City Research Online

City, University of London Institutional Repository

Citation: Apat, A. (2024). Young Adults Experience of Parental Cancer: An Interpretative Phenomenological Analysis. (Unpublished Doctoral thesis, City, University of London)

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: https://openaccess.city.ac.uk/id/eprint/33752/

Link to published version:

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online: http://openaccess.city.ac.uk/ publications@city.ac.uk

Life-threatening illness in a family: young adults experience of parental cancer

Aslihan Apat

City, University of London

Department of Psychology

2024

Portfolio for Professional Doctorate
in Counselling Psychology (DPsych)

“Dedicated to my mother, who I lost from cancer”

Table of contents

Appendices

Part C – Case study: Improving an ill patients' quality of life and Family Relationships: Working within a pluralistic framework……………………………………………………260

List of tables and figures

Introduction

Methodology

Analysis

Acknowledgments

I would firstly like to thank myself, for being who I am today and never giving up despite all the difficulties I have experienced through the process of my doctorate. It was a journey that took place at a time of my life that was full of pain and loss. I therefore want to acknowledge my strength and appreciate the women who I have grown in to.

I would like to thank my family who offered emotional support unconditionally during the whole journey of me becoming a counselling psychologist.

My mother was the person who inspired me to perform this project. She was not able to see it to the end, but I felt her support and strength within my heart throughout the process. If it was not for her encouragement and motivation from the onset of my education life, it would not have been possible to complete this piece of work or my professional doctorate. My mother loved studying and wanted me to continue with my studies until I made it as a practicing psychologist. She is who has made me who I am today with all that she has added to me with her presence and absence.

I would also like to thank my Dear husband for always being supportive and being patient. Thank you for being flexible and tailoring yourself around my needs and studies. It would not have been possible to start or complete this course without your understanding and caring presence.

I would like to thank my Dear supervisor Dr Julianna Challenor for her support and guidance. Her genuine curiosity and caring attitude made me feel at ease and increased my confidence in pursuing with my write up each time I felt overwhelmed. I also would like to thank my former supervisor Dr Trudi Edgington for her supportive and welcoming presence at the earlier phases of my research.

Lastly, I would also like to thank the participants as without them offering to share their experiences in depth, this project could not have been completed.

Declaration

I hereby declare that the work presented in this portfolio is my own. It has been developed under the supervision of Dr Julianna Challenor. Apart from her assistance any other assistance or inspiration drawn from elsewhere has been referenced appropriately within the portfolio.

I grant powers of discretion to the City, University of London Librarian allowing the copy of parts or the whole portfolio without reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

Preface

This project is part of the completion of the Professional Doctorate in Counselling Psychology as delivered by City, University of London. This doctoral portfolio consists of three individual pieces of work which reflects my training to become a Counselling Psychologist. This chapter includes details about the different sections of the portfolio, and then provides an insight into how they were developed and the connections between these sections. The preface will end with a reflection of my personal experience of putting this portfolio together and how it has contributed to my development as a Counselling Psychologist.

1. Sections of The Portfolio

Section 1: The first section of the portfolio presents the research study. The research aims to explore Young Adults experience of Parental Cancer.

This research employed a qualitative approach, and Interpretative phenomenological analysis was used to analyse the data. The aim of the research was to unravel the lived experience of young adults who experienced having a parent with cancer in the last 5 years. Unfortunately, although many individuals diagnosed with cancer have children that are adults, research on this population was minimal, and there were only a few qualitative studies. Vast majority of the studies were based on minor children and quantified measures. As a result, the richness of this subjective experience was not explored. Therefore, in studying the experience of young adults who have a parent with cancer, the aim is to capture their experience as expressed by them. And, to reveal gaps in the literature and enhance our understanding of this population. In turn, this will help direct future research and the development of therapeutic approaches or interventions that could support this population.

Section 2: The second section of the portfolio is a publishable format of my research study (focusing on one of the themes identified), written for the European Journal of Oncology Nursing. The article focusses on young adults' experiences of caregiving for their parent with cancer, particularly exploring the process of role changes.

