seemed to recognise was just a front for his fear. This affected him physically and mentally. He described having nightmares, grinding his teeth in his sleep and taking medication for high blood pressure:

> *'I was getting aches and pains, it could be the stress, the worry, you try not to worry but it never leaves you. You think, well, this has been a good week, it's been a good month, you've got no reminders and then my sister- in-law gets diagnosed and you think, oh, here we go again.'*

His fear was then compounded by the reoccurring references to cancer. As stated in the above quote, when I returned to interview Brian for the third time his sister-in-law had been diagnosed with cancer, as had some of their friends, which stirred up a range of unpleasant emotions. As a result, Brian's attitude to cancer changed. In interview one, after the initial shock, they adjusted to the treatment cycles. There were signs of hope for their future and he reflected that this experience had actually brought them closer together. While gruelling, the chemotherapy cycles were predictable and Karen was predominantly in the care of the nurses – which he so openly valued.

In interviews two and three there was a decline in his emotional wellbeing, because cancer was now everywhere – on the TV, in his bowling club and amongst his friends and family. There was a sense that he would not find any sense of peace until, in his words, the cancer 'was cut out'. However, he realised that Karen might not ever get the all-clear:

> *'See, the amount of people that I've spoke to, and they've had it 10, 15, 20 years ago, and they're fine. And they've never had a problem since. But there's nothing to say that it'll not*

> *come back. There's no reassurance. Because you read the stories about it, you read the story about the lady that started the Maggie's and she had it, and then it came back, and it came back again. You read other ones, you know, that had it, and it's come back, you know, and this is five, six years down the line. I don't know if that'll happen, but I just keep it shut in that wee back room at the back of my brain.'*

This was a significant moment (or a 'decisive moment' as Frank (1995) termed it), as it had the potential to influence the direction of the story. Brian had been circling around his anger and fear with the hope that these emotions would subside once they got some reassurance from the medical professionals. However, he was now committed to this plot of uncertainty so he embraced it. Throughout our three interviews he referred to 'paths', 'roads', 'journeys', 'distance', and an 'unfinished walk'. This brought a sense of movement into his narratives and led me with him as the drama unfolded. Extending the analogy, perhaps he was searching for his 'final destination' which was the peace that will come once Karen has received the all-clear:

> *'I don't know whether I'll get off this path, it's a nice path I'm on, as I say, it's made us stronger in the sense of the relationship, not that it was stormy or anything like that, but it's made us sort of look at things, a better perspective, and the fact that we do a lot of things together. So, I don't know if I'll ever get off this path. I don't think I want to come off it, I don't think I want to come off it, I think I want to… well, I don't mean it that I don't want to come off it, I think I want to stay on it as the protector.'*

He may never find the peace he was searching for (making it an '*unfinished* walk') but he has found meaning in the 'journey'. He began the passage not knowing whether to get off the path but stated at the end that 'I think I want to stay on it as the protector'. This unfolding realisation highlighted the positive benefits that can be associated with caring. It strengthened their relationship and he found purpose in his role as 'the protector'.

6.8 Paul's Story

'It's like having a baby'

Paul is a 50-year-old White Irish male. He has been in a relationship with Sarah for ten years. They are co-habiting and not married. Paul was recruited through a letter of invitation sent to his partner Sarah who had received support from a cancer service in the West of Scotland. Paul used to work in the hotel and hospitality industry but gave up work in order to care for Sarah. I interviewed Paul on three occasions between September 2017 and October 2018 in three different public libraries.

Sarah, also 50, was diagnosed with breast cancer in 2016. She had a mastectomy and received chemotherapy. Following the operation she then developed lymphe odema. At the point of our first interview Sarah had just finished treatment and was returning to hospital fairly regularly for checks. During the interview process Paul also became ill after developing a blood clot in his neck. This led to him spending time in hospital for surgery and he had two blood transfusions.

Setting the scene

Paul began the interview by telling me that he lost his sister to breast cancer. This set the tone for our conversation and linked his present experiences to his past. I immediately felt sympathy for Paul after hearing that this was his second experience with cancer and this drew me into his account.

He went on to list a number of complications that have impacted upon his life and relationship. This functioned like a plot summary for the three interviews that followed. These significant events included the death of his sister, moving from England to Scotland, Sarah developing lymphoedema, and giving up work to care. As part of this opening account he referred to himself as a 'full-time carer', suggesting he had accepted and internalised the role as part of his identity:

> *'She took lymphoedema at the same time and she's left-handed, so that's the main thing. Work, had to give that up obviously, as did Sarah, so becoming more or less full-time carer, doing the shopping, the paperwork had to be done by me. It was a challenge, it really was, I didn't realise until I was doing it how it can take up a person's full day… So, still worried about her because of the lymphoedema, she hates people bumping into her and stuff. And socially we both, you know, ever since we've just knocked it on the head really. But it's what happens, I mean, we bounce off each other and she's on the mend, so that's the main thing.'*

Paul seemed to want to normalise these events as ordinary, ‘it’s what happens’ cancer experiences. However, not wanting to stray too far from Sarah’s story he concluded with ‘she’s on the mend, so that’s the main thing’. He positioned himself back into the caring partner role, who prioritised Sarah’s health and wellbeing. Subsequently, it seemed the story he wanted to tell, at this point, was one of restitution – health overcoming illness and a return to a cured or ‘mended’ body. Paul reeled off these issues, quickly, like he was working through a practised list. This was an orienting phase, marking out the main features of the story in preparation for what was about to unfold. Aware that we had covered a lot of ground within the first couple of minutes, I then asked Paul to reflect back 18 months or so and contrast how things were now and then. I used the words ‘talk me through how things were’. I hoped to encourage Paul to adopt a slower pace in order to open up and add more detail to the challenges he had mentioned. At this point I was searching for some coherence, a thread that would help me to understand his experiences. By asking him to reflect back in time I was hoping that a chronological framework would help me to piece these different events together to understand his caring story.

A complete woman

> *‘I just drove up to Scotland for the wedding, just to be at the brother’s wedding before the operation, because we were speaking about it and she was very conscious of the fact that it’s the last time she’s going to be an actual complete woman for him and she wanted to be with her brother, so I said, fine, we’ll go.’*

I found the phrase ‘an actual complete woman’ thought-provoking as it brought some ambiguity into the conversation. Paul did not explain why Sarah may have felt that way but I assumed he was referring to her breast before she had the mastectomy. Why she felt she wanted to be a ‘complete woman’ for her brother is a gap in the story. Yet the words were placed there and left to linger. In my mind it raised issues around femininity, sexuality, gender expectations and, ultimately, loss. There was no evidence at this point that Paul may share Sarah’s belief that she will be less of a woman, not a ‘complete woman’ after her mastectomy, but it stood out in the passage and gave me, for the first time in the interview, insight into Sarah’s views.

Paul returned to Sarah's femininity a short moment later by beginning a discussion on the impact of her hair loss following cancer treatment:

> *'Watching her lose her hair, because she has very long, blond hair, watching her lose all that was soul-destroying, really was soul-destroying.'*

Paul positioned himself as being greatly distressed by Sarah's hair loss, repeating the word 'soul-destroying' for emphasis to persuade me how difficult it was. His detailed image of her hair had symbolic meaning. Long blonde hair in Western society is a symbol of femininity and physical attractiveness. Paul assumed that I would appreciate the significance, demonstrating how narratives are culturally situated, relying on shared conventions for understanding. He created effect by painting a visual picture of her appearance, to then state it was 'taken away'. As a result, I sympathised with his evaluation that it was 'soul-destroying'.

Identity claims

This discussion on hair loss then led to a significant passage in the interview where Paul identified what it was like to care for Sarah:

> *'Because of the lymphoedema, I was doing her nails for her, she couldn't really wash her hair so I had to wash her hair for her and stuff. And all those things and then I was doing the cooking and all the cleaning, stuff that we've always done anyway, and I work in pubs and hotels so I know the level of cleanliness, but since she came home everything had to be extra clean. So I was just… it was just like having a baby.'*

Structurally, Paul opened the narrative by orienting us 'back here' into the home, into their private space, in contrast to the treatment setting. Placing the discussion in the home laid the groundwork for Paul to divulge the range of care that he provided for Sarah, with some of it being quite feminine, such as 'doing her nails'. He listed the different tasks that he carried out such as 'cooking' and 'cleaning', with this listing of tasks leading to a point – 'stuff I've done anyway'. That is, there was nothing unusual about him doing all of these domestic jobs. Accordingly, he detached himself from more traditional discourses of masculinity by aligning to traditionally female care. Through this Paul presented himself as someone who was hands-on, considerate and unphased, taking on jobs that may seem traditionally ‘female’.

This culminated in ‘it was just like having a baby’. This disrupted the spousal, and by association, romantic/sexual relationship dynamic and moved it into a parent/child relationship dynamic instead. This posited Sarah as being helpless and unable to care for herself. How a participant defines their relationship to other characters can convey how they wish to be understood. In this case, Paul portrayed himself as being pivotal to Sarah’s care and wellbeing. A baby cannot survive without care from a parent. Therefore, I was led to consider that neither would Sarah.

Later in the interview, through recalling his feelings towards administering Sarah with injections, I learnt more about this protective relationship dynamic:

> *‘She said, you will be having the nurse visit every day to drain her fluid anyway but this injection was, I forget the name what they call it, but there’s two injections, you have to mix it and one goes in before the other. She said, I can show you right now if you want to do this, people say yes and people say no. They think they’re harming their loved one and stuff like that. I said, no, I’ll just, you know, I want to do it there and then anyway. So no, it was something I definitely did want to do, definitely, I didn’t want, because I felt, well she’s been broken enough, I didn’t want anybody else to be doing that. Definitely do it again, yeah, definitely.’*

Paul’s account moved chronologically through time. It reported past events and had a moral point that was introduced before he provided the resolution – ‘people say yes and people say no’. He persuaded me of his decision by stating ‘she’s been broken enough’. The word ‘broken’ conjured strong imagery, suggesting a fractured sense of self. This again emphasised Sarah’s vulnerability and seemingly his opportunity to ‘fix’ her by providing this element of medical care. He took control of this situation by taking the care from the nurse – ‘I didn’t want anyone else to be doing it.’ This allowed the narrative to finish with an evaluation and coda as he reflected by saying he would ‘do it all again’, consequently reinforcing his belief and convincing me that it was the right thing to do. Paul constructed this narrative in order to persuade me that, no matter how challenging the care was, he would do it all again, without hesitation – positioning himself as the ‘fixer’ aligned with the ‘looking after a baby’ comment discussed above. Paul used these examples as an opportunity to project himself as being essential to Sarah.

Pushed aside

Paul and Sarah moved in with Sarah’s mother in order to save money while Paul looked for a new job. Consequently, Paul described feeling pushed out of his caring role:

> *‘But since we moved in with Sarah’s mum, it’s like Sarah’s the baby and mum looks after her, and for a couple of months Sarah was going to that group, because Sarah was going there for the counselling. And then her mum would go with her instead of me. Oh, OK, and slowly and surely I was like, hang on a second, Sarah’s going for a blood test and mum’s taking her, I’m not, I was feeling, hang on. I was thinking like… why aren’t I going? It was something that her mum wants to do, I mean, and I can understand that, because it’s her daughter, her first daughter and it’s her baby, so… but the way I was trying to put into it was, well, you were 73 at the time and we had to look after you as well as trying to recover and stuff like that. We’re living with you, you’re doing us a favour by… Sarah used to live there as a baby, now she’s back again.’*

Paul interspersed his account with moments of thinking aloud – ‘why aren’t I going?’ He used a rhetorical question to make his point and in this moment I felt like he was providing me with direct access to his thoughts and feelings on this topic. That is not to say other moments were less authentic or lacked ‘access’, but by varying the use of features such as rhetorical questions into his speech, Paul can choose when to focus my attention on his point of view.

Yet, it seemed as he moved between interpretations that he was still trying to decide for himself whether he was challenged by Sarah’s mother’s actions or was grateful for her support. Sarah was referred to as ‘the baby’ again but this time she was positioned as her mother’s baby. Despite what he said earlier, about it feeling like he was caring for a baby, he could not compete with this relationship. He was not the parental figure in this caring role. Therefore, this left Paul in a state of flux as his carer identity, which was closely intertwined with his sense of purpose, was disrupted.

Two steps forward, 20 steps backwards

There were various shifts in the way Paul developed plot across the interviews. In interview one, he constructed a progressive narrative, or a restitution narrative. In this typology the plot is health, illness and then a return to health in the future. The ill body becomes an 'it' to be fixed (Sparkes, 2005) – Paul's exact words in relation to his care for Sarah, and also in relation to himself after becoming ill, were, 'I know I'm broken, I do think that every time I say, oh, I feel better'.

However, by interview two the progressive narrative was interrupted. Moments of positivity such as, 'it's going to be good, it's going to be alright', had gone. Instead, Paul talked about relationship strain, money problems and his own illness. This difficult combination of events all negatively impacted on his character positioning and the plot was now shaped by decline over time. In particular, Paul took personal responsibility for their money difficulties as he was not in full-time work:

> *'Well, we were arguing about finances and me not being in full-time work, and at that time because the DWP were onto us, they were saying, oh, I'm only allowed to work 20 hours, only allowed to work… they told us I'm allowed to work 24. I said, OK, and then they were taking money off of us straightaway, so it's money, basically money that I spent going to England was money that we didn't have at all, really, although I thought it was mine because I worked, it wasn't, because it was taken away from us again. So… and actually she pointed that out, but I didn't know, I just… trial and error. I went, well, I thought it was a good thing, I thought I could do with a break. Because I mean, we're arguing and we're not really speaking in the house at all.'*

Against the backdrop of a regressive narrative Paul introduced a new character into the story – the DWP (Department for Work and Pensions). They functioned as the 'villain' taking money from someone while they were ill and in need. Paul moved between 'us', 'our', and 'mine' within this exchange as he wrestled with ownership over the money. The DWP took *their* money but he suggested it was *his* as he earned it.

Notions of work are central to some forms of masculine identity as they provide a platform from which masculinity can be judged by self and others. In this relationship Paul has been the main earner and provider. Therefore, there was a level of pressure and obligation on him to find employment as Sarah could no longer work.

With his masculinity placed under threat, and arguments building, Paul needed to search for other ways to develop esteem. Yet, as discussed, the opportunity to build esteem through the carer role was now limited, as Sarah's mother was taking on more care. In reaction to these challenges Paul left for England on two occasions:

> *'I threw my toys out of the pram once or twice since I met you and just, you know, Sarah said that's it, we're finished, we're over with. So, I had nothing to do; my friends are back down in England, so I ended up doing something like a 36-hour trip by coach, down to England, in contact with Sarah all the time and then get to London, had to hang around for ten hours, get the same coach back. It was one of those things. I knew straight away, once I was on the coach leaving X, it was the wrong thing. So that happened twice.'*

He trivialised the strain he was under by suggesting it was a childish reaction – a moment of thoughtless behaviour. Giving up work to care appeared to be a catalyst for a number of problems – it impacted on his identity, psychological wellbeing and it led to relationship strain. However, in interview three, aware that our time together was coming to an end, I felt that Paul wanted to try and end the interview with hope for their future:

> *'I think we look at, not two months' time, but we're trying to look at six months now and we can give ourselves... I hope to be in a better place.'*

He also made a final claim that he was still comfortable caring for Sarah without any threat to his masculinity:

> *'I still do her nails and stuff like that. Still the manicurist'.*

Given his own illness and their financial situation, it was heartening to hear about his positive hopes for their future. Nevertheless, it was apparent that there was an emotional impact to caring that will never cease. I found this poignant as it applied to every participant in the study:

> *'I worry going out and stuff. It's always going to be part of the relationship and always part of the worry.'*

6.9 James' Story

'There's nothing you can do'

James is a 76-year-old White Scottish male. He has been married to Kathleen, 71, for 20 years. He is now retired and used to be employed as a carpet fitter. James was recruited through a letter of invitation sent to Kathleen from a cancer service in the West of Scotland. He has two daughters and a son from a previous marriage. His wife from this marriage died when he was 50.

Kathleen was diagnosed with a rare form of skin cancer in August 2017. She had a number of surgical operations to try to remove the cancer, received chemotherapy, and at the point of our first interview in January 2018, Kathleen was still attending hospital for check-ups and scans and receiving immunotherapy.

I interviewed James on three occasions in his home from January 2018 to February 2019. When I telephoned him to schedule our third interview, he told me that, sadly, Kathleen had died. I offered my condolences and suggested that we did not need to have a third interview. He was adamant that he wanted to continue, so I told him that I would telephone him again in a few weeks to see how he was feeling and arrange a date and time. We then carried out the interview as planned two weeks later.

Anything but cancer

James liked to talk – our interviews were just under an hour (apart from the last one) but not always about his caring experiences. He discussed his travel arrangements to get to the hospital, including the bus number and location of the bus stop, his shopping routines, details about his schooling and his childhood, his holidays, and anecdotes about his friends and family. There was very little discussion on topics covered in the other interviews, such as treatment side effects, relationship dynamics, emotional concerns or support needs. At first, I struggled with this. I was worried that none of this 'data' would be relevant to my research aims. While interesting, it did not tell me anything about the male carer experience. However, I reflected on this and changed my mind. This is a narrative study so I did not want 'data' – I wanted stories and these were his. James responded to my letter of invitation so he clearly felt he had something to contribute on male caring. He answered every question I asked him about topics such as his feelings, his caring responsibilities and his interactions with health care professionals. However, just because the answers led him to form 'off topic' stories, it did not make what he said any less relevant. That he chose to talk about anything *but* cancer was telling in itself.

I considered that James maybe found it difficult to talk to me about Kathleen's diagnosis and any emotional issues because he did not have these conversations with her:

> *'We don't bring it up a lot because I know mentally it probably worries her, I don't want her to worry. There's nothing you can really do.'*

He positioned himself into a protector role by blocking difficult conversations to shield Kathleen from any extra worry. His reasoning for this was that he did not feel there was much to gain from talking, as the fact remained she would still have cancer. He repeated 'there's nothing you can really do' on a number of occasions during our interviews, projecting quite a fatalistic perspective towards their situation. However, I did not feel that this stemmed from acceptance but from a sense of helplessness. He seemed determined that there was no way to change or even improve life with cancer and started to resent actions he had taken in the past:

> '*For years I bought the hospice lottery but it doesn't help if you can't… nothing you can do about it, nothing I can, you know, you can just support and…'*
>
> Interviewer: *'Yeah, so do you feel a bit helpless?'*
>
> *'Well, that's it, yeah. I make coffee and pour a glass of wine and stuff like that at night time.'*

In tandem with feeling that he had no control over the cancer, he also gave the impression that he was unsure how to support Kathleen – both factors then contributing to his feelings of helplessness. Yet, he spoke about making her meals, accompanying her to the hospital and doing more cleaning – 'running about, things that she used to like doing herself' – but he still lacked confidence that he was making a worthwhile contribution to her care.

Hiding away

Consequently, he seemed to detach. He wanted to just 'hide away', reflecting his difficulty in dealing with both his and Kathleen's emotions and his feelings of uncertainty for their future:

> *'I try and sort of hide away from it to be honest, just hope for… because you hear that many nowadays, and this is a new therapy, they have started this, you know, so we are hoping for the best with that. It's held it... just now anyway.'*

He alluded to them becoming more distant. He described how before Kathleen's diagnosis they used to go shopping together and on walks. He mentioned, more than once, how fit and active she used to be, 'even cycling around Loch Lomond', to develop contrast between her health then and now. However, she spent most of her time 'up there' now, in their bedroom reading and on the computer. Their bedroom, and her removal from the main living space in the house, actually became symbolic in the third interview as he discussed her death, stating at least now she's not 'up there' in pain.

And so, these contrasts felt bittersweet, as while he seemed more at ease talking about his past it drew attention to how things had changed. For example, in the following quote he started to describe how he met Kathleen. His conversation was relaxed and flowing but then, after pausing to laugh, he brought it to a halt by returning to the present:

> *'I knew her before, she worked in a pub in P Road, it was a wee lounge bar with carpets and dark wood, old worldly kind of thing. And after my first wife died I was going in with my friends and they were sitting there with their wives and it was a bit… and she only worked at the weekend as she was at uni at the time and she just worked a Friday and Saturday night. She stayed in P and she was telling me she had split up with her boyfriend as he would sit there and not say a word, and I don't shut up!'*
>
> Interviewer: *'That's nice, was that the appeal?' [laughs].*
>
> *'Anyway, we just get on and do what we can.'*

He returned to his default position which was to 'just get on', showing control of pain and vulnerable feelings. A similar approach was taken in a conversation about Kathleen's surgery. Almost mid-flow he broke his narrative and changed topic:

> *'Well, at first I thought when she got the operation, it was cut away, and they said successful, well, maybe that's the end of it, again six months later she's seeing these wee dots and they cut that away, so you don't know how… if you're sitting there, you know, it's going to get… do you want a coffee or anything like that?'*

Right at the point where he was about to discuss the prospect of the cancer spreading and becoming worse, he asked if I wanted a coffee. Perhaps he did not feel comfortable in continuing, so he created a distraction.

<u>*Untold stories*</u>

Accordingly, I found it quite difficult to sense in what ways, if any, Kathleen's diagnosis had impacted on James and their relationship dynamic. That partly stemmed from his decision to talk about other aspects of his life and the way he conveyed a sense of stoicism by deciding not to dwell on, or appear to be affected by the emotional burden of caring.

However, I also felt there was a reluctance to discuss some of these issues in depth as cancer, or this particular cancer, was a taboo subject. Kathleen's skin cancer had formed inside her genital region. However, James never told me this directly but instead used an idiom to convey meaning:

> *'They cut another wee bit away after that, it was three wee dots or something, they cut that away, but it's nothing new, but it's in the place where the sun… it was that… the one you get… the one they talk about sunshine and that, she had it where the sun never shines, down below, you know, and it was the insides, so they had a lot of bother.'*

I felt for James, as he was clearly uncomfortable and made a number of attempts before he finally said 'where the sun never shines down below'. However, using figurative speech allowed him to develop shared meaning between us without him having to refer to the anatomical term and causing further embarrassment. Sensing his discomfort, I then asked him about Kathleen's treatment in an attempt to steer the conversation back to something more routine and comfortable.

Notably, in our third interview, which took place after Kathleen's death, he was more matter of fact. While in interviews one and two he used words such as 'it' or 'that' to refer to cancer, by interview three his language was more open and direct:

> *'It was a skin cancer. And the doctor said he'd only ever seen three before, the specialist. Because, a skin cancer on the inside. So, normally people get it lying in the sun and stuff outside.'*

There were parallels between Angus and Stuart's situation, with both men not realising how close to the end of life their partner had become. He initially seemed troubled by this:

> '*He [the doctor] came down and said, you know she's dying, don't you? I said, no, well nobody said to us.'*

I asked him if he felt the health professionals could have communicated with him differently, but he maintained his stoicism:

> *'It wasn't going to make any difference whether they communicated or not really, you know. It was going to be. I think at the end of the day, she just decided I'm not going to hang about.'*

However, a little later in this third interview, I asked him about his support needs and he stated:

> *'Maybe a bit more knowledge, that's all. Because when she came home I thought she was maybe right, you know. I daresay they could've turned round and said she's not going to make it, but then nobody said that. I still thought that she was going to be…'*

He trailed off at the end, unable to complete his sentence, but he did not need to as I understood what he meant. It seemed too difficult to admit that the hopes he had held for her recovery were futile. Only after being asked did he tentatively suggest he would have 'maybe' liked more knowledge. But, in keeping with his positioning throughout our interviews, he played down his need for any support or assistance.

It was not always easy to sense what James was feeling or to interpret, from his perspective, what it was like to be a man and care for a spouse with cancer. His storytelling spiralled back and forth through time and to topics that seemed irrelevant. However, his experiences and subsequent ways of communicating about them came from a man who faced illness with the mindset that there was nothing he could do to change the situation.

6.10 Angus' Story

'If you're not positive you give up'

Angus is a 71-year-old White Scottish male. He has been married to Kate for 15 years. Kate was diagnosed with breast cancer, had surgery to remove the lump in her breast, then received chemotherapy and radiotherapy. Angus is retired but used to be a minister. When Angus was 45, his previous wife (Christine) was also diagnosed with breast cancer and she died 18 months later. He has three sons from this marriage.

Angus was recruited by word of mouth as a friend of his was also a participant in this study. I interviewed Angus on one occasion in a café in central Scotland in October 2018. A couple of weeks before our interview he had just moved to a very remote area of Scotland, so he suggested meeting in the café as it was a more accessible place. I telephoned the café in advance and asked if we could be seated in a booth so we had more privacy.

I sent Angus two reminders for our second interview but, unfortunately, I never heard from him again. At the time he seemed committed to a follow-up interview but he also spoke about his wife returning to hospital for further tests as they were worried the cancer had spread. This was possibly the reason why he did not make contact with me again. At 35 minutes long, this was the shortest interview in this study. Partly because of the café environment (public and noisy), it felt harder to encourage Angus to talk for longer stretches of time. Also, he just seemed more comfortable with a question and answer format rather than weaving his caring experience into longer narratives about his personal life.

Here we go again

As an immediate response to my opening 'tell me your story' question, Angus referred back to his past. It seemed that before he could tell his current story he needed to make this connection. This added a layer of complexity to his experience and initially placed him in an early storyline of grief and sadness:

> *'By the time it was diagnosed in those days it was already stage three and after all the treatment she only lived for 18 months, so that was quite a shock to the system when you compare that to my recent wife who was just diagnosed and your first reaction is, here we go again.'*

However, rather than dwelling on this he appeared to want to steer the conversation forward by making the first (of many) references to 'trying to be positive'. Angus used the word 'positive' or 'positively' on 17 occasions in our interview, as he moved between seeing benefit in approaching a challenging situation with positive thinking, but then also recognising that masking the reality of a situation with positivity was not always helpful.

To begin with, while still talking about his previous wife, he suggested there was a 'need' to feel positive:

> *'I think most cancer patients, they are fairly positive and you feel the need to be positive with them and you don't know anything.'*

Notably, he chose to position his wife as a 'cancer patient', shifting perspective from a personal account to a socially constructed role. This acknowledged the wider and shared nature of his wife's experience and placed it within wider discourses associated with the societal meanings of cancer. Discourse can structure 'appropriate' ways to act, think and feel and so, for that reason, he appeared to feel an expectation to mirror her emotions and project positivity.

He continued to talk about this but then shifted from 'patient' to 'my wife'. Focusing now on her personal perspective rather than that of a generic 'cancer patient' allowed him to go a little deeper into their personal circumstances:

> *'My wife herself was very positive, she took the attitude, some people say why me, and she was well, why not me, I'm just one of the population. I may be a Christian but that doesn't excuse you from health issues. I suppose her positive attitude helped me. Initially I suppose I panicked I guess but I just carried on thinking positively I guess. But if I had known how serious it was I think my attitude would have been a lot different.'*

Angus positioned his wife as being selfless, making it known to me that she did not see herself as a victim, or feel any sense of injustice that other people can feel when diagnosed with an illness such as cancer. He related her attitude to her Christian faith, which aligned to his professional positioning as he used to be a minister. Identity claims carry connotations which, as he was alluding to, can affect attitudes and behaviours. The influence of religion on coping with illness has received scholarly attention, as religious/spiritual resources can be beneficial when dealing with situations involving an element of personal threat, such as a diagnosis of cancer (Thune-Boyle et al., 2006). This seemed to be the case for Christine, as Angus associated her Christian faith with her ability to accept and adjust:

> *'My first wife, she had her downs like everybody does, but it was really her spirituality that gave her the bravery to face the prospect that lay before her.'*

However, I did not perceive that Angus was entirely convinced that positive thinking was the best way to cope with their situation. In the quote above he expressed doubt, by beginning his statement with 'I suppose', then admitted to feeling 'panicked' – a rare disclosure from him that underneath the façade of positivity he was experiencing distress. He then used a 'but' to create a moment of suspense before adding a complicating action to disrupt everything that had just been said about thinking positively.

To explain what he meant by 'how serious', he then shared that he did not realise, at the time, that Christine's cancer was terminal. As he found himself caring once more for a spouse with cancer, difficult emotions resurfaced. He expressed resentment and guilt and it became clearer why he seemed a little doubtful about being positive as, reflecting back, it created false hope:

> *'I was never called in and told this is going to end badly. I was conscious it could end badly, just with the type of treatment she was receiving, but I think because they surround cancer patients with this confidence and sending good messages, but there becomes a point where this becomes a bad thing. Because if they had been more brutally honest, things could've been slightly different. Particularly with the children.'*

He closed this sentence by referring to 'the children', hinting that there was more to be told, a further twist in the tale, and with the addition of new characters into the conversation this sparked my curiosity.

In my interview with Stuart I heard about how he moved between the responsibilities he carried as a carer and a father. While a different set of circumstances to Angus, it was significant that Angus referred to his children while discussing his caring experience , as it highlighted how caring, while initiated in the context of a spousal relationship, is likely to impact on relationships in the wider family. His decision at this point to present his parental identity to me then influenced the development of our discussion. It allowed him to make sense of this situation but from a different perspective. Shifting from husband to parent created an opening for Angus to express remorse that he did not have more open and honest conversations with his children before his wife's death:

> *'I can remember in the very final stage, and my three boys were with me, and I had to take him out the hospital and walk him round the grounds because he was in bits because I don't think he had realised this was the end. And that shouldn't have happened that way.'*
>
> Interviewer: 'A*nd how was that for you, having to talk to the children?'*
>
> *'It wasn't easy. There was an element of stoicism about it. And looking back, maybe we didn't talk enough father to son.'*

Angus took responsibility for his son's distress, suggesting he should have had more 'father to son' conversations. Notably, his preferred identity claim was now 'father'. The shared gender in the father/son relationship can be a source of long-lasting psychosocial and developmental influence (Floyd & Bowman, 2006). For example, in an attempt to adhere to expectations embedded in traditional masculine roles, fathers may encourage emotional distancing between themselves and their sons (Miller, 2013). Indeed, when presented with this moment to express vulnerability and, ultimately, honesty about Christine's prognosis, he stated that there was 'an element of stoicism'. However, Angus appeared to regret the way he approached this situation and wished that he had been more communicative. Given this was 25 years ago, his evaluation came with the advantage of hindsight. That is not to say there was anything untruthful about his claim but to recognise that perhaps over time his expectations for fatherhood, particularly within the context of being bereaved, may have shifted toward being a more emotionally open father.

Constant comparison

Given the significance of his past experience, our interview did not follow a chronological linear sequence. Angus moved from past to present and vice versa to discuss poignant moments in relation to both of his caring experiences. Subsequently, this meant he was able to make a number of comparisons between his past and now. Above all, he seemed grateful for medical advances:

> *'Comparing when my first wife died, eight out of ten women died and now it's only four. Aye, and also comparing what stage it's caught. So my current wife, there were two lumps, I forget the technical term, one was in situ and not aggressive, and one was aggressive and if that hadn't been caught that could have been serious. So we are very thankful that she had the treatment she had. But in 26 years or whatever it's been, there's been such a change in the treatment.'*

He also felt that there was more support available:

> *'I would say this time I felt much more supported, both of us. Maggie's were good at supporting the patient and the partner.'*
>
> Interviewer: '*Did you seek it out more this time do you think, or was it just there?'*
>
> *'It was just there. It was there for the giving, you didn't have to seek it out.'*

I was struck by Angus' situation and considered how difficult it must have been for him to face a threat to his spouse's life again. As I listened to how he lived with this constant comparison between 'those days' and now, I became slightly concerned that it may become too painful to keep drawing from these memories. I asked:

> *'So, I guess this must have been quite reflective then, me asking you to think back 25 years ago. So I really hope it's been OK, not too difficult I hope?'*
>
> *'Oh no, no. You forget so many things.'*

Reading this back I could have been more direct. I did, of course, hope it had not been too difficult for him. However, if I had not shared these hopes it may have been easier for him to say if it had felt upsetting. Nevertheless, I was reassured by his response (oh no, no) and his body language (open, relaxed), signalling that he was happy to continue. Upon reflection, I responded with worry as I assumed that recalling these memories may have been difficult. However, as well as verbally reassuring me that it was OK, it became apparent that he took some comfort and reassurance from these comparisons. He said that this was a different, an improved cancer landscape in which he found himself once more. In his own words, he stated 'this is a completely different situation', trying possibly to convince himself that things would be easier. He even found gain in the fact that he was retired, stating, 'this time I can completely focus on my wife'. Consequently, among the challenges he has found benefit. He suggested this was a second 'chance' to care differently:

> *'And you are always going to have regret because you are walking on a road you've never walked before. And if you have a chance to do it a second time, you will do things differently.'*

Unfortunately, I never got to interview Angus again. I would have liked to have known more about what things he found himself doing differently. Nevertheless, while this was a shorter interview, it provided important insight into the experience of returning to a spousal caring role. Thankfully, this is not likely to be a common situation – but given the increasing prevalence of cancer and changing family dynamics, it may become more common.

Chapter Summary

These eight caring stories reflected a range of different accounts. I will conclude this chapter by drawing attention to five threads that stood out as I analysed these stories. These concepts then shaped the content of the scenes which are detailed in the next chapter. They are:

- Change.
- Expectations.
- Responsibility.
- Self-awareness.
- Enduring emotional burden.

I chose these threads as they provide understanding on *why* the caring role is both challenging and rewarding. In summary, these five threads describe a process of role acquisition and role renegotiation. Shifting from being spouses/partners to carers was bound up with particular assumptions, expectations and emotional reactions. What is more, the adoption and experience of acquiring this role was perceived within a framework of masculine ideals and norms. Consequently, the 'male carer' role is something that is socially situated. The men's movement between hegemonic performances of masculinity to contrasting forms of masculinity represented by, for example, expressions of love, was a source of conflict for the men. It is from this starting point that the interplay between individual experience and social context will be explored as I represent a year spent caring though four scenes.

CHAPTER SEVEN: PERFORMING IDENTITY

Structure of chapter:

- *Constructing the scenes*
- *Scene/participant selection*
- *Performing identity – one year caring*

Overview

In chapter six, I explored the unique nature of each person's life history. The aim was to appreciate the depth of detail that stemmed from each person's account. This retained narrative coherence and provided an opportunity to reflect on the richness of their experiences. The stories provided accounts of how each person's life had changed and how they coped with the challenges and opportunities that arose through caring. This chapter builds on these ideas but explores broader issues relating to masculinity and caring *across* the participants. Goffman (1959) suggests that 'social actors' (in this case participants) stage performances of desirable selves. Similarly, gendered identity can be performed and produced for an audience in a social situation. Therefore, I decided to capture the way that identity was constructed and accomplished within social interaction by writing the findings as scenes, as would be found in a theatrical play. Accordingly, by choosing to represent the data this way, my hope was to highlight the performative nature of identity expression.

7.1 Constructing the Scenes

I concluded my analysis of the individual stories with five concepts or threads that summarised a process of male caring for a spouse with cancer over time. However, the participants did not always tell their stories in a linear manner. As I turned to developing the ordering of the scenes, my aim was to locate each participant's perceptions of their experiences in time and place with a focus on meaning and consequences of actions (Bruner, 1986). This chapter is my interpretation of commonalities and moments of divergence across the eight participants. I returned to the interviews and used the techniques of narrative analysis that were discussed in chapter five. The narrative threads provided temporal structure, with each scene representing a move forward in time and a significant moment or transition. Thus, these scenes represent the evolution of experiences, rather than approaching caring as something fixed and/or short-term.

As I was selecting data for the scenes, I considered the overarching structure and the relationship to plot. As discussed in my methodology chapter, particular structures hold the story together and enable the listener (or in this case reader) to follow and determine what is important. For instance, the classic three-act structure of beginning, middle and end, as first observed by Aristotle in his work on Greek tragedy, provides sequence and coherence (Fergusson, 1961). Stories (or verse/drama from Aristotle's perspective) arrange their elements in a particular sequence for effect. In my analysis of the individual stories I identified how structural elements such as 'complicating action' and 'evaluation' can convey importance, evaluate challenges and make statements.

I have also discussed how people use narratives to make sense of illness. Frank's (1995) identification of three types of narratives, as told by people with illness, describes the illness experiences in three ways. Illness as something to overcome (restitution), illness as something that is meaningless and devoid of purpose (chaos) and illness as a journey or a quest involving perseverance and hope for the future (Ezzy, 2000). Davies (1997), focusing on studies of people living with HIV/AIDS, devised a similar typology based around peoples' understanding of time. Davies described three forms of temporal orientation – living in the future, living in the empty present and living with the philosophy of the present. There are parallels and contrasts between Frank's and Davies' approach. However, my wider point is that it has been theoretically recognised that structural, moral and temporal orientations can shape the lived experience of illness.