The publishable paper summarizes the key findings from the research project and focuses on the second superordinate theme; ‘A process of role transformation’. I decided to focus on one superordinate theme rather than trying to present a full summary of the findings, as I felt that this would allow me to represent the participants’ experiences in more detail and to discuss the implications in greater depth. There is no research that has focused solely on the process of changes that occur on facing a parent’s cancer diagnosis. I believe it is crucial to understand this process of changes, to support not only the ill individual but their whole family.

The theme “A process of role transformation” aims to capture the young adult’s experiences about the process of change that occurs after their parents’ diagnosis of cancer. It describes and reflects how the ill parent, the roles, responsibilities, and dynamics in the family have changed. Furthermore, this theme explores the changes and feelings the participants have experienced in their role as a child of a cancer patient, with particular focus on changes they have made in their lives, decisions, and responsibilities. I believe this theme has important implications for health professionals including nursing teams, carers, and psychologists. Hearing the process of changes and the difficulties that comes with these changes, is useful for practitioners as it can help them understand how to better support individuals experiencing parental cancer within their therapeutic journey. This article is intended for submission to the *European Journal of Oncology Nursing.*

Section 3: The third section of the portfolio is a discussion of a clinical case study. Titled: Improving an ill patients’ quality of life and Family Relationships: Working within a pluralistic framework.

This case study was a significant section not only of my portfolio but also for my development as a counselling psychologist. It involves my work with a client impacted by a life-threatening health difficulty, which in turn leads to difficulties in her relationships with her family. The aim of this part of the portfolio was to demonstrate my ability as a trainee counselling psychologist working within a specific therapeutic framework. In this case study I worked within a pluralistic framework. This work includes details of my client and my formulation, along with details of the approach I employed during the therapy process. Following this, a segment from the session is provided, along with my critical reflections on my work as a therapist. I have chosen this case study as it was an example of how a life-threatening illness can impact an individual and their family. It was another example of how the dynamics in a family can change when a member of the family is experiencing a significant illness. In this instance, the person experiencing the illness was the adult child.

The connection between the different sections

The three sections of my portfolio are ultimately different pieces of work with different aims as explained above. However, they do have connections, and my overall portfolio aims to provide an insight into the experience of the impact of a life-threatening illness on the dynamics between the parent and their adult child. The first section of my portfolio is dedicated to researching the experience of young adults impacted by parental cancer. The second section is an article that reflects on the process of role changes that take place when a parent is impacted by cancer. The third section of my portfolio is dedicated to reflecting on my capacity as a counselling psychologist and has focussed on the impact of a life-threatening illness (diabetes and kidney failure) on an individual and her relationships with her parents. My overall aim is to uncover the experiences that occur when a life-threatening illness occurs in a member of the family, particularly examining the psychological burden in the members and shifts in familial relationships. In other words, the main connection between these three separate sections of my portfolio is that all sections provide insight into how a life-threatening illness can change the dynamics between a parent and their adult child.

Assembly of the Portfolio

My interest in studying experience around life-threatening illnesses and the parent-child relationship roots from my own personal experience. My mother developed cancer when she was 36 and underwent various surgeries, many doses of chemotherapy and radiotherapy. As a young adult trying to adjust to the demands of studying, working, and building a family I struggled significantly. Observing the changes in my mother and seeing her suffer with pain was extremely difficult and I believe has influenced my development as a person. During her treatment, she was often offered a space to talk or given information about services she could attend. However, this form of support was never an option for me or my siblings even though, we were also impacted by our mother's cancer, trying to adjust to the changes, manage the new responsibilities, and suffer from the thought of losing our mum. We had to battle with our feelings and suffering on our own. It was almost as if there was no room for our voices and we were not seen.