With this in mind I gathered the eight stories and adopted the position of narrator. As the narrator, it was my responsibility to reflect on the data, my chosen theoretical framework, current literature and then select the most fitting and convincing events in order to craft something that was reportable. An obvious beginning was diagnosis, as it was the catalyst for storytelling. However, it was how the participants managed the disruption, and how and why this was related to their sense of self, that led me from one scene to the next before arriving at the ending. Drawing out the interconnecting elements, the 'whys' and 'how's', was my route to generating new understanding of male carer experiences.

Importantly, the end of the research process did not reflect an end to the participants' caring stories. For that reason, I wanted the final scene to capture the enduring emotional weight attached to caring. Ricoeur (1984) considers that to understand a story is to understand in what way the successive episodes lead to a conclusion. Considering that each scene was an episode, my intention was twofold – to shape the data from four isolated events to a logical sequence with meaning and to recognise both the individual person and the contribution of wider context. A holistic approach to analysis such as this aims to exhibit the connections between participants, motivations and actions in order to generate explanations for particular outcomes (Polkinghorne, 1995).

In summary, the men described dramatic changes to their roles and relationships and their outlook. There were accounts of the emotional, physical and financial strain associated with caring and also moments of positivity, such as a heightened appreciation for their partner and increased feelings of self-esteem and purpose. During the interviews the men created suspense and curiosity as they brought me into their lives and shared their experiences. Therefore, another reason why I chose to use scenes, rather than, say, themes, was that they captured the dramatic unfolding of a year spent caring. This helped to magnify the voices of a group of people whose caring stories are not always told or heard and gave them an (albeit metaphorical) stage to disseminate their experiences.

7.2 Scene Overview

The following table (table 10) summarises the relationship between the five narrative threads, scene content, theory and context in order to guide the reader through my process of scene construction and interpretation. This will also be used as the basis for discussion in the next chapter, in which I will contextualise these findings in relation to theory and current literature.

Scene title	***Scene overview***	***Narrative thread***	***Theoretical underpinnings***	***Context***	***Performative features***
Scene 1 'In that moment life changes'	Adjusting to the news of their partner's diagnosis.	Change	Psychological reactions to the diagnosis (distress, anxiety, anger, fear) as trying to cope with a threat to their spouse's life. Subjective temporality – changes in their representations of the past and plans for the future.	The degree of adjustment to the change was related to a combination of factors – perceived control, practical pressures (e.g. work and finances) and the nature of the change. For example, changes to their partner's body image.	Setting the scene – opening accounts were used to position self in relation to family and wider circumstances. Participants drew me into their accounts through choice of topics, use of emotive language and setting out an early story arc of life

					before and after cancer.
<u>Scene 2</u> 'Caring but not a carer'	Becoming and recognising/ resisting being a carer.	Expectations Responsibility	Identity – role acquisition and negotiation. Transition theory (Montgomery & Kosloski, 2009). Uncertainty and instability as a person moves from one state/role to another. Successful transitions require adequate knowledge, support and self-efficacy. Male roles and normative expectations.	Transitioning into a new role is bound up with new responsibilities. Some participants resisted the carer role in favour of prioritising the spousal role. Particular responsibilities and expectations to behave in certain ways caused difficulties.	Preferred identity claims – reference to being a husband and father. Rejection (by some) of the carer label. When the role was embraced this was done to highlight importance, purpose and self-worth.

Scene 3 ‘Opening the valve’	Perceived need and use of support	Self-awareness	Masculine norms around emotional control, stoicism and help-seeking. Cognitive reframing and acceptance.	Masculine norms to protect their partner were prioritised over their own needs or wellbeing. Judgements over need and vulnerability impacted on use of support.	Positioning towards and against different versions of masculinity. Contradictions between ideal role and lived experience.
Scene 4 ‘Repercussions’	The long term consequences of caring	Enduring emotional burden	Fear of reoccurrence. Living with uncertainty and loss	All participants reported negative emotions (e.g. fear) years after their partner’s diagnosis. These were lessened or exasperated by clinical, social and psychological factors.	Preferences and expectations for conclusive stories.

7.3 Scene One – 'In That Moment Life Changes'

After my opening request to 'tell me your story', with the exception of Jack and David who wanted me to clarify where they should begin their story, each participant, without hesitation, began to describe the lead up to their partner's diagnosis. However, time orientations varied. Five men began their accounts in the weeks and months leading up to the diagnosis, whereas, before beginning with their present situation, Jack, Angus and Paul talked about how a family member of theirs, or in one case a previous partner, had been diagnosed with cancer. Making this link to their past and emphasising previous loss developed the idea that their partner's diagnosis was going to be particularly hard to come to terms with:

> *'I was close with her dad, Billy, and that was a shock to me when, obviously, it happened with him. It was so, so quickly. He was in here [the hospital] as well and to go through that was strange. And now, to be going through it with Natalie as well, it's even stranger. It's unbelievable.'* (Jack).
>
> *'I had visions of my sister, I had visions of Sarah, my dad had throat cancer, just any time I hear about cancer I feel the hairs stand up on the back of my neck.'* (Paul).

Therefore, rather than just relaying a series of statements to me, the initial moments within the first interviews were used for scene setting. Participants used this time to position themselves with regards to their family and work circumstances, their life history and past experiences:

> *'My wife and I are really, really close, we've got a great relationship, and the idea that anything could happen to her terrified me beyond belief.'* (Stuart).

Accordingly, once background and context had been established, the men arrived at the point in the interview where they described hearing the words 'it's cancer'. Their reactions included shock, fear, denial and anger. Some of the men seemed to process the news immediately. Brian described sitting in the consultation room and feeling like a 'bomb had gone off'. Mark stated his wife was fine but 'he broke'. In contrast, Stuart stated that he felt calm. It was only at the point when his wife's treatment had started did 'the penny drop' and he felt 'terrified'.

However, Jack and Paul described their reactions in a different way. They reacted from the position of someone who has gone through the experience:

> *'They said, it's cancer, and it changed everything completely.'* (Paul).
>
> *'Your life completely changes in that second.'* (Jack).

Rather than describing how they felt in the moment, or in the days following their partner's diagnosis, they shifted their perspective to allow them to reflect back. The magnitude behind the statement was considerable – that 'life' and everything that has been known and taken for granted changes. As well as making a dramatic statement about the disruptive impact of illness, framing their opening account within the context of change sparked curiosity. It signalled that there was a story to tell and it also marked out an early story arc, which was the contrast between life before and after cancer.

Change was a significant part of the men's caring experiences. They described changes to their daily routines, to their employment and to the dynamics within their relationships. Different perceptions around the significance of change were aligned to their emotions. For example, negative emotions arose when the men began to reflect on the permanency of the change in terms of psychological and physical side effects:

> *'She's had the mastectomy, that's a loss. You know, she said it's just a lump of fat with a nipple on the end but to a man it's a wee bit more than that.'* (David).

For the most part, as change was unplanned and unwanted, the men struggled to adjust to their current situation. David was probably the most reflective about this, summarising the challenges associated with change as 'loss'. As his quote above exemplifies, changes to his wife's physical appearance also affected his masculine identity. He suggested that there was deeper significance to his wife's breast than it just being a 'lump of fat' and that this view was not just held by him but by 'men'. Aligning himself to a wider group of men strengthened his point, which he may have felt the need to do with a female researcher, that is, he may have considered or assumed that as a female I would share his wife's perspective.

What was particularly challenging for these men was how, in trying to adjust to change, it led to a longing for their previous 'normal' life, before cancer. Jack described the feeling as being 'derailed'. This captured the way that caring had impacted on his impetus to move forward.

It was this state of flux of being caught between trying to adjust to change, but hoping for a return to their earlier life, that was upsetting:

> *'It has left scars and wounds and normality as we knew it has gone. We are entering a new norm. The old norm was preferable but the new norm is all we have.'* (David).

David's clever use of 'scars and wounds' had double meaning. His wife was left with physical scars following the mastectomy, but these scars also symbolised permanent emotional pain. As the men tried to come to terms with the realisation that their 'old' life had gone they were left with no choice but to move into a new reality:

> *'Everyone is living their normal life but you can't and you don't feel jealous towards it, it's just a loneliness. Feeling as you want to step back into how things were before but you can't, as you've just got a weird thing hanging over you.'* (Jack).

I felt that this particularly captured why Paul and Jack reported feeling compelled to start their stories with this time-stopping moment of change. They perceived change as loss. Their emotions, which included worry, sadness and loneliness, stemmed from their belief that life had completely changed and crucially, at this point, they had no idea how they were going to adapt.

7.4 Scene Two – 'Caring but Not a Carer'

After the initial shock began to fade, this second scene marked the point in which the men began to transition into their new roles. In the main, this was described in terms of their involvement in new tasks and responsibilities, such as accompanying their partner to hospital visits, taking on a greater share of cooking, shopping and cleaning, administering medical care and providing emotional support. For spousal carers like these men, as they live with the care receiver, this is a 24-hour-a-day, time-intense role. Both practically and emotionally, all the associated responsibilities and expectations permeated every aspect of their lives.

Mark, in particular, was consumed by these new responsibilities. He struggled to manage the care of his wife and children alongside the upkeep of their home. What was particularly challenging for Mark was that these new care requirements did not sit within his pre-existing beliefs as to how men should behave:

> '*She ended up in hospital and I was thrown into the whole looking after the kids. I'm a worker, I go out. In here, even though there's a big age gap between us, I'm kinda old school, I go out to work, I do the stuff.'* (Mark).

He seemed to be more comfortable engaging in practical tasks with a clear benefit, rather than providing emotional care:

> *'Yeah, I feel there's very few men who approach it emotionally, it's all practical. If I do that, it will make her life easier. It's not how she feels. I don't think I really think about how Gemma feels, I just think about how if I do a certain thing then she won't have to.'* (Mark).

When the care needs of their partners increased beyond the normal boundaries within their existing relationship, like Mark, all of the men spoke about altering their behaviour in some way but with varying degrees of struggle. In an extreme example, Paul left his job to provide full-time care as they had no other sources of support:

> *'The hard thing was just the two of us, she had all of her family up there in Scotland, so we had to do it all on our own. And then she took lymphoedema at the same time, so work, had to give that up obviously, as did Sarah.'* (Paul).

Other changes included taking more responsibility for meal planning, different hours at work to accommodate their partner's hospital visits and spending much less time on their own hobbies and interests. Accordingly, the magnitude and nature of these changes had an impact on their self-identity. Stuart, for example, jokingly referred to himself as an 'auxiliary nurse' as he described administering medication and cleaning his wife's feeding tube. According to Montgomery and Kosloski (2009), when the individual alters their behaviour to accommodate these changes, this is the point where the individual may self-identify as a 'carer'. Yet, the majority of the participants in this study did not identify with the term carer. The essence of this was captured by Stuart, when he stated:

'I'm caring but I'm not a carer'.

It was notable that, across all of the interviews, no one referred to a precise or defining moment when they felt that they had transitioned into or acquired the role. Even though they were engaging in tasks that caused them to perceive their role differently, this was done from the position of a husband rather than a carer:

> *'Yeah, and to be honest they [health professionals] never referred to me as a carer. People would say to me, oh, you're entitled to Carers Allowance. I'm not a carer, I'm Helen's husband. I'm not a carer.'* (Stuart).

Positioning theory considers that there is a discursive nature to how someone may self-identify as a carer. For example, in the above quote from Stuart, by focusing on how language can position someone, there were two contradictory moments. He stated that the healthcare staff never referred to him as a carer, but 'people' (presumably his friends) did by discussing his eligibility for Carers Allowance. Perhaps if he had been discursively positioned into the role by health professionals, he may have felt more inclined to self-identify with the term. However, he rejected the label, repeating twice for emphasis that he was not a carer. His reasoning for this became clearer when he stated:

> *'I'm no claiming Carers Allowance. If she was terminally ill maybe and it was affecting my life, but I don't really see, I've never really claimed anything before in my life, so I couldn't be bothered, but I'm doing what I'm doing and Helen is going to get better. She doesn't need help getting dressed, she can go to the toilet herself, and these are key questions on these forms.'* (Stuart).

Stuart rejected this support on the grounds that Helen was not terminally ill. In addition to the fact it was a 'carers' allowance, he associated it with end of life care. Therefore, to claim such support would be a defeat and a sign that things had become unmanageable.

Jack did not identify with the term but for quite different reasons. He did not believe that he was doing enough to be deemed a carer:

> *'I like the idea that I'm in a caring role, 'cause I feel like I'm doing something at that point. But I feel she almost doesn't need it. I don't know, I think she would cope well, even if I*

> *wasn't there. But I can't help but just constantly try and do what I can. But I don't know if I see myself as a carer, as such, but I'd like to, I guess, think that I'm doing what I can.'*
>
> Interviewer: *'It sounds like you're doing a lot. What do you think would change it so you would feel more of a carer?'*
>
> *'I'd probably feel more in a caring role if I was doing more physical tasks. Because I feel, at the moment, I'm just constantly sitting, looking at her, worried.'* (Jack).

Jack aspired to feel associated with the role in order to reinforce his sense of self-worth. However, he questioned the suitability of the term to summarise his contribution as he was not carrying out many 'physical tasks'. This echoed Mark's view, when he stated that men approach it 'practically', the implication being that individuals may transition into the carer role with pre-existing expectations around the type of care that they *should* be providing. When, as in Jack's case, these expectations were not met, it caused further strain.

However, not everyone dismissed the term. Paul and Angus, without any prompting from me, directly referred to themselves as a carer. Angus mentioned that his wife had other health problems, so it felt 'normal' for him to use the term:

> *'Yes, well, I have very much been my present wife's carer because she has other health issues, she had to give up work as she had spinal problems. So I had already been caring, so this is just another dimension. I've been in the caring situation for a long time [laughs] can't get rid of it. It's gone on for so long you just accept it as normal.'* (Angus).

Paul, immediately after telling me he had given up his job, referred to himself as a 'full-time carer'. The juxtaposition of these two pieces of information seemed intentional to highlight how time-consuming the role was. Therefore, this justified his decision – he could not work as caring is a full-time job. Subsequently, his caring role appeared to increase his self-esteem and provide purpose at a time when things were emotionally and financially difficult.

For Paul, the carer role came with particular responsibilities and expectations. This was exemplified when he spoke about wanting to administer his partner's injections as, despite it being a difficult task, he wanted to take ownership of it:

> *'She [the nurse] said, I can show you right now if you want to do this, people say yes and people say no, they think they're harming the loved one and stuff like that, I said, no, I'll just, you know, I want to do it there and then anyway. So, no, it was something I definitely did want to do, definitely, I didn't want… because I felt, well, she's been broken enough, I didn't want anybody else to be doing that.'* (Paul).

The activation of his role identity in this situation allowed him to feel purposeful and accomplished. However, in our second interview I asked him, 'so, do you feel like a carer?' (for context my intention was to understand more about how the language can position somebody and impact on their embodiment of a role) and he replied:

> *'I mean, in that respect, yes, because, I mean, that's the way just because, oh, even when I go to medical appointments, this is your partner, your carer, your carer, your partner, and I don't know if I like the word carer. I know that's what people do – I'm thinking to myself, no, that's my love and I want to make her better. You know, it's just like children really, isn't it, you go out of your way to do anything for them.'* (Paul).

Paul was identified as a carer by the health professionals, something that was not the case for Jack. However, his movement between 'partner/carer' suggested that there was some ambiguity from both him and the medical professionals around the preferred or appropriate use of the term. Despite his early desire to be referred to as a 'carer', he reflected that he did not know if he liked the word. His thoughts unravelled as he was talking to me and he corrected himself – '*no,* that's my love'. This seemed to stem from his reoccurring desire to position himself as a parent who was providing unconditional love to a child. This, more than his carer positioning, perhaps fulfilled his need to feel valued and useful, particularly as his partner's health had started to improve so that he was providing less care.

This brings to the fore how the term 'carer' does more than describe a role. Labelling, positioning and identification was bound up with different expectations and meanings. In particular, as discussed in the next scene, it had implications for the use of supportive services.

7.5 Scene Three – 'Opening the Valve'

A range of factors impacted on the participants' feelings of burden and distress. Clinical factors such as secondary cancers and treatment side effects were associated with worry, anxiety and fear. There were expressed needs for more information on the cancer diagnosis, dealing with side effects, and assistance with medical equipment:

> *'If they could just tell you in plain English rather than, listen, we're going to be telling you things and you're going to get your hopes up. Don't get your hopes up. The bad side is she's going to lose her hair, she's going to get tired, she's going to get grumpy, that's all they need to tell you.'* (Brian).

There were clear statements of distress, reflecting the negative emotional impact of caring:

> *'Guilt, lack of drive, lack of motivation and very unsettled. So that's where I'm at. I mean, I definitely feel better seeing Natalie enjoying things again but there's always a crash that follows it, so you can never feel too good for long.'* (Jack).

Dissonance between relationship norms and new requirements within the caring role was associated with distress. For example, Mark found himself engaging in new domestic activities that were not congruous with his previous role identity. Stuart became troubled by the visual reminders associated with his new responsibility, to assist with his wife's feeding tube:

> *'I hated that thing in our bedroom and connecting up to these feeds every night. I hated that thought.'* (Stuart).

Yet, their distress and information needs rarely prompted any form of action. For the most part, masculine social norms to be strong and stoical and to protect their partner were prioritised over their own needs or wellbeing.

James was probably the most resigned, revealing very little about the emotional impact of caring. He positioned himself into a protector role by blocking difficult conversations to shield his wife from any extra worry. His desire to 'hide away' and 'just get on with it' meant he never disclosed what his needs were.

Subsequently, the way each participant viewed their roles and responsibilities within the context of their relationship had implications for their perceived need and use of supportive services. Paul stated:

> *'I've been offered all these complementary therapies, massages and stuff like that…'*
>
> Interviewer: *'Yeah, have you done any?'*
>
> *'No, no.'*
>
> Interviewer: *'Why not?'*
>
> *'Don't know, I think it might affect my masculinity or…[laughs]… dunno. just not for me.'*

Paul implied that masculine norms discouraged him from utilising the support – presumably as therapies and massages were deemed to be too feminine. However, he laughed when he said this to me, signalling that he did not take the expectations embedded in these norms too literally. Interestingly, Paul was more open to attending counselling (his partner was accessing counselling so he was offered it) but he stated that 'he didn't need it'.

There was also a link between perceptions of need and support uptake. Focusing on the reasons why the participants expressed that they did not need any support was insightful. Jack, initially, suggested it was because he did not have enough time:

> *'I just don't know. I just don't feel I've got time for it, and I don't think it would benefit me too much. And I know it probably would, I don't know. Maybe in the future. Right now, I just couldn't see myself. Nothing bad, I just don't know how to explain it.'*
>
> Interviewer: '*Because you're just thinking about other things just now?*
>
> *'I almost feel like I don't need it. Like, I'm still managing to function, and all that kind of stuff, and I feel I'm doing a good enough job at the moment, and I just don't want to take any time out of my diary that's not required.'* (Jack).

However, as he went on, I could sense that he was conflicted. There appeared to be a more complex relationship between identity, behaviour and the use of support services. He initially suggested that time was the barrier and he tried to suggest, or perhaps convince himself, that he would not actually benefit from the support. Yet, he lacked confidence in this belief, stating 'it wouldn't benefit me too much', which led him to immediately change his mind and state that he would maybe use it in the future.

At the root of his uncertainty was the standard he had set himself around levels of need and ability to cope. Seemingly he had set the bar rather low, as for him 'just managing to function' was not an indicator of need. From my perspective, 'just functioning' would suggest an immediate need for support. However, his health came second because he said he was doing a 'good job'. In other words, his sense of need was closely intertwined with the way he performed as a carer. Satisfied that he was managing, he did not feel that he should spend any time on himself. This emphasised how perceptions around self-esteem and worth may impact on an individual's willingness to seek help.

Stuart did not perceive any need for support as he did not self-identify as a carer:

> *'I don't think I'm doing anything special. I'm just doing what I'm supposed to be doing, in sickness and in health.'* (Stuart).

However, he clearly gained from attending a patient support group with his wife:

> *'So, I don't like these things, my name's Steven and I'm an alcoholic, I just feel very uncomfortable. But anyway, I went in and it was brilliant. To hear other people talking and realising they are not exclusive to you. But when you hear someone else who has had the same operation and is suffering in a very similar way, I'm thinking, alright, so I don't need to unduly worry.'* (Stuart).

Listening to these shared views helped to normalise his situation and reduce worry. Yet, he initially mocked the support group format as he associated it with an Alcoholics Anonymous meeting. This highlighted the extent to which pre-existing perceptions, preferences and biases for different types of supportive interventions may impact on help-seeking behaviours. However, as discussed in Stuart's individual story, by interview three he was more open to the idea of accessing support. He talked with greater insight of how he should 'let off steam' to help prevent stress from building up. Once 'the valve has been opened' through talking to others, it helped to reduce stress. Notably, it took Stuart one year to make this realisation as until then, his time, focus and energy had been on his wife.

There were parallels with David's description of his experiences, but with one crucial difference. I interviewed David at 'Maggie's' because he and his wife had both accessed support there. When we walked in he was on first name terms with the staff members and he helped himself to a coffee. There was an established level of familiarity and comfort with a supportive service – however, this took time. Like Stuart, David went through a process in which the way he viewed his roles and responsibilities within the context of his relationship had implications for his perceived need and use of support. For example, when his wife was first diagnosed he emphasised how reliant she was on him:

> *'I was there to encourage her. "Will I be OK?", you'll be OK. "Will you stay with me?", yes I was going to stay with her, of course. "Don't leave me", I'll not leave you. "Don't leave the house". So, there were three weeks when I didn't leave the house, she wouldn't let me go through the front door because she was paranoid.'* (David).

The 'emotion work' involved in supporting his wife meant suppressing his own needs and, practically, as he was confined to the house, he could not travel to access support from an organisation such as Maggie's. At this point David had little control over his time and, in his words, felt 'lonely and isolated'. Consequently, this prompted him to seek local guidance from friends in the church.

This step, or to carry on with Stuart's analogy, this 'opening of the valve', when David began to reach out to friends for support appeared to change his perceptions on accessing it. However, he was aware of the way in which masculine discourses can position, explain and restrict help-seeking behaviours:

> *'Jane was having counselling and I thought, maybe we could do it together, and I was told by the counsellor it wasn't a man thing to do, but I says, well…'*
>
> Interviewer: *'Oh really? What did she mean, like going to counselling or…?*
>
> *'Yeah. She says it's very… it's… she says it's difficult for men, especially Northern Irish men to. And she's married to a Northern Irishman, so she knows.'*
>
> Interviewer: *'And do you agree with that do you think?'*

> *'Yes, I do. Yeah. I would. I think men hide their feelings more. I think there's a big mental health issue in men that they… you know, they don't always express what they think. I don't always express what I think. So I'm not unique.'* (David).

David admitted to suppressing his emotions in response to dominant masculine ideals. However, he also appeared to want to break away from these restrictive norms. He used different strategies to explain and justify gendered support utilisation and to generate a masculine position that men do not seek out help, but women do:

> *'I think men handle stress in a different way than women do. I think women have a greater outlet for it because they have a bigger social circle of friends.'* (David).

Consequently, this allowed him to position himself as the exception and he regained strength from being vulnerable:

> *'I've spoken to other husbands and their wives have had cancer and they very much clam up, don't want to talk about it, it's a weakness. But men need to. It's having to realise it… your own vulnerability in that. And you can't hit every expectation. Not beat yourself up too much about it.'* (David).

David appeared to forgo traditional views of masculinity and by interview three had fully embraced his need for support.

However, even though the majority of the men were not accessing formal support, the interview process allowed them to 'open the valve'. The following quote captured a striking example of the power of story-telling to help someone make sense of illness:

> *'I've really enjoyed it [the interview process] and I actually think people like you are really important for the aftercare. Because obviously I've seen you, and I know at times I'm a restless sleeper, I've been a restless sleeper because of what's happening, and I felt after we chatted I got a more relaxed sleep.'* (Brian).

7.6 Scene Four – 'Repercussions'

In this final scene, the participants' stories come to a conclusion. Yet, there were no obvious endings. Their stories seemed incomplete, or 'in-process', as the men were still grappling with the long term repercussions of caring. One particular element that was deeply impacted was the spousal relationship. For Mark, Jack, David and Paul, changes brought on by their partner's diagnosis caused stress, leading to arguments, distance and moments of tension:

> *'We're arguing and we're not really speaking in the house at all, well, we're sitting in the same room, there's no conversation.'* (Paul)

Jack and David both reflected on how, as the distance between them and their partner increased, it led to feelings of apprehension and loneliness:

> *'Very distant with each other. But with each other more than we've ever been, in the full 14 years we've been together. Distant, but together all the time. So, it's just small talk, it's weird.'* (Jack).
>
> *'She wasn't able to have a conversation with anyone and I felt very lonely and isolated.'* (David).

Certain situations, personality traits, emotions and coping mechanisms appeared to contribute to relationship tensions. Anger and frustration at new role expectations caused friction. For example, Mark found Gemma to be overly controlling, which impeded his ability to cope:

> *'Gemma isn't here, so I'm doing it myself and it's tense. Then we grind off each other and it causes quite a bit of tension in the house. And when I'm tense everything is a problem for me. Something like, if the kids drop something, I go OK, but when I'm tense I'm like. why did you drop that? I'm on them and they get upset so it can cause quite a bit of friction.'* (Mark).

Dependency and independence also caused relationship problems. David struggled with his wife's dependence on him and, at times, used the interview to vent his frustrations at the way she was behaving. Yet, despite these moments of strain, he ultimately wanted to shield her from distress, so he spoke about 'lying' to his wife to make her feel better:

> *'She said to me one day "Are you coping OK?" and that was another lie, I said "I'm fine, we'll get through this". And there was one day in that three weeks and she said, "You're not coping are you?" and I said "No, I'm struggling" and she burst into tears. And I went "Oh".* (David).

I felt that a source of David's strain was his unexpressed views and emotions. He described this as 'lying', expressing a sense of conflict as he withheld the 'truth' from his wife about matters such as her appearance, her behaviour and if the treatment had been effective, which he was just as unsure about as her. As exemplified in the quote above, when he finally allowed himself to reveal a level of vulnerability, his wife became upset. He then decided that he was not going to let her see him upset again.

Second and third interviews were held one to two years after their partner's diagnosis. However, even after this amount of time, for most of the men, persistent feelings of uncertainty and/or fear of reoccurrence remained as a pressing concern. Brian and Stuart's partners both showed signs of physical improvement, but their health remained a stressor:

> *'The worry never leaves me. I'm very happy, in the sense that I've got her here. We celebrated her birthday, the hair's coming back. But the wee niggling thought in the back of my mind is that it's coming back. And until somebody actually physically tells me, and tells her, this is not coming back, you're alright, I'm still gonna have that though.'* (Brian).
>
> *'The worry is always there and I'm always aware. I'm always watching.'* (Stuart).

Feeling constantly worried and 'on call' left a strain on the men. Learning to live with these feelings and overcome the uncertainty was going to be an ongoing challenge. There were mixed reactions as to how they were going to master a life of uncertainty. A strategy used by Paul and Stuart was to express gratitude. Comparing their situation to others who were less fortunate helped them to move forward:

> '*There are a lot more people that are worse off than ourselves, I'm afraid to say. I mean, it's one of those things. It's just part of what happens. We just have to see what comes out on the other side. You've got to stay positive, got to stay strong. And see what happens.'* (Paul).

> *'And I'm just so grateful that we got through it. Worse things happen to people, much worse things. Really, the things that happen to people. We've been really, really lucky.'* (Stuart).

There was a desire to try to establish something meaningful from the uncertain. This perspective was particularly expressed in the final interviews. Aware that our time together was ending, I sensed from some of the men that they wanted to try and provide me with a satisfying ending. To do so, Brian and David looked forward:

> *'The journey's been good, long may it continue. We'll see what it takes.'* (Brian).

> *'Yes. We have a future together and we are actively planning it.'* (David).

Feeling like they *could* look or move forward was powerful. Recall that Jack described himself as being 'derailed' to describe the negative emotions associated with feeling stuck, with no motivation or incentive to move forward. For Jack, Mark and James, they never moved forward. Their interviews very much ended at a point in their lives where they were living with the distressing repercussions of caring. However, Stuart, Paul, Brian and David associated looking forward with hope. While they still had challenges to face, feeling like they were moving towards something was used to re-establish a sense of control and emotional adaption.

Chapter Conclusion

These four scenes represent a year spent caring. In essence, they reflect change, transition and self-awareness as the men were launched into a role that came with new responsibilities and expectations. Scene one explored the men's reactions to their partner's diagnosis. There were expressions of shock and fear. However, once these emotions had settled, the more profound realisation was that their 'old' life had gone. Cancer permeated every aspect of their life, changing their representations of the past and their plans for the future. Moving to the next scene, as their partner's care requirements increased, there were mixed attitudes towards whether they viewed themselves as a carer – or not. Labelling, positioning and identification was bound up with different expectations and meanings. Not everyone saw themselves as a 'carer', wishing instead to be defined by the pre-existing relationship they were in. For some, the movement between ‘partner’ and ‘carer’ roles reflected uncertainty around the preferred or appropriate use of the term. This was amplified by identification and acknowledgement of the role, or a lack of, from health professionals.

As the next scene explored, this had implications for their perceptions of need and use of support. The men prioritised their partner’s needs over theirs. At the point of our first interviews, no one was using any form of formal support. By interview three, two participants had begun to consider the benefits associated with using support. However, this realisation took time. Every participant reported negative impacts on their lives but masculine norms to protect and project a calm and strong front had a powerful influence on behaviour and their expressions of need. As the last scene captured, caring is not a static concept but something that is constantly evolving. Many months from diagnosis, the men reported feeling fearful that their partner’s cancer may return. Relationships were disrupted and there was a sense of loss for a life that had now gone. However, in situations where the cancer was treated successfully, the possibility of moving forward towards an imagined future became a powerful vessel for hope.

Through narration, these eight men made sense of their caring experiences. They used language to inform, persuade and entertain. They took me into hospital waiting rooms and oncology consultations and introduced me, through their stories, to their partner alongside other family members and friends. I sympathised with their difficulties and listened to the way the men both identified with, and resisted, oppressive and restrictive masculine norms. In essence, focusing on identity helped me to capture what happens to someone’s sense of self during a time of disruption and uncertainty. In particular, there was a sense of conflict or failure in the men when they expressed a contradiction between an ideal or expected role and their lived experience. In the next chapter I will take forward these ideas and ground them in theory and current literature.

CHAPTER EIGHT: DISCUSSION

Structure of chapter:

- *Positioning my findings*
- *Claiming and resisting identities*
- *Emotion management*
- *Negotiating power*
- *One year caring*

Overview

The overarching aim of this study was to explore the relationship between informal caring and masculinity. This aim was supported by questions seeking to understand the challenging and positive aspects of the caring role and the accounts of caring for a partner over one year. The purpose of this chapter is to discuss how the data responds to these questions and to contextualise this understanding within existing theory and literature. This includes the literature obtained in an updated search carried out in June 2020. To my knowledge, this is the first longitudinal, narrative study to explore caring for a partner with cancer from the perspective of men. The exploration of what factors shape the enactment of gender – the socially guided, perceptual and interactional activities that are expressed as masculine-gendered identity, are largely absent from the cancer carer literature. Accordingly, I will set out the unique contribution to knowledge that this study has made on male caring within the context of cancer.

In the previous chapter I presented four scenes that captured key elements from the participants' stories, including perceptions of change, feelings of burden, temporal framing, transitioning into and negotiating a new role and perceived need and use of support. In essence, my study aim was to capture how caring was articulated from a male-gendered position. Challenging life experiences can disrupt and change an individual's construction of their identity and the way in which they perceive the world. For that reason, in the first section of this chapter, I will consider how the men constructed and interpreted their male carer identity and how gendered discourses made particular subject positions available, with implications for identity and caring experiences. In tandem with this, I will discuss how the perceptions reported here converge and diverge from the current literature. However, before moving into a discussion on identity, I will first position my findings into the current knowledge base on gender and informal caring.

8.1 Positioning my Findings

Research on men in the psycho-oncology field (and indeed more broadly in psychology too) is dominated by quantitative, correlational research (Moynihan, 2002). This limits the questions that can be asked and the knowledge gained in an already small field of enquiry. A case in point is my reflection on the number of male participants in cancer carer studies over time. For example, from 1995 to 2005 there were 1,036 female participants compared to 807 male participants – almost a quarter more. While the number of male participants has increased over time, peaking in 2015 to 900, it is still consistently lower than the number of female participants. From 2015 to 2018, the overall number actually decreased to under 300 (Young et al., 2020). Focusing only on the qualitative studies from 1997 to 2018, a total of 266 men took part in interview or focus group research. Therefore, in the studies included in my review, over a period of 21 years, we have learnt about male carer experiences from less than 12 men a year.

This raises two implications for the conceptualisation of informal caring and the positioning of my findings into the academic literature. Firstly, the knowledge gained from existing literature is skewed towards female experiences. This obviously provided a rationale for this study. However, it also means that the interpretation of concepts in the literature may be limited by not including the perspectives of men. I will expand on this later in the chapter by considering how the processes by which men engage in 'emotion work' may have been disregarded.

8.1.1 Returning to the evidence gap

As noted in my literature review (chapter two), in the main, quantitative cross-sectional studies do not acknowledge how people engage in making sense of their family and caring circumstances. For example, societal norms can shape the way that men respond and adjust to their caring circumstances (Calasanti & King, 2007). Expectations to think, behave and express themselves in a certain way – in a way that is strong and invulnerable – may make men less likely to report the distress that is asked of them in carer surveys. Without insight into contextual factors such as family and household responsibilities, I am cautious of research that claims that either sex may be more severely impacted by carer stressors. There is evidence to suggest that, rather than internalising distress as sadness, men may 'externalise' it through other outlets such as aggression, overworking, criminal conduct and substance abuse (Lomas, 2013). That is, not in ways that are always measured in outcome-based studies.

For that reason, I have positioned the findings from this study into the caring literature as a way of unravelling the interrelationship between norms, behaviours and outcomes. I identified high levels of burden amongst the men in this study. In correlational studies it is assumed that the variable under influence (e.g. gender) is associated with the distress. This does not shed light on *why* gender may, or may not be, related to different expressions of distress. Furthermore, when concepts are measured, the assumption is that they are reasonably stable traits (Boynton & Greenhalgh, 2004). Theoretically, this is at odds with the idea that gender is fluid and contextually dependent.

For that reason, a range of methodological approaches are required to understand the relationship between variables such as gender and burden. However, there are processes of interpretation amongst men and women that cannot be solely 'captured' through surveys. Not all caring behaviours follow gendered norms but it is evident that informal care has a significant and potentially different health and psychosocial burden on men and women. Therefore, my route to accessing and understanding strain (and other emotions) was through a narrative interview. Through storytelling, the men in this study used language to give expression, build identities and have their experiences legitimised and endorsed. However, when a man becomes a carer there are areas of conflict between different discourses. Men's relationships with the ideals of masculinity are multifaceted and the process of aligning to, or resisting, particular 'rules' and expectations was not straightforward.

8.2 Claiming and Resisting Identities

As set out in the theoretical chapter (chapter three), embracing the plural nature of identity opened up analytic possibilities that may be missed when identity is considered to be static (Riessman, 2003). This allowed me to explore the performative nature of masculinity over time and in the context of a challenging life event. The participants' narratives cast a light on many different expressions of masculinity that were shaped by an array of factors including relationship dynamics, age and socioeconomic status. However, common to all, was their endorsement of traditional models of masculinity.

This concurs with Lopez et al. (2012) and Calasanti and King (2014), who found in their qualitative studies about men's accounts of caring that men drew on traditional models of masculinity in their caring approaches. For example, Calasanti and King's (2014) analysis revealed that the men in their study, who were caring for a partner with Alzheimer's disease, used different strategies to help them reduce the problems associated with caring. They focused on tasks, blocked emotions and self-medicated with alcohol. The authors considered that these strategies were related to their structural working class/professional positioning, as men in American society. Similarly, I found that the men in this study engaged with different strategies while performing a number of roles, including the 'macho-man', the protector, the provider, and the stoic man who shielded his pain from his family. One way to explore masculinity in this sample of men was in the way that it socialised them to adhere to the hegemonic ideal.