My personal experiences made me gain an interest in to hearing other individuals who may be experiencing significant pain relating to their parents' cancer. As I investigated research in this area, I realised that there were significant gaps in the literature. Many studies used quantitative approaches and the real voices of this population were again neglected. It is helpful to know if these people have diagnosable depression, anxiety etc. However, difficulties in life are not limited to those that can be diagnosed with assessment tools. My personal experience coupled with the gaps in the research literature made me realise that the population of people who have a parent with a life-threatening illness such as cancer is not receiving the attention they need. This led me to base my research and journal article on the voices of young adults impacted by parental cancer.

Additionally, when working in a clinical setting during my placement, one of my participants were experiencing a significant health difficulty herself. She had kidney failure and diabetes. In addition to that, she was experiencing significant difficulties in her relationships with her parents particularly resulting from her care needs. The context was different from my research, as it was the adult child with the illness this time. However, the impact of an illness on the parent-child relationship was a highlight for me. I realised that an illness in a family home, regardless of who it is can causes various changes in the family relationships and dynamics. It felt almost like the illness was a first-order problem causing the second-order problem, which was the familial changes. Hence, to unravel my patients experience and develop a portfolio examining the impact of a life-threatening illness on the parent-adult child dynamics, I chose to reflect on this case study.

My personal experience and the consequent research I did about it has led me to make a firm decision about the subject of my study. My passion for the topic allowed me to enjoy the whole process while also developing my skills as a counselling psychologist. My presence in this topic this time was as a researcher and a person willing to learn from other people's experiences. I strongly believe that gaining more insight into the experiences of adults impacted by parental cancer will not only assist my work as a therapist, but it will also support other clinicians in providing treatment for this population.

Reflections on my professional development

In studying the Professional Doctorate in Counselling Psychology and completing this portfolio, I have developed many skills as a Counselling psychologist, and I would like to take this opportunity to reflect on this process.

The opportunity to indulge in real human experience and obtain the chance to analyse it closely has shown me how diverse and rich human experience in various contexts can be. Categorising human experience into quantitative measures can be important to reveal information, however, is very limiting to understand the complexity of the human mind. Each individual experience is unique and subjective. I believe that Counselling psychology and therapy acknowledges the complexity and uniqueness of human experience and offers an opportunity for tailored therapy. Qualitative research in this field can offer some insight into possible similarities in experience and therefore can direct both research and therapeutic interventions.

Moreover, to complete this portfolio, I had the chance to engage in two different roles: Researcher and Counselling psychologist. Distinguishing between these roles gave me the opportunity to clarify the boundaries that relate to both positions and reflect on the experiences of the participants or patients from different perspectives. For example, the researcher role allowed me to reflect on experience as expressed by the participants without formulating or looking for direction for treatment. This was different from my role as a therapist and meant that I was not focusing on the whole picture but on each experience of the person separately. I believe that this skill I have developed as a researcher may contribute to my approach as a therapist too, by helping me explore difficulties of patients in a more detailed way without being occupied with a rush or need to formulate.

PART A – Research study:

Young Adults Experience of Parental Cancer: An Interpretative Phenomenological Analysis

"In a way a bit of my life had shattered"

Aslihan Apat

Abstract:

The majority of individuals diagnosed with cancer have children who are adults. These adults also go on to play vital caregiving roles for their ill parent. However, research exploring their unique experiences and needs continues to be understudied. The aim of this study is to explore young adult's experiences of having a parent with cancer. This study employed a qualitative research design. Six participants who have experienced having a parent with cancer in the last 5 years were interviewed using semi-structured interviews. The data was analysed using Interpretative Phenomenological Analysis (IPA). The analysis revealed four superordinate themes and eleven subthemes. It was found that young adults who faced their parents' cancer diagnosis experienced significant psychological pain, worries about the future with regards to their parents' mortality and their own risk of developing cancer. It was also common that, young adults observed their parent deteriorate, becoming more needy and vulnerable. Consequently, young adults played a significant role in the care of their parents, and took on their parent's responsibilities, neglecting some areas of their own lives. Findings also revealed commonly used methods to cope with this process, which included portraying an invulnerable self and estranging self from others. Other forms of support they benefitted from were also discussed. Despite the negative challenges caused by the experience of parental cancer, participants did report on positive aspects of this experience. Changes in family relationships, personal way of being and behaviours regarding a healthy lifestyle were expressed. The experience of parental cancer amongst young adults is a unique and subjective experience that can foster negative and positive factors in a person's life. The similarities revealed in this study suggest important clinical applications through increasing the insight into the difficulties and challenges this population experiences. Suggestions for future research and the development of interventions that could support this population in the best way possible are given.