Stoicism, defined as a lack of emotional involvement or the exercising of emotional control and endurance (Wagstaff & Rowledge, 1995) can involve men displaying themselves as being unhurt and in control of their lives and emotions. As discussed in scene three 'Opening the Valve', the men rarely disclosed their feelings of strain to anyone and, crucially, not their partner. They spoke about 'just getting on with it', they were reluctant to cry in front of others and they blocked negative emotions such as worry and fear in order to project a calm and resilient front. The stoic approach has also been captured in the wider male carer literature (Greenwood & Smith, 2014; Girgis et al. 2017). Within the context of older male carers caring for a spouse with a range of health conditions, Milligan and Morbey (2016) noted, in their qualitative study, that the men were reluctant, or refused, to seek help. Their need to take control and provide for their wives meant that seeking support was perceived as a failure. Adhering to a stoic ideology had negative repercussions, with the men trying to cope and adjust to their caring circumstances without any support, while feeling pressured to act and feel in a particular way. It may therefore be reasonable to assume that those who endorse stoic attitudes and behaviours may be at greater risk of experiencing negative outcomes. Yet, there is debate as to whether adhering to a trait such as stoicism is problematic. McAteer and Gillanders (2018) found, after surveying male cancer patients (note, not carers), that endorsement of a stoic ideology was *not* correlated with higher levels of psychological distress. With the caveat that these were patients not carers, in line with other masculine values, stoicism may be drawn upon in *both* adaptive and maladaptive ways. This is interesting as, in fact, the adaptive aspect of stoicism aligns itself more accurately with the philosophical tenets of the Stoics, who emphasised *accepting* one's life situation, even when faced with challenges (Inwood, 2005). I will return to this point later in the chapter when I consider that adhering to masculine norms within the context of caring can have a positive and protective function.

Another and somewhat related component of the hegemonic ideal is the avoidance of femininity (Connell, 1995). Mark, for example, in the most extreme case, spoke about (before his wife's diagnosis) being allowed to be 'a man'. He aligned to a worker/provider identity and rejected tasks such as cooking, cleaning and looking after their children as they were all his wife's responsibilities. In contrast, Stuart and Paul embraced their domestic responsibilities and did not appear to be phased by taking greater responsibility for tasks such as cleaning and cooking. Yet, like all of the men, they positioned themselves away from feminine traits such as being sensitive and emotionally expressive. For example, Stuart disliked the idea of expressing his views in a cancer support group, making a joke that support groups were just for people with addictions, such as an AA meeting. However, he then admitted that he found listening to other people's experiences reassuring, as he and his wife were facing similar issues. By positioning this supportive activity as a means of obtaining information rather than as help-seeking, he was able to cast the experience in a positive light. Unlike the men in Milligan and Morbey's (2016) study, Stuart did not indicate that he felt he had failed in his role as a husband by accessing support. This may have been because he and his wife attended the group together. Therefore, he was not prioritising his own needs as they were jointly learning about the illness and managing the stressors together.

The sociological understanding of gender as an accomplishment or enactment (West & Zimmerman, 1987) can be applied here as I propose that the men in this study 'do' gender when they 'do' care. To explain, they approached caring as more than an act required due to illness – it was a role to be mastered with the intensity of a full-time job. The attainment of mastery is related to masculine preoccupations with control and autonomy and perhaps amplified in this context after transitioning into a role that is typically feminine. This was particularly relevant to Paul, who had left his job to care for his partner. After losing his status as the main provider, he directly positioned himself into 'full-time caring' (to use his words) to validate his contribution, fill the void created through being out of work, and to emphasise the intensity of the caring role. By highlighting their varied and challenging responsibilities, such as administering medical care, monitoring the side effects of chemotherapy, and taking on crucial household tasks, such as meal preparation, all of the men positioned themselves as being *essential* to their partner's care. This generated feelings of purpose and allowed them to feel in control against the backdrop of change and uncertainty. This illustrates one (of several) coping strategies used to manage the demands of the role.

This aligns with research which reports that men take a more task-based, rather than emotional, approach to caring than women (Geiger et al., 2015). Mark emphasised sex differences in his relationship by suggesting that women are emotional and men are practical. He claimed, in relation to himself (and men in general) that 'very few men will approach it emotionally'. It has been theorised that this allows men to feel a sense of competence and reflect efforts to reframe the role in more masculine terms (Spendelow et al., 2018). Ussher and Sandoval (2008), after interviewing 13 carers of someone with cancer (seven women and six men), found that male carers primarily gave accounts of 'caring as a competency task', which had positive consequences in terms of their self-mastery. However, Ussher and Sandoval (2008) suggested that this was only adaptive in the short term, as perceiving the role as a job to be mastered created pressure.

I noted a similar issue. Jack, for example, reported feeling like he was never 'doing enough' to care for his partner. In turn, his positioning into the carer role was tied to how much care he was providing. He explained to me that he only thought of himself as a carer when he was carrying out a number of different supportive tasks, such as taking his partner to hospital and preparing her meals. When he started to provide less care his identification with the role was disrupted. Therefore, approaching this as a role that should be done 'correctly' or in a certain way, created an extra layer of challenge. Stuart also told me how he turned to his sister (who had previously had cancer) for advice and she said there were times when he 'wasn't getting it right'. Consequently, by setting these standards around the right or wrong ways to care, there were times when the men expressed that they could not master the role, leading to feelings of frustration and inferiority.

However, when responsibilities diminished due to involvement from other family members or because their partner's health was improving, this produced feelings of helplessness. A loss of structure or grounding, even if triggered by a seemingly positive experience such as their partner's health improving, can cause distress. This is a significant point as it pushes against the assumption that progress (from the partner's perspective) will be associated with a positive gain for the carer. It also contradicts survey research that links a decrease in male carer burden, over time, to an improvement in the care receiver's health (Cairo-Notari et al., 2016).

There is an established literature base which recognises that patients and carers cope and adjust to illness together. Dyadic coping models propose that spousal couples take joint responsibility for managing stressors caused by illness (Acquati & Kayser, 2019). The men in this study, and their partners, shared a number of stressors and negotiated them together, such as employment, medical care and balancing domestic responsibilities. However, in the scenario just described, it is important to consider the difficulties that may arise within the dyad when stressors are perceived differently. A gain for the care receiver may be a loss for the carer. However, as I discuss next, positioning towards and against these different expressions of masculinity seemed to help the men regain a state of balance as they grappled with different pressures and emotions over time.

8.2.1 To protect and provide

A reoccurring thread across the men's narratives was their eagerness to protect their partner. In general, the protector 'cultural script' involves men in heterosexual relationships taking a more central and protective role than women (Glick & Fiske., 2001). This role can often, as I found in this study, align with conventional gender roles that cast men as breadwinners and providers. Collectively, these roles have gained dominance through perceptions and values embodied in hegemonic masculinity regarding male strength, status seeking and competence (Connell, 1995). Yet, also, from the reality of the division of work and care in families. While numbers are increasing, on average only one in four women earn more than their male partner (ONS, 2018). Notably, the five men in this study who were in employment were all the main financial provider. These cultural scripts provided the lens through which the men and their partners adjusted to their caring circumstances.

The men actively positioned themselves into the protector role as they adjusted to their new caring circumstances. The spousal relationship is obviously a key context for establishing such a dynamic but there was a sense that, in order to cope with the threat to their partner's life, this role was brought into greater focus. The men wanted to feel that they had an essential role – particularly within the context of a disease such as cancer, which left them feeling fearful and unsettled due to its unpredictable trajectory. The positioning into this role may have been fuelled by existential threat rather than the discursive need to be the breadwinner and/or the 'strong' one in the relationship.

Bury (1982), writing about 'biographical disruption', suggested that people may re-evaluate their lives following illness. To counter the threat, the men tried to establish meaning and purpose in other ways. Of course, they could not actually protect their partner from cancer or from the range of negative side effects that were impacting upon their lives. So, to protect meant to take control and to shield their partners from as many difficulties as they could. This 'shielding' was expressed in a range of ways. David spoke about lying to his wife in order to protect her from his views on such things as her appearance (due to her hair loss) and his concerns over whether her treatment had been effective. Similarly, Jack did not disclose all of his frustrations to his partner about their level of sexual intimacy for fear that it would upset her and also because he did not want to be seen to be prioritising his own needs over hers. Brian was angry that his wife had been diagnosed with cancer, as it meant yet another setback for them in a life where they had had to work hard for everything. In response, he claimed he would 'kill anyone that got in her way and caused her pain'. His protector positioning allowed him to channel his anger towards something and by using violence he was taking action against the cancer within a framework of hegemonic masculinity that reveres strength and aggression.

8.2.3 The male mask

Analytically, the relationship between the participants' *expectations* of men's behaviour in society, and their *expressed* behaviours, was insightful. They drew from cultural norms that dictated how they should respond – both emotionally and behaviourally – as they cared for their partner. It was common among the men for them to talk about their wish to protect their partners from their *own* distress. This has been reported elsewhere (Oldertroen et al. 2019). By concealing their emotions, they were fulfilling expected norms that position men as being stoical and invulnerable. Nevertheless, my impression was that it was an expression of love and support. This is worth emphasising as concepts such as love and nurturing can be disregarded in studies on male caring – but there is evidence that men do combine traditional masculinity with nurturance (Russell, 2001). In turn, aware that they were acting to prioritise their partner's wellbeing before their own bolstered feelings of courage and autonomy. The essence of this was captured by Stuart, when he remarked that he was 'strong enough not to let anyone see he was cracking'.

This aligns to Goffman's (1959) dramaturgical metaphor involving two elements – a 'front' and concealment. Stuart's front to his wife and children was that he was 'strong'. In presenting this image he was able to reframe his vulnerability as a strength – thereby also casting himself in a positive light in the interview setting. This is a coping strategy reported in previous research with men caring for someone with cancer (Lethborg et al., 2003). Similar to the discussion on stoicism, this may be adaptive in the short term, as it reinforces the idea of being a man who is competently engaging in mastery and coping. However, managing impressions and presenting particular 'fronts' can generate a sense of fragmentation when it is perceived as a concealment of their 'true' emotions. Living up to masculine ideals resulted in contradictory experiences of strength, autonomy, worry and inadequacy. By protecting their partner from their own distress they had to hold onto the burden themselves. Non-disclosure and the failure to divulge distress to others is recognised to be more common in men than women (Charteris-Black & Seale, 2013; Felsten, 1998). As discussed in chapter seven (scene three), hardly any of the men, to begin with, accessed any form of formal support, so there was no outlet for their distress. This raises major implications for male carer wellbeing.

8.3 Emotion Management

Emotion work theory is underpinned by feminist theory as it shines a light on the often underappreciated and hidden elements of work (in the public and private sphere) which are usually done by women (Hochschild, 1985). Therefore, interpreting emotion management within the context of male caring is novel. It encourages reflection on the hidden elements of 'work' associated with the role. For instance, Russell (2001) noted in a qualitative study on men's experiences of caring for a spouse with dementia that their effectiveness as carers was usually judged on their performance of tasks, rather than their emotional investment.

Within this study, the men spoke about concealing their emotions. They were not, even though this was the private sphere, 'offered freely'. Consequently, maintaining their protector role required a degree of emotional labour. Importantly, this was not that the men had difficulty in expressing their emotions, as some scholars have suggested is characteristic of male carers (Li et al., 2013). Rather, this was a conscious controlling and suppression of emotions to particular people and within particular contexts. While caring occurs within the private sphere, not the public one, the discourses that circulate in carer and masculinity spheres place demands on the individual, like an organisation may do. In particular, the expectations and norms that are ingrained within traditional masculine identities evoked particular performances from these men and set demands for behaviour. By paying greater attention to the emotion work involved in male caring, it highlights the efforts required by these men to try and be a particular version of a man – all while maintaining an emotional and mental focus towards their partner.

Unsurprisingly, this was difficult. Jack explained that it was hard to project a positive front when he was so worried:

> *'I know she needs me to be sane and, more than ever, she needs me to be confident and positive, and all that. And this is the one time that I just don't feel like it.'*

This illustrates Hochschild's 'suppression of feeling'. This was common amongst the men and linked with David's comments about having a 'private tear', Brian's remarks about driving to the shops to cry so his wife would not see him, Mark hiding his pain with anger and Stuart stating that he did not want his wife to see that he was struggling. Emotional work was required to make their partner feel supported and to *appear* calm and in control, rather than seeming to be exhausted, scared and anxious. Therefore, the emotional work was used to affirm masculine ideals that the men believed were part of their partner's (and perhaps society's) needs and expectations. Drawing across Goffman and Hochschild's theoretical models provides an alternative lens to understand how the men managed their emotions in order to present an expected version of their masculinity. Moreover, it disrupts the assumption that emotional work is mainly done by women.

At the crux of this discussion is the idea of a 'real' versus a performed self (hence reference to the 'male mask') and the difficulty of having to constantly bridge these two roles. These difficulties were expressed as helplessness, shame and guilt when the men described letting the mask slip. The role of guilt has been reported as a factor contributing to quality of life in male carers of someone with cancer (Yeung, 2017; Duggleby et al., 2014 & 2015). In these quantitative studies, guilt was measured within a survey and categorised as a predictor variable for quality of life, with higher levels of guilt associated with lower quality of life. While Duggleby's most recent (2015) study had a free text component to the survey, it is not clear why or in what context the men may have expressed guilt. Therefore, to improve knowledge about emotions such as guilt and the relationship to wellbeing, then narrative research such as this, which shines a light on the contextual underpinnings of *why* carers may feel guilty, is valuable.

Taking this idea forward, Hochschild (1985) suggests that performed emotional displays are inauthentic. The implication is that the 'real' (authentic) self is the ideal, so distress and negative emotions stem from the repression and the acting. This feeds into the previously covered discussion in the theoretical chapter on the way that social norms can create pressures by setting 'rules' about the expected way to think and act. However, it is important to acknowledge the complexities and nuances when interpreting gender norms and to be mindful of the fact that what may feel oppressive and restrictive to one person may not for another. Thus, it is important to consider individual motivations. For instance, Brian reflected in our final interview:

> *'I don't know if I'll ever get off this path. I don't think I want to come off it… I think I want to stay on it as the protector.'*

Brian had found meaning in his ability to protect his wife. He was still worried and fearful, but in moments of chaos being calm, measured and practically-oriented had benefits. This blurs the division between real and performed selves – not everyone may find acting in accordance with expectations and norms an insincere performance or a violation of their 'true' self. This is perhaps because realigning the emotional internal self in masculine terms (as the protector) may create a sense of authenticity.

8.3.1 Emotional disentangling

Whether publicly or privately, individuals draw on the production of different emotions to meet social and cultural demands and to evoke a particular response from others (Goffman, 1959). However, over time, David became more aware that he did not have to 'hit every expectation', a sentiment that was also shared by Stuart. By our third interview they saw benefit in accessing support. For David, this ability to 'open the valve' allowed him to stop performing a role that was hard to sustain. The reflexive practice of 'disentangling the true self from the false self' (Giddens, 1991:79) was key. For those who could, like David and Stuart, gaining a greater degree of self-awareness came with benefits. They seemed less burdened, more accepting of their limitations (emotionally and practically) and generally seemed more hopeful for their future. I do not believe I would have captured this 'disentangling' if I had interviewed them only once, drawing attention to the benefit of capturing caring experiences over time. The constant negotiation between their different selves in combination with the existential nature of cancer was demanding. Therefore, the ability to be more open seemed cathartic. In line with other research, it seems that there are advantages to men who challenge and resist hegemonic norms in their lives (MacDonald, 2011; Way et al., 2014).

The men in this study had shared and distinctive views and relationships to masculine norms. What counted as 'hegemonic' was reproduced, resisted and then reworked as they went about their lives and adapted to their new caring circumstances with both negative and positive consequences. It has been considered that adhering to particular masculine ideas may provide a sense of belonging and a sense of satisfaction by living up to and embodying expected standards (Addis & Mahalik, 2003). Lomas (2013) has coined the idea of 'critical positive masculinity' to recognise the potential for masculinity to include positive elements but not to lose sight of the fact that there are problematic dimensions. The next and penultimate section of this chapter takes these ideas forward by considering the role of power within male caring. Hegemonic masculinity is part of a theoretical framework developed to analyse men's power over women and other men. However, power is relational and negotiated in different ways within the carer/care receiver relationship.

8.4 Negotiating Power

The care receivers were (at times) positioned as being more vulnerable than the men. For instance, when I asked Stuart why he felt he had to conceal his emotions from his wife, he said it was because of how dependent she was on him. David spoke about 'not leaving his wife's side' because she needed him and Paul described his caring role as though it was like 'looking after a baby'. Through their knowledge of this situation and by drawing attention to their partner's dependency, the men, by positioning themselves as not being ill and reliant, created the mechanisms for experiencing and exercising power. Referring back to the discussion on power (chapter three) and Foucault's (1980) views on power/knowledge, this fits with the view that power is omnipresent – produced through actions and relations between people. It brings into focus the idea that individuals can exercise power by drawing upon discourses which frame their actions within an 'acceptable' light. For example, the carer discourse acted as a frame of reference for the dynamic described above. Otherwise, it may have seemed a little strange to describe a marriage as like 'caring for a baby'. Yet, discourses embed assumptions and expectations about what is appropriate, typical and/or 'normal'. That is not to say that this power/vulnerability dynamic was negative or domineering but it recognises the way that power is a discursive relation that flows and is negotiated rather than being fixed.

However, in terms of discursive power, it is not always the case that the person who occupies the position of power *feels* powerful. The men certainly made no reference to such a claim. Indeed, it has been suggested that, particularly in the family domain, men can feel powerless (Adams & Coltrane, 2005). This draws on the ideology of separate work and family spheres, with the former being occupied by men and the latter by women. If these ideologies are sustained, men may find it difficult to bring together their positions as fathers and husbands, as the underpinnings of family functioning include 'feminine' qualities such as affection, care and emotional involvement (Thomson & Walker, 1989). Mark, who had power and status in his world of work, struggled with his new domestic responsibilities. However, his situation was actually rather complex as his difficulties were amplified when his wife appeared to retain power through her insistence that the domestic tasks had to be done in a particular way. This could be interpreted as her resistance to the 'vulnerability' of the patient discourse. Consequently, at many points during our interviews, Mark expressed his frustration at feeling like nothing he was doing was 'good enough'. He swore, he shouted at his daughter, and told me how he had started arguments with strangers. In their situation the power flowed between him and his partner and when he was under threat he responded with displays of anger and aggression.

A further example of fluctuating power was when David told me about an occasion where he had admitted to his wife that he was not coping. While he had hoped this would help him to unburden a little, his wife actually became upset, causing him more distress. She perhaps needed or expected him to be strong and stoical. Subsequently, through demonstrating her vulnerability, she exercised power by dictating her preference for how she wanted the caring dynamic to function. In summary, across the sample, power was contested, negotiated and enacted during their personal encounters – it was not something imposed by a man towards a more vulnerable woman. There were various different power dynamics at play which impacted on the men's positioning towards and against different roles with consequences for their behaviours and emotions.

8.4.1 Providing status

Occupying power through the protector role, meant, as discussed, that the men reported feeling useful and valued. This should be acknowledged in understanding why men may position themselves into such roles and highlights a positive part of caring. This aligns with the observations of Spendelow et al. (2018), derived from their systematic review on coping and adjustment in male carers, that coping strategies driven by traditional masculinities may have positive value. That is because aligning their carer role to a protector role may have helped to reduce any discomfort that the men in this study may have experienced from being positioned into the lower status of a carer role.

Returning to the idea that some domains can make people feel more, or less, powerful, the caring domain can be particularly difficult to negotiate as carer discourses position carers as having low visibility, recognition and value (Larkin & Milne, 2014). Carers only became established as a prominent group in 1996 with the implementation of the Carers Act. As caring is largely a hidden activity that occurs in the home, scholars and organisations who campaign for carers' rights have termed carers 'invisible', in the sense that they are not recognised or appreciated for their vast and essential contribution to society (Larkin & Milne, 2014). While there has been considerable progress over the last 20 years (politically and academically) in terms of understanding carer experiences and providing support for carers that does not necessarily translate to an individual's perception of their status within society.

Jack, for example, recalled when he walked out of the consultation room as he felt ignored and underappreciated by the medical professionals. He stated, 'they forget about you, they are focused on the patient'. This interaction exemplified how conversational practices, such as medical consultations, can provide or exclude people with rights, duties and entitlements. Therefore, without any interaction or acknowledgement he reported that he felt invisible. This was not a shared view across all of the men. In fact, in the main, they all seemed relatively satisfied with the level of attention they received from the health professionals. Notably, the two older men in the study, when I asked about their interactions with health professionals, were quick and keen to clarify that they would not fault the NHS. Nevertheless, Jack's articulation of his experience was not unusual.

Research has reported that communication between healthcare professionals and carers can be sparse and lack compassion (Waldropp et al., 2012). Carers, like Jack, have reported feeling unwelcome, ignored and dissatisfied with the level of information provided on topics like side effects (Mazanec et al., 2018; Lund et al., 2015). Indeed, Lund et al. (2015) found through a survey distributed to 590 cancer carers that younger carers (aged 18-49) noted the most problems with healthcare professionals. Jack was the youngest participant in this study and spoke about his age several times during our interviews. In his words he expressed that the medical professions just thought he was some 'daft boyfriend'. The adequacy of communication in cancer consultations can impact on outcomes such as satisfaction, self-efficacy, frustration and isolation (Gilbert et al., 2012). The wider implications of this are discussed in the next chapter.

Individuals negotiate positions for themselves to establish a balance of equality and power (Johnson-Bailey, 2003). For the men in this study, labelling, positioning and identification with new and different roles and identities was bound up with different expectations and meanings. Stuart, Mark, and to some extent Paul and Jack, all rejected the carer label in favour of prioritising their spousal/partner role – a preference that has been captured in studies with male carers (Hilton et al., 2000; Robinson et al., 2014). Caring is fundamentally a nurturing activity. Therefore, by reframing care as 'protection', and through internalising their distress to remain positive for their partner, this may have helped to maintain a sense of 'being male' and as a result increased their 'masculine capital' (Spendelow et al., 2018; Gough, 2003).

There are parallels between the notion of masculine capital and Bourdieu's (1985) ideas about social capital (raised in chapter three). Social capital refers to the resources – such as shared values, trust and norms – that are obtained from interactions between individuals or networks of individuals. In social behaviour, individuals (men) may accrue or lose symbolic social capital. This is because 'capital' is an important source of authority and power (De Visser et al., 2009). The caring role creates opportunities to both accumulate and lose 'capital'. Bringing this discussion back to my previous point, there was a sense of failure when they could not maintain these roles. Therefore, helping men to utilise traditional masculine traits in an adaptive rather than restrictive way might provide a useful basis for gender-sensitive carer support.

8.5 One Year Caring

Each participant told their caring stories over one year and time brings change. To my knowledge, there is only one published qualitative longitudinal study on male caring within the context of cancer. I do acknowledge there is a literature base on patient/carer experiences (as in dyad studies) over time but this is still a small field of scholarship in comparison to correlational studies that focus on one time point.

Turning to the longitudinal carer study – Lopez et al. (2012) interviewed 15 male spouses/partners of women with breast or gynaecological cancer four times over one year and analysed their data using content analysis. Each interview point coincided with time from diagnosis, with the first being within 0 to 3 months and the last interview at 12 months. The authors' focus was on physical and psychological burden and they did not interpret their findings within a specified theoretical framework. This was a UK-based study and the participants had a similar age range and ethnicity to the men in this study. A notable difference was almost half of the men in the study by Lopez et al. (2012) had been to college or had a degree, which differed from my sample. The men expressed similar challenges – tiredness, burden associated with extra housework, feeling unprepared, fear of the unknown and finding it difficult to confide in others for support. In terms of the construction and management of their carer role, Lopez et al. (2012) reported that at three months after diagnosis the men reported that they wanted to protect their partner, instil positivity and enhance their partner's coping – all of which I also evidenced in this study.

However, there were two main differences in our findings. Lopez et al. (2012) stated that, at the six month interview, the men described that things had 'settled', they said they had a routine and life was returning to 'normal'. The authors linked this change to the physical health of their spouse being 'less prominent'. In contrast, I found that an improvement in the care receiver's health was not always associated with a gain for the carer. For the men in this study there was a sense of *never* returning to 'normal'. They longed to return but struggled with the realisation that their 'old' life had gone, with no return. The second point of divergence in our interpretation was the suggestion by Lopez et al. (2012) that, even though carers have problems, they focus on protecting and being positive, which they proposed was an effective form of coping as opposed to avoidance or being disengaged and helpless. This aligns to the idea that some behaviours driven by traditional masculinities may have positive value.

However, the interpretations of Lopez et al. (2012) do not consider the participants' motivations, their 'backstage' thoughts, or why this may be a positive coping strategy. All qualitative research involves interpretation but it can vary in depth and level of abstraction. A holistic analytical approach keeps the perceptions of the individual together, as opposed to using content analysis which fragments data to extract themes and categories. My focus on gender as a socially constructed phenomenon allowed me to explore how alignment to normative expectations within masculinity influenced the men's positioning into the protector role. Consequently, I do not think the view that wanting to protect and instil positivity, as an expression of coping, gives enough consideration to the underlying processes that motivated the men to act in that way, or to the idea that people may stage performances of desirable selves for effect. Nevertheless, different approaches will produce different interpretations. Their acknowledgement that the concerns of male carers may be mediated by *different* factors to those of females is valuable. Furthermore, the study contributes to a much-needed exploration into understanding male carer experiences over time.

Nevertheless, improvement is just one way of understanding change. While carrying out the analysis I was sensitive to the many possible types of change and how and why these changes may have occurred. Over one year the men described positive and negative changes to their daily routines, their relationship dynamics and their outlook, many of which I would not have known about if this had been a single interview study. One of the biggest strengths in investigating this topic over time was capturing the complexity of caring experiences. Three interviews, as opposed to one, gave me insight into fluctuating emotions, altered perspectives, new responsibilities and, ultimately, the way that life and their caring roles remained closely entwined as they moved through the year – even though some of the men did not feel that they were actively caring anymore.

8.5.1 Generating momentum

Illness is an interruption which requires a process of reconfiguration (Bury, 1982). As presented in chapter seven, this process was related to a combination of factors. These included perceived control over their situation, practical pressures (e.g. work and finances) and the men's efforts in trying to adjust to a spectrum of change – from working a different shift pattern at work, to witnessing their partner's hair fall out, to not being able to have a sexual relationship anymore. Over time I heard about how the men were forced to confront their unsettling and difficult present. Illness had stopped them from being able to look forward, so they had to find alternative ways of creating momentum.

The metaphorical idea that life is a journey is a key line of thought in cancer discourses (Harrington, 2012). The words used by the men to capture their sense of movement included 'path', 'going through', 'finding the direction', 'crawling on my hands and knees' 'marathon', 'derailed', 'finding my way' ,'sailing on' and 'moving on'. The journey metaphor can allow an individual to travel along their own 'path' and embrace the idea of moving in different directions (Harringdon, 2012). This metaphor was powerful as it kept the men moving towards a destination – which can bring meaning and emotional comfort (Kirmayer, 1992). This seemed particularly beneficial when routines were characterised by the repetitive nature of chemotherapy cycles and hospital appointments. However, in some instances the journey was arduous and physically demanding, like a 'marathon'. Also, after being 'derailed' (Jack's phrasing), it was harder for some of the men to start their journey again. This was the case for Jack, who ended up separating from his girlfriend, and the two men who became bereaved.

Journey metaphors have been linked to the idea of self-transformation (Metzner, 1980). Seale (2002) found, in an analysis of international newspaper reports on people with cancer, that the journey metaphor was emphasised in reports of women with breast cancer, whose skills in emotional labour were highlighted, in contrast to men who were portrayed as less able to work on, or change, their feelings. With the acknowledgement that Seale (2002) focused on people with cancer and not carers, I believe the role of emotional labour in male carers has been disregarded or conceptualised as emotional inexpressiveness. I identified that the men in this study were in a state of conflict as they tried to mute their feelings to align with particular expectations embedded in masculine discourses. In contrast to what was noted in Seale's (2002) study, every man in this study, to varying degrees, expressed views about psychological change and/or transformation. These included changed priorities, such as being less motivated by work and money, altered perspectives, such as seeing strength in their character rather than weakness, a greater appreciation for their partner, feeling an increased bond, feeling fortunate in comparison to those with less resources, new levels of gratitude and deciding to 'give back' in terms of providing time and money to cancer charities. Together, these amount to a considerable degree of change and transformation.

Yet, Seale (2002) only found occasional themes in newspaper stories about men which were related to the experience of transformation. The wider message contained in the media about men was that 'while cancer is a setback, if you have the right character you can get through it and regain the normal life you had previously' (Seale, 2002:116). This message feeds into wider discourses about 'appropriate' masculine ways to act and feel in the face of illness. What is striking is the restrictive idea of having the 'right' character to cope with an existential threat. Moreover, returning to 'normal' is not possible for a majority of people. Therefore, cultural discourses within the context of illness provide a framework for the masculine route through carer experiences. These frameworks provide opportunities but also inhibit change, movement and growth.

Chapter Conclusion

In this chapter I have identified my contribution to knowledge. In summary, I have presented three unique findings. Firstly, by focusing on the performative nature of masculinity, I considered how the men endorsed traditional forms of masculinity through roles and behaviours such as hiding their distress, being their partner's protector and taking a task-based approach to care. This created feelings of purpose and competence but also frustration and pressure.

Secondly, the men's desire to protect can be viewed as an alignment to traditional masculine discourses which, in turn, provide a sense of belonging, satisfaction and the opportunity to gain masculine 'capital'. However, this desire was fuelled by an existential threat to their partner's life, not just by the discursive need to be the 'strong' male. Behind the protector 'front' were 'backstage' feelings of fear, worry and guilt. Emotional work was required to make the care receivers feel supported and to enable the men to *appear* calm and in control, rather than seeming to be exhausted, scared and anxious. This is significant because, as there is a lack of qualitative research on male caring within the context of cancer, there are evidence gaps in terms of understanding the motivations and perceptions surrounding masculine performances. Drawing across Goffman and Hochschild's theoretical models provided an alternative lens to understand how the men managed their emotions in order to present an expected version of their masculinity. Moreover, it disrupts the assumption that emotional work is mainly done by women.

Finally, caring is not a static concept but something that is constantly evolving. Therefore, longitudinal interviewing provided insight into fluctuating emotions, altered perspectives, changed relationship dynamics, new responsibilities and the way that life and the caring role remained closely entwined – even though some of the men did not feel that they were actively caring anymore. In the next and final chapter of this thesis I will consider the implications from this study for future policy, research and practice.

CHAPTER NINE: CONCLUSION

Structure of Chapter:

- *Study strengths*
- *Future directions*
- *Limitations*
- *Thesis conclusion*

Overview

This study provides an original and significant contribution to the evidence base on male caring. Research focusing on the specific accounts of men who care for someone with cancer is limited. Within the psycho-oncology literature, gender has largely been conceptualised as a variable that impacts on outcomes such as depression and anxiety. By approaching gender as a socially constructed phenomenon, I have contributed new evidence that brings into focus why a gendered lens is crucial for understanding caring experiences. In this final chapter I will expand on the strengths of this study and make interrelated recommendations for policy, research and practice. Specifically, I suggest that this work is used to spark further thinking on carer identification and engagement, particularly with groups of people, like men, who are underrepresented in carer research samples. This will encourage a change from thinking about carers as being one homogeneous group to recognising the diversity of that group. This chapter concludes with study limitations and final remarks on the thesis as a whole.

9.1 Study strengths

Using a multi-layered, holistic and bespoke form of narrative analysis was a major strength to this study. By combining a structural and a performative approach to my analysis, I was able to carry out a multidimensional examination of male carer experiences. This depth of insight produced findings on both perceptions and emotions alongside a consideration of the context, including sociocultural norms, interview dynamics and the social and clinical circumstances of the participants. Caring is an act, an experience and an identity. However, crucially, the men in this study transitioned into caring within the context of an existing relationship. They had preconceived ideas and expectations about what caring entailed and they had established particular roles and responsibilities within their individual relationships. For that reason, inviting someone to ‘tell their story’ provided them with the opportunity to fuse illness and carer experiences into their personal life and circumstances. This was valuable to the participants as it legitimised their experiences. It provided a platform for a largely invisible group to articulate their thoughts and feelings and it conceptualises caring as more than something that can be measured in isolated component parts, such as through ‘burden’ or quality of life.

Subsequently, this depth of exploration extended current thinking and set this study apart from other qualitative studies on male caring (Lopez et al. 2012). As presented in the literature review, the challenges associated with caring are well documented. As other researchers have done (Oldertroen et al. 2019; Gilbert et al. 2014) I identified difficulties relating to carrying out new tasks without adequate training, financial stress due to giving up work, and feeling isolated, anxious and under strain when trying to ‘put on a front’ and remain calm and positive while coping with the strain of watching a loved one’s health deteriorate. I also corroborated previous research (Calastani & King, 2007; Fitch & Allard, 2007) on identified positives, such as feeling a sense of purpose and a closer bond to the care receiver.

However, most studies do not detail the evolution of caring. This is a major gap in understanding as there are a number of factors (clinically and personally) that can impact on an individual’s caring role and the way that their experiences are expressed through narratives. Without the longitudinal design I would not have captured the unravelling of relationships, the way that, over time, David and Stuart shifted their views on accessing support, changed views on the ‘carer’ label and, sadly, the fact that Mark and James both became bereaved before our final interviews. Complementing this, by writing my findings into scenes I emphasised the performative nature of storytelling and engaged the reader by bringing them with me along the temporal journey of caring.

By applying a range of theoretical frameworks, stemming from disciplines such as psychology, sociolinguistics and sociology, I was able to make sense of and generate novel interpretations into the views, meanings, perceptions, actions and enactments that I identified in the men's narratives. On a number of occasions I have also drawn on seminal theory stemming from the patient perspective (Frank, 1995; Bury, 1982) to demonstrate the applicability of the illness experience to carers. Theorisation is a crucial part of enabling qualitative research findings to be transferred to different contexts (Meyer & Ward, 2014). Yet, in the qualitative papers I reviewed on male caring, there were only fleeting references to theoretical frameworks (with the exception of Milligan and Morbey, 2016 and Gilbert et al., 2014). However, I have presented theoretically-informed conclusions that can act as the foundation for understanding male caring within different contexts.

Related to this, it is common for men's accounts of their experiences to be interpreted *only* under frameworks of hegemonic masculinity, which can mask the subtleties and nuances in men's experiences. Scholars have recognised that it is far more complex than men just aligning to, or resisting, hegemonic norms. Instead it should be conceptualised as a negotiation (Gilbert et al., 2014). Another strength of this study is that this research suggests that, for male carers, this 'negotiation' may evoke feelings of fragmentation and conflict, particularly over the manipulation of emotions. This provides a new depth of understanding as to why men in caring roles may report feelings of strain.

9.2 Implications for policy, research and practice

9.2.1 Implications for policy

Recent guidelines (NICE, 2020) recognise that previous carer strategies have failed to provide the mechanisms for improving levels of support for carers. As such, there is a substantial literature base on carer burden and unmet needs, particularly in relation to receiving information, skills training and communication with healthcare professionals (Coumoundouros et al., 2019; Lambert et al., 2012). The two main challenges are carers *recognising* themselves as carers and being *identified* as a carer by health and social care professionals. Therefore, in a promising step forward, these new guidelines (NICE, 2020) shift responsibility for identifying individuals in a caring role to health and social care professionals. In summary, the guidelines state that professionals should be involved in identification because people may not identify as a carer, they may have too many demands on their time to access support, or it may take time for someone to consider themselves as a carer.

Therefore, the rationale behind these guidelines chimes with my own findings. There are also a series of recommendations covering areas such as assessing carers' needs, helping carers to remain in employment, providing carers with psychological support and providing interventions that focus on skills training, such as managing medication – all of which I have touched upon and would promote for the men involved in this study. However, while these guidelines, and also wider policy responses to carers (Department for Health 2018; Scottish Government, 2018), have emphasised crucial elements of the experience such as support and workplace modifications, the issue remains that the expectation to provide unpaid care falls onto family members, without question.