Introduction

1: Overview

This chapter will aim to highlight and review the existing literature on the lived experience of young adults who have experienced having a parent with cancer. I will begin by providing a note on the terminology used within previous literature to describe some of the conceptual complexities when describing this population and the relevant findings to clarify the terms used within the proceeding text. I will then provide a brief overview of cancer with details regarding prevalence rates and causes of the disease. I will then go on to outline and discuss the literature on the impact of parental cancer on young adults, considering the psychological distress, post-traumatic stress disorder responses and symptoms, caregiving experiences, coping needs, and the positive growth experiences. I will complete the review with the rational for the current study, its relevance to counselling psychology and the research question.

1.1 Terminology

Much of the existing literature on children who have a parent(s) with cancer frequently use the term “Parental cancer” to describe the experience of this group. The term parental relates to a person’s parent or parents (Dictionary, 1989). Therefore, parental cancer refers to the experience of a parent who is diagnosed with cancer. Throughout this report, the term Parental cancer is used to describe the experience of young adults who have a parent with cancer.

The focus of this present research is on the experience of young adults’ experience of their parent’s cancer. However, research in this area has studied the experience of children from various ages. To differentiate between the different age groups, researchers have used terms such as “minor children”, “young children”, “adolescents”, “young adults”. There may be various other terms used to categories these groups. However, the above terms are the ones used in the literature encountered during my search and therefore are the terms used throughout the present literature review too.

The focus of the present research is on the experience of adults aged between 23-35, and the term used to describe this population in this study will be “Young adults” throughout the thesis. Note that, according to the World Health Organization (WHO, 2016) an adult is a person older than 19 years of age. As the experience of having an ill parent may vary significantly in different stages of life, the aim was to achieve a homogenous sample by recruiting between the ages of 23-35. Facing the possibility of losing a parent in different stages of life could be a distinctive experience itself. Having a parent being diagnosed with cancer during young adulthood is unexpected and incongruent with social expectations of when someone may have to face the death of a parent (Puterman & Cadell, 2008). Therefore, young adults may have a different experience to an individual who is older and has an elderly parent that is ill. As a result, this research was interested in gaining the subjective experiences of young adults who has experienced having a parent with cancer within the last 5 years at the time of recruitment.

Introduction to Cancer

This research was conducted with the aim of exploring the lived experiences of young adults impacted by parental cancer. Before closely examining the literature on this population, it is worthwhile to get a deeper understanding of cancer itself. Understanding the prevalence rates, causes and risk factors can contribute to the understanding of individuals impacted by cancer as well as the findings reported in the following study and literature.

Prevalence of Cancer

Statistics show that cancer is a disease that affects a significant amount of the population across the world. There are around 375,000 new cancer cases in the UK every year, that's around 1,000 everyday (Cancer Research UK, 2018). There are more than 200 types of cancer and every two minutes someone in the UK is diagnosed with the disease (Cancer Research UK, 2014). Incidence rates for all cancers combined in the UK are highest in people aged 85 to 89 (Cancer research UK, 2016-2018). Each year more than a third (36%) of all cancer cases in the UK are diagnosed in people aged 75 and over (Cancer Research UK, 2016-2018). This means that individuals diagnosed with cancer are more likely to have children that are adults. According to research, the types of cancer that has caused the most deaths worldwide is lung (1.37 million), stomach (736,000), liver (695,000), colorectal (608,000), and breast cancer (458,000) (IARC, 2008). Cancer is known as the abnormal division of cells that occurs in an uncontrolled way and sometimes cancer may eventually spread into other tissues. It starts when a gene change makes one cell or a few cells begin to grow and multiply too much, which may cause a growth called a tumour. A primary tumour is the name for where a cancer starts, and a secondary tumour or a metastasis is when the cancer has spread to other parts of the body. Research has revealed that most cancer start due to gene changes that can occur due to environmental factors over a person's lifetime. More rarely, cancer can start due to inherited faulty genes passed down in families (Cancer Research UK, 2018).

Causes and Risk Factors of Cancer

Although 5-10% of cancer types are considered genetic, 90-95% of cancers occur due to a combination of environmental and lifestyle factors (Anand et al., 2008). The five leading behavioural and dietary risks for developing cancer are: tobacco use, alcohol use, overweight and obesity, physical inactivity, and low fruit and vegetable intake (World Health Organization, 2013). High exposure to UV radiation through sun exposure is also a behavioural risk factor (Cancer Research UK, 2018). The American Cancer Society estimates that in 2015 about 171,000 cancer deaths will be caused by tobacco smoking alone (American Cancer Society, 2015). In addition, approximately one-quarter to one-third of the 1,658,370 cancer cases expected to occur in 2015 can be attributed to poor nutrition, physical inactivity, overweight, and obesity. Much of the suffering and death from cancer could be prevented by more systematic efforts to reduce tobacco use, improve diet and physical activity, reduce obesity, and expand the use of established screening tests. Avoiding the use of tobacco products and exposure to second-hand smoke, maintaining a healthy weight, staying physically active throughout life, and consuming a healthy diet can substantially reduce a person's lifetime risk of developing or dying from cancer (Doll & Peto, 1981).

Introduction to the experience of Parental Cancer

Research has shown that a life-threatening illness such as cancer can have significant impact on the ill individual, as well as their families. Over the last 20 years it has been recognized that cancer is a disease that affects the entire family, and that family members are "second-order patients" with unique needs (Arnaert et al., 2010). Family members are also crucial figures in the support and caregiving of cancer patients, impacting disease morbidity and mortality (De Boer et al., (1999). However, despite the growing awareness of the interplay between the biological, social, and psychological processes in adaptation to psychical illnesses (Suls & Rothman, 2004), the social context of illnesses, such as the experiences of cancer patient’s family members, continues to be understudied (Suls & Rothman, 2004). The focus on the patient in isolation from his or her social context, may reflect western individualistic thinking. Generally, in an individualistic society, the self is viewed as independent and autonomous from collectives such as the family (Armstrong & Swartzman, 2001).

Most studies that were conducted in this area, have reported on the impact on younger/minor children. Young adults impacted by parental cancer has not been the focus of literature, as it was assumed that the impact was minimal (Northouse, 1994). This causes a serious concern as more than half of the individuals diagnosed with cancer are aged 75 and over (Cancer research UK, 2018). Therefore, those that are parents are more likely to have affected children that are adults. Research exploring the experience of the young adults impacted by parental cancer is crucial for multiple reasons. Firstly, young adults may experience increased levels of anxiety or sadness related to their experiences with parental cancer (McPhail et al., 2017). Certainly, observing a parent's extreme physical and emotional suffering and possibly preparing for bereavement may be traumatic. In addition, young adults may recognize their own genetic risk and may begin to face their own mortality along with other existential issues (Wellisch et al., 1992). Secondly, many young adults become their ill parents’ source of social support, which may impact the quality of life and even survival of their ill parent. For instance, De Boer et al., (1999) reported that social support played a significant role in overall disease morbidity and mortality. Thirdly, statistics imply that approximately 20% of primary family caregiver patients are their children, whom are women and are employed outside of the home too (Ferrell, 1998). These caregivers have been reported to experience significant psychological distress due to the multiple roles demands, such as balancing responsibilities related to caring for their children, caring for parents and employment (Kim et al., 2006). With this awareness, it is fundamental for research to be carried out on this population, and gain a greater understanding of their experiences, difficulties and needs. Providing support for the adult child would also benefit their parent diagnosed with cancer.