This raises issues relating to carer value, status and visibility. In Germany, for example, individuals are given the choice to use state services or take money to fund a family member to care (Wegner, 2001). System reform is clearly beyond the scope of this PhD but in order to take steps to help improve carer visibility and status, particularly amongst underrepresented groups of carers such as men, more work needs to be done around carer identification and engagement. Furthermore, within these NICE guidelines (and most policy documents), carers are largely conceptualised as a homogenous group. I acknowledge the need to have guidelines that can be applied across carer populations and settings. However, a 'one size fits all' approach does not reflect multiple identities and within-group diversity. As such, the risk is that these recommendations (and future guidelines) will fail or will only be applicable to certain pockets of the carer population. As discussed, there would great benefit in assessing carers' needs and providing support in a *gender-sensitive* way.

9.2.2 Implications for research

To that end, research is required to understand the views and expectations of the professionals who are responsible for identifying carers and how this 'identification' takes place. The NICE (2020) guidelines state that they are intended for professionals working across primary care, hospital services, voluntary services, social care and the emergency services. Therefore, there will be vast differences amongst the settings and professions in terms of opportunities to engage with carers and their expectations on how they may incorporate this into their practice (if they have not already). Considering the cancer setting, I captured mixed views on how valued or visible the men in this study felt to the oncologists treating their partners, the most extreme was an example where a participant (Jack) described being completely ignored by a doctor during an outpatient consultation he was attending with his girlfriend.

How medical professionals interact, communicate and involve carers and patients in conversations is of critical importance. To date, especially in the field of cancer care, the focus of research around carers has tended to focus on the burden and experience of caring, with communication an under researched area. It is known that communication with healthcare professionals is a concern for carers and communication has important implications for carers' status, identity and wellbeing (Gilbert et al., 2010). Therefore, the lack of evidence here potentially hampers understanding on why carers face barriers to being identified and then accessing support.

Returning to the need to look beyond the idea of carers and men being homogenous groups, the performance of gender in different contexts requires attention. Future research should seek to understand how different components of advantage and disadvantage may impact upon carer reports. I encourage researchers to explore male carer experiences from other positions, including gay men, caring amongst friends and non-spousal family relationships, men from black, Asian and minority ethnic groups, and men of a range of ages. The experiences of older men who care has received some scholarly attention (Milligan & Morbey, 2016) but young men's carer experiences are largely neglected. Alternative methods of researching accounts that draw on creative and digital data collection methods should be considered in order to increase access and engagement amongst different groups of men (Jestico et al., 2015; Hammond, 2018).

I also propose that research is conducted to focus solely on male carer experiences amongst people who are socioeconomically disadvantaged. There are higher incidences of cancer in deprived areas – 20,000 extra cancer cases each year (Cancer Research UK, 2020). Moreover, in these areas, people are not only more likely to be diagnosed with cancer but they are also more likely to be diagnosed at a later stage and therefore die from the disease (Tweed et al., 2018). Delayed diagnosis compounded by COVID-19, will also drive increases in the number of cases (Helsper et al., 2020). Consequently, there are potentially more people in deprived contexts who will transition a caring role and in complex clinical circumstances. Yet, it is not the norm for research samples to be socioeconomically diverse. Evidence suggests that, historically, people who are socially disadvantaged and those from black, Asian and minority ethnic groups are underrepresented in cancer research (Giuliano et al., 2000). However, experiencing issues such as unemployment, low income levels and poorer health will make caring particularly difficult. Research is therefore required in terms of identifying strategies to increase the diversity of carers who take part in research and to understand the experiences and challenges of men from disadvantaged groups.

9.2.3 Implications for practice

There is evidence (Scottish Government, 2019) that men are less likely to claim Carers Allowance and are more likely to think of themselves within the spousal relationship rather than as a 'carer' (Judd et al. 2019). In tandem with this, there is evidence on the risk of loneliness and isolation in carers (Gray et al., 2020). Carers can lose contact with friends, social groups and family members due to the pressures of the role and their desire not to leave the person they are caring for in case something were to happen. There is also an emotional loneliness stemming from the perception that they do not have anyone to talk to and that no one can relate to what they are going through; both issues were addressed in my findings. Considering these issues together (loneliness and carer identification) raises particular implications. The majority of the participants in this study did not identify with the term carer and no one referred to a precise or defining moment when they they had transitioned into or acquired the role. Therefore, in terms of carer identification, men may need extra encouragement that they are in a carer role and that even though what they are doing for their partner is done within an intimate relationship, they are altering their behaviour and taking on new responsibilities to provide this care. In other words, identification is only one part of the process – this should be followed with a discussion on expectations around what a carer role may entail. As the professional identifying the carer may not be the best person to have this discussion (in terms of appropriateness, skill level and time to have the discussion), the role of integrated services across sectors will be important (Snowden et al., 2020).

In addition, when professionals identify carers they should discuss with them that the term 'carer' is universally used but it may not embody how that person perceives their role. This is a point that has been discussed in the literature, with Molyneaux et al. (2011) considering that a more accessible term may increase uptake of support services. However, not everyone in this study dismissed the term. One participant (Paul) happily referred to himself as a 'carer' in our first interview, as this positioning appeared to increase his self-esteem and provide purpose as he had given up his job to care. However, by our second interview, he was less sure, stating that he did not know if he liked the term. This contradicts evidence that it can take time to transition *into* the carer role as over time (four months) Paul actually transitioned *out* of the role. However, this was associated with his partner's recovery and growing involvement from other family members – a situation that could very well be experienced by others. Paul also spoke about caring being like looking after a baby. I considered that, more than his carer positioning, this fulfilled his need to feel valued and useful, particularly as his partner's health had started to improve so that he was providing less care. Evidence from this study points to the fact that men may respond differently to taking up and being positioned into the carer role. They may use the role to generate esteem or they may reject it on the grounds that it does not describe their relationship. Accordingly, identification is bound up with different expectations and meanings related to carer labelling and positioning. This has implications for professionals involved in carer identification and for the services that aim to support male carers.

Returning to Molyneaux et al. (2011), referral or signposting someone to support is only one part of the process. If the individual does not identify with the term, or dislikes the connotations associated with the term, they are not likely to access a carer-supportive service (Carduff et al., 2014). On top of this, the men in this study did not feel that they had time to access support and were reluctant to prioritise their needs before their partners', the latter issue being amplified when their needs were sexual. Once more, this highlights why carers may be particularly prone to feelings of isolation and loneliness. As such, none of the men, to begin with, accessed any form of formal support. Yet, the men were distressed, so it should not be assumed that there is a relationship between someone feeling distressed and their likelihood of taking actions to reduce the distress, particularly amongst men. Distress can come in many guises so 'lower' levels of distress in male carers (in comparison to female carers, Ussher et al., 2008) does not mean that their concerns or needs feel less severe to them.

A solution may be in improving ways to reach out to men who are caring to encourage their use of support. In the context of mental health, 'male sensitive' materials that encourage men to access counselling have had success, improving attitudes and reducing levels of self-stigma (Hammer & Vogel, 2010). Cancer charities, such as Macmillan Cancer Support and Maggie's, may wish to consider male-tailored approaches such as this that could be issued by health professionals during cancer consultations where the carer is present. Of course, research to determine what 'male-sensitive' entails would be required first. To explore this in practice, I contacted the lead psychologist in Scotland from Maggie's and asked if she had a sense of why men access support from them. While this is purely anecdotal, her perception was that it was practical 'hooks' that got the men through the door such as advice with finances or employment (Howells, 2020 personal communication). There is a growing literature base on what male carers of women with cancer may want from supportive interventions (for example, Bamgboje-Ayodele & Levesque, 2020). This is valuable but it should run alongside research investigating motivations and barriers to accessing the support in the first place.

A wider and final point relevant to policy, research and practice is attitudes towards men. By concealing their emotions from their partners the men in this study were fulfilling expected norms that position men as being stoical and invulnerable. This was challenging for the men as they had to manage two different masks. These difficulties were expressed as helplessness, shame and guilt when they had let the 'mask' slip. However, their actions were largely motivated by love and the desire to protect in the face of a life-threatening illness. What is more, owning status through the protector role meant that some men felt useful and valued, which acted as a buffer against the negative consequences of caring. My aim with this research was to magnify the voices of a group of people whose caring stories are not always told or heard. Therefore, these findings should be used as the catalyst for positioning men and understanding their perceptions if policy makers, researchers and practitioners wish to close the male 'empathy gap' (Farrell et al., 2016).

9. 3 Study Limitations

Limitations of the study design are acknowledged. In terms of the sample, I prioritised recruiting spousal carers because it is documented that they usually provide the most intense level of care with a subsequently detrimental impact on their wellbeing (Jeong et al. 2020; Macmillan Cancer Support, 2016). However, in terms of transferability and representation of the study findings, different relationships will have particular dynamics, with consequences for how the role is experienced. The wish to protect and provide is unlikely to feature in male sons' or male friends' accounts of caring. Other factors such as proximity to the care receiver (co-habiting or not) and if the person has other caring responsibilities (such as children and/or elderly parents) will shape perceptions and behaviours. I did not recruit any men who were in same-sex relationships, from an ethnic minority group, or with a disability (to my knowledge). In part, this reflects the fact that 98% of Scottish residents identify as White and only 0.5% of co-habiting couples in the UK are same-sex (ONS, 2018).

This brings into focus the concept of intersectionality (Valentine, 2007; Gough, 2018). Within my findings I referred to the men's age, their work and their social class. Yet, I did not use intersectionality as an analytical framework. That is because my main focus was on the application of discourse to understand the enactment and performance of gendered identity. However, aligning with the principles of intersectionality, and therefore the wider tenets of social constructionism, I was guided by the view that categories such as masculinity are plural and shaped by social context. Therefore, while I did not directly apply an intersectionality framework, my exploration and interpretation of the data was shaped by the need to explore masculinity beyond the influence of dominant discourses such as hegemonic masculinity.

There were limitations to the recruitment strategy that will have impacted on who volunteered to participate. Related to my point about the demography of the sample, there was no effort to target men from non-dominant groups (in terms of sexuality and ethnicity). While I never set out to explore the perception of experiences of caring amongst diverse groups, if researchers do not consider ways to seek out the voices of those who may not respond to the more obvious forms of recruitment, then the cycle of their underrepresentation will continue. However, as recruitment was challenging I used a number of different recruitment strategies, including snowballing, social media, a letter to the participant's partner and a poster in my place of work in order to reach a wider pool of potential participants. These different strategies will have reached different groups of people. For instance, snowballing has the potential to reach 'hidden' carers who may not engage with information posted online by the cancer charities. This is also an important issue to consider in relation to the point that some people do not relate to or dislike the term carer. If I was to conduct this study again I would use more 'neutral' sites for recruitment. For example, placing a newspaper advert or advertising in social spaces (such as church groups, bowling clubs and community centres). That is, places and spaces with no connection to cancer. Nevertheless, the men in this study spanned a broad age range, they had a range of professional backgrounds (sales, trade, hospitality or retired) and their partners had a range of cancer types. This opens up the possibility of considering how the findings from this study have wider transferability to different carer samples.

Access to research participants can require working with gatekeepers (Clark, 2011). I was fortunate that I had access to a community cancer service which sent out recruitment letters on my behalf (to the care receiver) and two cancer charities which posted information on their social media pages. However, one element of 'gatekeeping' that I had not considered was from the female partners of the men. The recruitment letter was the slowest method of recruitment – it took me one year to recruit four men. On one occasion, I received a returned copy of my recruitment letter from one of the female partners and she had written across it that her husband would not talk to her and therefore he would not talk to me. Receiving that letter made me reflect if there had been other instances where my request for participation never actually made it into the hands of the man. I will never know, but recognise that an indirect recruitment method like that has its limitations.

A requirement for inclusion in this study was a willingness to be interviewed. However, a limitation to using an interview to capture someone's account of an experience is that potential participants may find the thought of discussing an emotive topic, such as caring, intimidating. As raised in the section on recruitment challenges (chapter 5.3.1), emotions play a significant role in the discussion of illness. Some men may be reluctant to talk about their caring experiences and so did not volunteer to take part. I also found that during the interviews that some of the men wanted me to clarify if what they had shared was 'OK' or relevant. These men consented to take part and (all but one) returned for three interviews, so I am reassured that they were just seeking some clarity in an unfamiliar situation. However, it is important to recognise that these emotions may deter people from even getting to an interview, which prompted me to think about the possibility of using digital/creative methods when researching accounts of experience.

9.4 Final reflections

The COVID-19 pandemic has shone a light on a number of inequalities in society. The latest report produced by Carers UK (October 2020) highlights that carers have been affected considerably during the pandemic due to financial pressures, poor mental health, the needs of the care receiver increasing and restrictions or closures to public services. There are now on average 4.5 million *new* carers in the UK and probably many more who have not self-identified as a carer (Carer's Trust, 2020). Therefore, the recommendations and implications have become even more relevant as governments, public health agencies and third sector organisations across the UK develop policies and interventions to mitigate the direct and indirect harms of COVID-19.

Concluding this thesis marks the culmination of five years part-time study and seven years working as a researcher investigating the experiences of people affected by cancer. I have learnt a great deal in this time and remain passionate about continuing to engage in research that improves the lives of those with diverse needs. To that end, while finishing this thesis, I was offered a new job as a social researcher within The Scottish Government. I will be working in the COVID-19 analytical division and so these recommendations have taken on a new meaning. It will be within my remit to document public attitudes and behaviours towards government regulations and to understand how the pandemic has affected wellbeing amongst different sub-groups (including men and women) within the population. This is quite a step away from the world of cancer research and so I have reflected on one matter that I believe resonates beyond the boundaries of this study.

As raised, there is a risk in referring to 'men' as one homogenous group. Similarly, I have challenged the use of 'carer' as a homogenous category. The term 'carer' appears gender neutral but it used, in the main, to refer to women's experiences. Therefore, when considering implications such as the need to engage with and identify carers (whether male or female) the ethos should be that every ‘group’ contains a broad array of diversity with numerous connections between characteristics such as gender, race, age, sociodemographic status and so on. This was study about *men’s* perceptions, within the context of illness. Of course the illness was the reason why these particular men had stories that I wanted to capture but any study that prioritises subjective experiences should not lose sight of the contextual richness and life histories behind those experiences.

The challenges faced by the men in this study were numerous but not routinely discussed outside of the interview. I have shone a light on the way that male carers perform and reflect on their negotiation with masculine discourses while supporting their partner. My findings illustrate that ‘caring’ is so much more than the practice of looking after someone. The shift from being a partner to being someone who provides care due to illness is bound up with particular values, assumptions and expectations. Some men embraced the role and some rejected it - a telling indication that there are complex processes involved in positioning oneself, or being positioned, as a carer.

Globally, caring is positioned as a feminine practice. In tandem with this, researchers who are interested in emotionally complex topics may not always prioritise men’s experiences. Therefore, this research acts to disrupt such assumptions and close the gap between the number of men who care and their representation within research literature.

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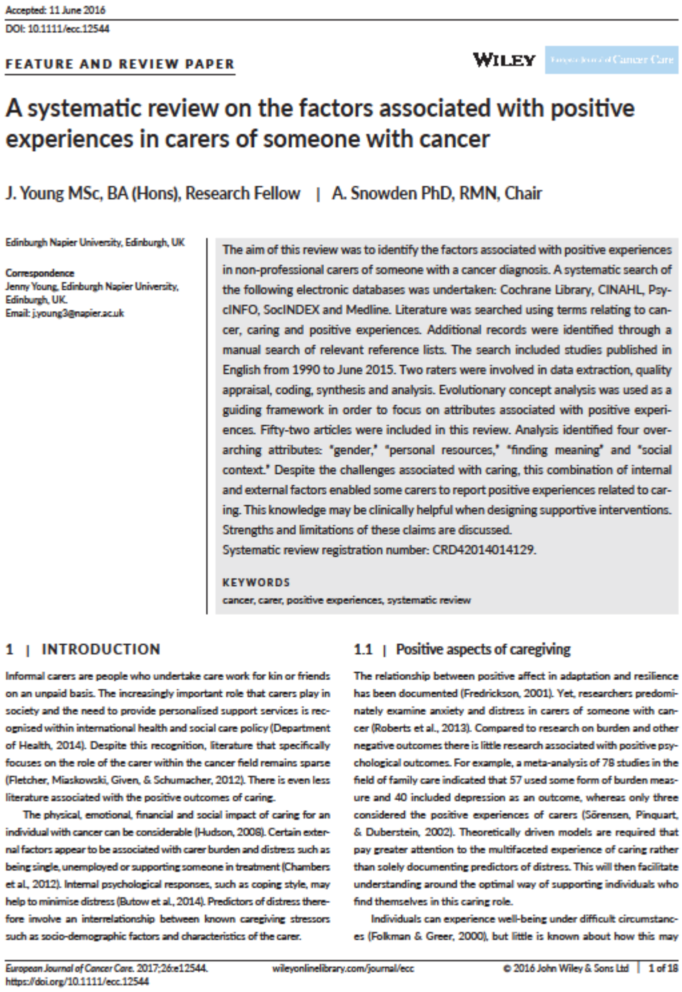
Appendices

Appendix 1: Systematic review on positive caring experiences



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FEATURE AND REVIEW PAPER

A systematic review on the factors associated with positive experiences in carers of someone with cancer

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The aim of this review was to identify the factors associated with positive experiences in non-professional carers of someone with a cancer diagnosis. A systematic search of the following electronic databases was undertaken: Cochrane Library, CINAHL, PsycINFO, SocINDEX and Medline. Literature was searched using terms relating to cancer, caring and positive experiences. Additional records were identified through a manual search of relevant reference lists. The search included studies published in English from 1990 to June 2015. Two raters were involved in data extraction, quality appraisal, coding, synthesis and analysis. Evolutionary concept analysis was used as a guiding framework in order to focus on attributes associated with positive experiences. Fifty-two articles were included in this review. Analysis identified four overarching attributes: "gender," "personal resources," "finding meaning" and "social context." Despite the challenges associated with caring, this combination of internal and external factors enabled some carers to report positive experiences related to caring. This knowledge may be clinically helpful when designing supportive interventions. Strengths and limitations of these claims are discussed.
Systematic review registration number: CRD42014014129.