Search strategy and selection criteria

The following literature review reflects on research which has examined the experience of young adults impacted by parental cancer. The literature review was conducted using a systematic approach. Therefore, a rigorous research methodology was used, to limit bias in all aspects of the review (Bettany-Saltikov, 2016). To facilitate the systematic review and identify keywords for the research process, the PEO framework, which stands for population, exposure, and outcome was used. PEO is used most frequently for qualitative questions (Khan et al., 2003) to identify different parts of the research question and reveal keywords that may be used in the literature search. For this research, the population I was interested in was young adults. The exposure was parental cancer. The outcome was the experience of having a parent with cancer (See table of the PEO framework (See table 1).

Table 1: PEO for Young adult's experience of parental cancer

Population	Young adults Adults Family Caregivers/carers Familial caregivers
Exposure	Parental cancer Familial cancer Maternal cancer Paternal cancer Ill-parent
Outcome	Experience Impact Changes Post-traumatic/growth

During this search, numerous electronic libraries covering subjects such as health sciences, psychology and nursing were accessed. The keywords used in this search included those in Table 1. The main databases used included the Cochrane library, PsycInfo, PubMed and Medline. The selection process began with the consideration of journal titles, a review of the journal abstract, and finally reading of the full manuscript. Reference lists of relevant articles were also searched to find relevant studies and enhance the search.

A large volume of studies was found during this search. However, not all were relevant. Studies exploring the experience of parental cancer on minor or adolescent children were eliminated. Efforts to find qualitative research in this area only revealed a few studies and vast majority of research in this area were performed using quantitative research methodologies. This may be because the studies were mainly concerned about investigating the measurable effects of having a parent with cancer, and assessment tools measuring levels of depression, anxiety, Post Traumatic Stress Disorder, or general burden were used. Therefore, this review revealed that the experiences of the young adults as expressed by them has not been the focus of research. In addition, it occurred that recent literature exploring young adults' experiences of parental cancer was minimal. Therefore, there was no control over the date range of the studies during this literature search. Some older studies (dated 1990's – 2000's) were included in this review, as they were classic papers that have revealed significant information about this phenomenon. However, these studies were critically evaluated with regards to their generalizability and reflectiveness of the modern contemporary society. In an aim to detect more recent literature, grey literature was also explored, and results yielded no unpublished studies or thesis that was specifically about young adult' experiences of parental cancer. Research focussing on other life-threatening illnesses or populations such as caregivers of Alzheimer's patients and dementia patients, or the experience of spouses was included in this review where findings were applicable. However, this was minimal as the aim was to stay close to the phenomenon under research and unravel the experience of parental cancer amongst young adults in thorough detail.

To reflect on the areas research has focussed primarily on, the literature review is broken down in to the following 5 sections; Emotional distress that comes with parental cancer, Parental cancer and post-traumatic stress symptoms, The experience of caregiving for a cancer patient, Coping and support needs for caregivers of cancer patients, and Growth that comes with parental cancer. Each of these sections aim to provide an extensive review of the literature, reflecting on the knowledge known so far with regards to the experience of having a parent with cancer amongst young adults. In turn, the attachment theory (Bowlby, 1979) and Family systems theory (Kerr & Bowen, 1988) that can provide an insight into the experiences of young adults impacted by their parents' cancer was explored.