KEYWORDS
cancer, carer, positive experiences, systematic review

1 | INTRODUCTION

Informal carers are people who undertake care work for kin or friends on an unpaid basis. The increasingly important role that carers play in society and the need to provide personalised support services is recognised within international health and social care policy (Department of Health, 2014). Despite this recognition, literature that specifically focuses on the role of the carer within the cancer field remains sparse (Fletcher, Miaskowski, Given, & Schumacher, 2012). There is even less literature associated with the positive outcomes of caring.

The physical, emotional, financial and social impact of caring for an individual with cancer can be considerable (Hudson, 2008). Certain external factors appear to be associated with carer burden and distress such as being single, unemployed or supporting someone in treatment (Chambers et al., 2012). Internal psychological responses, such as coping style, may help to minimise distress (Butow et al., 2014). Predictors of distress therefore involve an interrelationship between known caregiving stressors such as socio-demographic factors and characteristics of the carer.

1.1 | Positive aspects of caregiving

The relationship between positive affect in adaptation and resilience has been documented (Fredrickson, 2001). Yet, researchers predominately examine anxiety and distress in carers of someone with cancer (Roberts et al., 2013). Compared to research on burden and other negative outcomes there is little research associated with positive psychological outcomes. For example, a meta-analysis of 78 studies in the field of family care indicated that 57 used some form of burden measure and 40 included depression as an outcome, whereas only three considered the positive experiences of carers (Sörensen, Pinquart, & Duberstein, 2002). Theoretically driven models are required that pay greater attention to the multifaceted experience of caring rather than solely documenting predictors of distress. This will then facilitate understanding around the optimal way of supporting individuals who find themselves in this caring role.

Individuals can experience well-being under difficult circumstances (Folkman & Greer, 2000), but little is known about how this may

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Appendix 2- Propp's 31 Functions

1. Absentation: Someone goes missing
2. Interdiction: Hero is warned
3. Violation of interdiction
4. Reconnaissance: Villain seeks something
5. Delivery: The villain gains information
6. Trickery: Villain attempts to deceive victim
7. Complicity: Unwitting helping of the enemy
8. Villainy and lack: The need is identified
9. Mediation: Hero discovers the lack
10. Counteraction: Hero chooses positive action
11. Departure: Hero leave on mission
12. Testing: Hero is challenged to prove heroic qualities
13. Reaction: Hero responds to test
14. Acquisition: Hero gains magical item
15. Guidance: Hero reaches destination
16. Struggle: Hero and villain do battle
17. Branding: Hero is branded
18. Victory: Villain is defeated
19. Resolution: Initial misfortune or lack is resolved
20. Return: Hero sets out for home
21. Pursuit: Hero is chased
22. Rescue: pursuit ends
23. Arrival: Hero arrives unrecognized
24. Claim: False hero makes unfounded claims
25. Task: Difficult task proposed to the hero
26. Solution: Task is resolved
27. Recognition: Hero is recognised
28. Exposure: False hero is exposed
29. Transfiguration: Hero is given a new appearance
30. Punishment: Villain is punished
31. Wedding: Hero marries and ascends the throne

Appendix 3 – Constructing Stories

Example taken from interview with Angus

Stage 1 - read transcript

Yes because in the back of your mind you're aware of the situation but grateful for the advances in research and treatment and even in the approach that they take doing the biopsies and scans and the marking. When they do the operation they go to the exact spot whereas it used to be a bit gung ho in a way [laughs]

Interviewer - and have things changed in your day to day life, well I assume they have things like hospital appointments and things?

Yes that's all consuming and quite tiring sometimes you feel as though you have gone through the radiotherapy it's so tiring.

Interviewer- absolutely

It's good to be there though. And these days you've got the Maggie's centre they are amazingly supportive we would have a coffee and a chat with people there.

Interviewer - and how did you find that?

Very supportive I would say this time I felt much more supported both of us. It's such a difference from so long ago. Because most people haven't had an experience of cancer they are bewildered and in a state of shock. Initially you have no idea how serious it is.

Stage 2 - Note taking to develop the story

Transcript	**Margin notes**	**Structure and content**
Yes because in the back of your mind you're aware of the situation but grateful for the advances in research and treatment and even in the approach that they take doing the biopsies and scans and the marking. When they do the operation they go to the exact spot whereas it	Gratitude 'Advances' – important as he is able to make a comparison. Sees a positive Using humour to lighten the tone	Plot- a present shaped by the past Link to the past gives me the 'bigger picture' He used evaluations (shock, tiring, bewildered) but embeds them in

used to be a bit gung ho in a way [laughs]		statements of positivity- link male/carer expectations.
Researcher - and have things changed in your day to day life, well I assume they have things like hospital appointments and things?	Attempt from me to get him to talk more freely about his day/routines.	'Most people' – identity claims (i.e. he's not most people)
Yes that's all consuming and quite tiring sometimes you feel as though you have gone through the radiotherapy, it's so tiring.	'You' – such a big impact on him he felt as though he was going through it too. Although not 'I'- level of detachment. 'Quite' tiring to 'so' tiring - is he holding back? Reluctance in carer to talk about their strain.	
Interviewer - absolutely	Demonstrating understanding/sympathy	
It's good to be there though. And these days you've got the Maggie's centre they are amazingly supportive we would have a coffee and a chat with people there.	OR and EV –it's good to be here (also links with his gratitude) 'These days'- comparison again	
Interviewer - and how did you find that?		
Very supportive I would say this time I felt much more supported both of us. It's such a difference from so long ago. Because most people haven't had an experience of cancer they are bewildered and in a state of shock. Initially you have no idea how serious it is.	OR – 'this time' Benefit of hindsight EV- bewildered/state of shock	

Appendix 4- Ethic Approval

Edinburgh Napier University
School of Nursing, Midwifery and Social Care
Research Integrity Committee
9 Sighthill Court
Edinburgh
EH11 4BN

7 February 2017

Dear Jenny

Project Title: Exploring male identity and the experience of caring for a partner with a cancer diagnosis
Project start date: 1/1/17
Project reference: *FHLSS/1729* ***Version no****. 2*

Further to your application for Ethical approval to undertake a research study at Edinburgh Napier University, I am pleased to inform you that the committee have approved your application and we wish you all the best with your study.

May I remind you of the need to apply to the Research Integrity Committee prior to making any amendments to this study or of any changes to the duration of the project and provide notification of study completion. All documents related to the research should be maintained throughout the life of the project, and kept up to date at all times.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

Yours sincerely,

[redacted]

Dr. Barbara Neades
Chair

Appendix 5- Participant Information Sheet

Title of study: ‘Exploring male identity and the experience of caring for a partner with a cancer diagnosis’

What is this study about?

The aim of this research is to understand what it is like to be a man and support a partner/spouse who has a cancer diagnosis.

Who can take part?

You have been contacted because you are male, over 18 years old, speak English and support a partner/spouse with a cancer diagnosis.

What is involved if I take part?

You do not have to take part but if you would like to you will be interviewed by a researcher. This will take place on a day, at a time and in a location that is convenient for you. The researcher wishes to gather stories from all the participants in this study about what it is like to care for a wife/partner with a cancer diagnosis.

You will be asked to tell your story providing any details that you think are relevant. You will be interviewed 3 times over one year. An interview will last for about 45 minutes but this is flexible. We understand that this is a big commitment so we will contact you before each interview to see if you would still like to take part. Your contact details will be securely stored on a password protected computer within the university. They will only be used to contact you to arrange the interviews.

The interviews will be audio-recorded so the researcher can listen to them again and make a typed transcript of what was discussed. After each interview the researcher will email you a summary of what was discussed in the last interview. This will allow you to check if you feel it is an accurate summary of what we discussed. You can provide comments if you would like to.

What are the potential benefits of taking part?

There may be no direct personal benefit to you in taking part in this study. However, sharing your thoughts and experiences in a safe and confidential environment can be a positive experience. Also, your participation will help us learn more about males who care for a partner. There is not a lot of research in this area so this study will allow us to develop understanding that may be useful for thinking about the best ways to support males who care for someone with cancer.

What happens if I don't want to carry on with the study?

If you decide to take part in the study but later change your mind you can withdraw at any point. You do not have to give a reason for withdrawing. Any audio-recordings will be deleted and any transcripts destroyed.

What if there is a problem?

The research team is not aware of any risks associated with this project. However, as we are discussing a sensitive subject you may feel upset. After each interview we can take some time to see how you feel and the researcher will provide contact details for information and support if you feel you need them.

What happens to the audio-recordings?

The recordings will be transferred onto a password-protected computer in a locked office in the university. Only the named researcher (Jenny) can access this. After the recordings are transferred onto the computer they will be immediately deleted from the dictaphone (the equipment that was used to make the audio-recording). The researcher will listen to the audio-recordings in order to produce typed transcripts of what was discussed in each interview. Only the researcher and the researcher's supervisor will have access to these. The data will be stored securely until the researcher has completed their PhD. After this all data will be deleted.

Will anyone know who I am or what I have said?

All data will be anonymised. The results may be published in a journal or at a conference but we will not use your name. The name of your partner, any other people or identifiable information such as place names will be replaced.

Ethical approval

The study has been given a favourable opinion by Edinburgh Napier University ethics committee.

What do I do next?

If you wish to take part please return the slip in the provided stamped addressed envelope with your contact details. The researcher will then contact you to arrange the interview. Or you can phone the researcher on the telephone number provided (0131 4552943).

Do you have any further questions?

If so, please contact:

Ms Jenny Young	Professor Austyn Snowden
PhD Student	Supervisor for this research
Edinburgh Napier University	Edinburgh Napier University
School Health and Social Care	School Health and Social Care
EH11 4DE	EH11 4DE
[redacted]	[redacted]
[redacted]	[redacted]

If you have any questions/comments and wish to speak to someone who knows about this study but is not directly involved please contact:

Dr. Barbara Neades, Edinburgh Napier University

T: [redacted]

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now return the reply slip.

Appendix 6- Welcome Letter

Researcher contact details:

Jenny Young, PhD Student

Edinburgh Napier University

Emai[redacted]

Telephone: [redacted]

Hello,

My name is Jenny Young. I am a PhD student from Edinburgh Napier University. As part of my studies I am carrying out a piece of research. I am writing to you to ask if you would be willing to pass this letter to your husband/partner. My study is called ‘Exploring male identity and the experience of caring for a partner with a cancer diagnosis’. You have been contacted because either you or your partner (or both of you) have used the service ‘Improving the Cancer Journey’.

If you do not have a male partner please accept my apologies and you can throw this letter away.

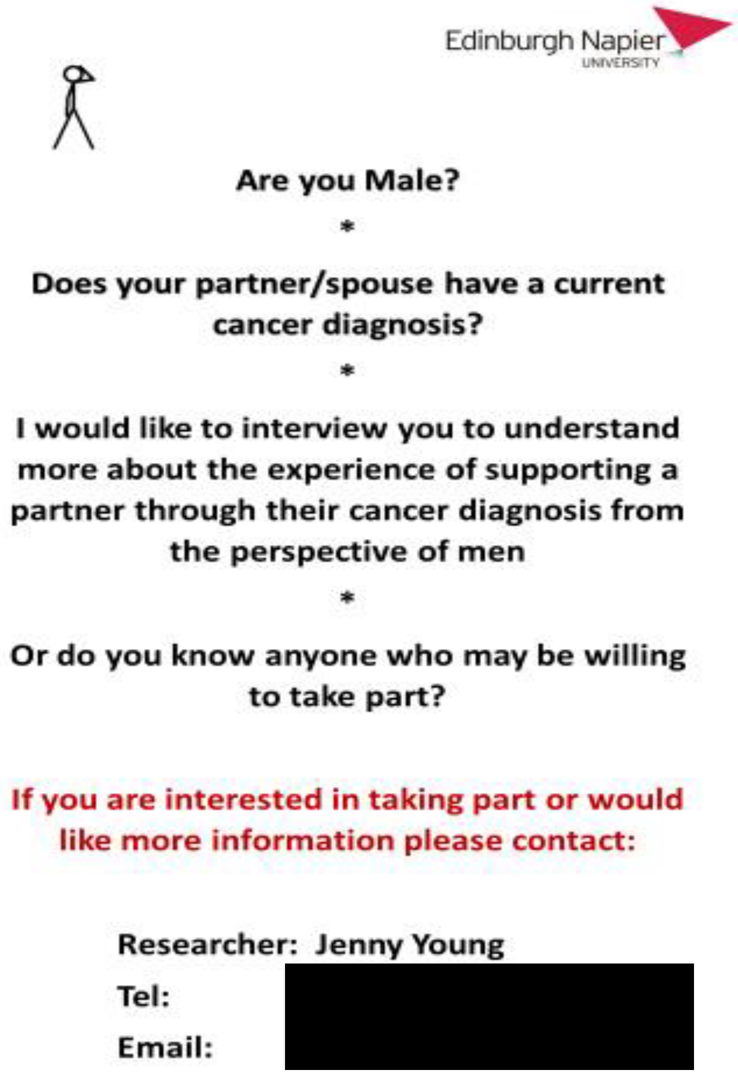
Please see the information sheet for further information. If your partner would like to take part he can complete the reply slip and send it back to me in the stamped addressed envelope or give me a phone.

Please contact me (Jenny Young) if either of you need any further details or have any questions.

Best wishes,

Jenny Young, PhD Student

Appendix 7- Recruitment poster


Edinburgh Napier UNIVERSITY

Are you Male?

*

Does your partner/spouse have a current cancer diagnosis?

*

I would like to interview you to understand more about the experience of supporting a partner through their cancer diagnosis from the perspective of men

*

Or do you know anyone who may be willing to take part?

If you are interested in taking part or would like more information please contact:

Researcher: Jenny Young
Tel:
Email: [redacted]

Appendix 8 – Consent Form

Edinburgh Napier University Research Consent Form

Exploring male identity and the experience of caring for a partner with a cancer diagnosis

Edinburgh Napier University requires that all persons who participate in research studies give their written consent to do so. Please read the following and sign it if you agree with what it says.

Please initial this box if you agree

1. I freely and voluntarily consent to be a participant in the research project on the topic of caring for a partner with a cancer diagnosis to be conducted by Jenny Young, who is a postgraduate student and staff member at Edinburgh Napier University. ☐
2. The broad goal of this research study is to explore your caring experiences. Specifically, I have been asked to take part in 3 interviews, which should take no longer than 3 hours (over one year) to complete. ☐
3. I have been told that my responses will be anonymised. My name will not be linked with the research materials, and I will not be identified or identifiable in any report subsequently produced by the researcher. ☐
4. I also understand that if at any time during the interview I feel unable or unwilling to continue, I am free to leave. That is, my participation in this study is completely voluntary, and I may withdraw from it without negative consequences. However, after data has been anonymised or after publication of results it will not be possible for my data to be removed as it would be untraceable at this point. ☐
5. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
6. I have been given the opportunity to ask questions regarding the interview and my questions have been answered to my satisfaction. ☐
7. I have read and understand the above and consent to participate in this study. My signature is not a waiver of any legal rights. ☐

Furthermore, I understand that I will be able to keep a copy of the informed consent form for my records.

Participant's Signature Date

I have explained and defined in detail the research procedure in which the respondent has consented to participate. Furthermore, I will retain one copy of the informed consent form for my records.

Researcher's Signature Date

Appendix 9- Field notes

Participant 5 – Jack (Interview 1)

Pre- interview first impressions

Jack's girlfriend saw my tweet through Cancer Support Scotland (think about how messages reach people –good and 'bad' gatekeeping). We spoke on the phone to arrange the interview and he sounded quite young- I was surprised. He was chatty and had a strong local accent. We arranged to meet at the Beatson café. I told him what colour hair I had and what colour coat I would be wearing - felt a bit awkward doing that…. (why awkward- feels like a date?! Formal/informal boundaries). He was well dressed and seemed relaxed. We took the lift up to the 4th floor and as we were waiting for someone to let us into the office we were just making small talk – I started thinking please don't tell me everything now! I guess a worry about getting the 'best' data but no need to worry I could have just asked him to 'tell me more' if I had wanted him to discuss anything again.

We made our way into the office – it felt really strange to be in Dr X's office. Far too formal. It seems too clinical. I was also thinking about my positioning as a researcher not a clinician. I want to be a listening ear, someone who he wants to share his story with not someone who medically treats. However, I'm thinking about the fact I was able to access this private office for an interview - does that give me credibility/authority? Wonder if this setting has changed his perspective. He seemed relaxed though and easily began chatting.

Interview

This was the first time in this study I interviewed someone younger than me (by about 3 years) – I enjoyed the ease at which our conversation flowed and I sensed as he spoke about his age (on a number of occasions) we had a shared understanding. 'Funny situation to be in at this age' – our age? I kept saying things like 'yes it must have been hard' am I trying too hard to want to make him feel better/ to convey sympathy? Read back the interview and consider moments where I need to let his words just sit and see where he takes the conversation.

He mentions trying meditation and watching ‘positivity’ videos – I’m surprised – note that I had begun to form an impression of him and this disrupted that.

Feel such a pang of sadness when he said he realised that life would never be the same again. This is major. Come back to the process of the realisation – what was the catalyst?

Emotions – guilt, frustration, helplessness. Come back to these in next interview.

Tasks – driving gf to hospital, cooking (healthy smoothies!) – do these change?

Work – given up to care (self-employed though) so has flexibility not too big a financial impact or at least he doesn’t say that?

Positioning

I thought about my age and researcher positioning more in this interview than the others. When I’m normally in The Beatson I’m a researcher but in terms of authority and status I feel secondary to the oncologists. Today I had my researcher ‘hat’ on again but I did not want to have medical status as I was worried he would treat it as a consultation rather than an interview. Perhaps we were both outsiders to the medics and the patients. At the end of the interview when we were walking out he asked me what I had studied at university and it turns out I was at the same university, doing the same course as his girlfriend (she was a year lower though). I am now thinking about how that will impact on his positioning of me. I think it gives the experience for him a more human element to it, perhaps it will help with rapport and trust and talking about sensitive issues.

Appendix 10- Scene titles

Example taken from interview two (November 2018) with Jack:

Scene 1 - Doesn't get any easier

Scene 2 - Post treatment abandonment

Scene 3 - Losing carer identity

Scene 4 - Derailed

Scene 5 - Lack of sex (first hints)

Scene 6 - Physical burden

Scene 7 - Loneliness

Scene 8 - Side effects

Scene 9 - Lack motivation

Scene 10 - Fear of reoccurrence

Scene 11 - It's just life

Scene 12 - Masculinity expectations

Scene 13 - Being the statistic

Scene 14 - The crash that follows