LITERATURE REVIEW

Emotional distress that comes with Parental cancer

The experience of parental cancer at any point and especially during young adulthood is unexpected, but in young adulthood, it is also incongruent with social expectations of when someone must face the life-threatening illness of a parent and the possible death of that parent (Puterman & Cadell, 2008). Parental cancer can be a traumatic event for the offspring, regardless of the type of cancer that the parent is facing (Mosher & Danoff-Burg, 2005). These young adults are also learning to develop their own identity while trying to balance time with their family and friends and time spent on academic pursuits (Schmidt & Welsh, 2010). Most young adults haven't gone through the experience of parental cancer and therefore a young adult who has experienced this may not have the required amount of social support and understanding from their peers (McPhail et al., 2017; Puterman & Cadell, 2008). Young adults who are students and are dealing with a parent's illness are also expected to confront issues in adjustment to university or college because of the separation from their families and their increased independence (Schmidt & Welsh, 2010). A young adults well-being can be affected by his or her attachment to his or her parent, his or her coping mechanisms, and social support. If a young adult doesn't have adequate support or methods of coping prior to a family member becoming ill, then their well-being may suffer, especially if the illness becomes severe (Schmidt &Welsh, 2010).

An extensive review of the literature published since 1990, reflected that a "sizeable minority" of adult offspring of cancer patients experience psychological distress, including anxiety, depression, and posttraumatic stress disorder (PTSD) (Mosher & Danoff-Burg, 2005). This review solidifies the notion that parental cancer may cause psychological suffering in some adults. However, it also points out that not all adults are impacted and/or impacted in the same way by parental cancer. The impact of parental cancer may be influenced by various factors, and future research is needed to unravel these. In addition, most of the research included in this review have been limited by a lack of comparison groups as well as a lack of longitudinal designs. In studies of adjustment without control groups, one cannot presume that the source of participants' emotional distress was their experiences related to parental cancer. True prospective designs are needed to evaluate changes. Future research should examine the relations between intrapsychic and contextual factors that may influence psychological adjustment to parental cancer.

Hodges et al., (2005) conducted a meta-analysis examining psychological distress on family members of cancer patients, noted that, in most of the studies adult children are heavily underrepresented. Of the 21 studies they included in the analysis, 17 of them the participants were exclusively spouses. In the remaining four studies, most participants were still spouses, with adult children and other family members accounting for less than 5% of the sample. Also, in the studies that have included the adult children, the age range of adult children are not distinguishable. As a result, it is important that future research should examine the experience of the impact of cancer on the family beyond the spouse-patient dyad.

The studies who have started exploring the impact of parental cancer on adults have focussed chiefly on the experience of middle-aged daughters of breast cancer patients. For instance, Wellisch and Collegues assessed the psychological adjustment and quality of life of daughters of breast cancer patients using self-report measures. They reported that there are no significant differences in psychological symptoms between women with and without maternal histories of breast cancer (Wellisch et al., 1991, 1992). However, daughters of breast cancer patients reported significantly less frequent sexual intercourse, lower sexual satisfaction, and greater feelings of vulnerability to breast cancer. Findings indicate that parental breast cancer does not increase psychological distress, however, it may have other significant impacts on young adults' lives which were not accounted for in other studies. Therefore, these studies have revealed an important area that future research should explore. Nevertheless, despite the important findings that emerged from well matched participants, the sample was restricted to middle-class women, all of whom were Caucasian. In addition, the authors did not analyse the potential effects of the time since diagnosis of parental cancer, the cancer stage at diagnosis, or any cancer-related treatments received.

Daughters of breast cancer patients have been reported to display higher levels of general distress, anxiety, somatization and depression on the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982) in comparison to women with no family history of cancer (Gilbar, 1997, Valdimarsdottir et al., 1995). Furthermore, Kash et al., (1992) reported that 27% of women with First Degree Relatives (FDR) with cancer and who self-referred to a cancer prevention centre experienced high levels of distress on the BSI consistent with a need for psychological counselling. In a later study, this figure increased to 53% amongst daughters impacted by parental breast cancer and who were attending an education program about breast cancer (Baider et al., 1999). However, in both studies the participants were individuals who self-referred. In other words, there was an unavoidable selection bias limiting the generalizability of the findings. This group of women impacted by parental breast cancer may not be reflective of women that does not seek help or attend an educational program.

On the other hand, Zakowski et al., (1997) concluded that FDRs of cancer patients did not report higher general distress. Other studies have also highlighted low levels of general psychological morbidity in this population and no differences between levels of depression in comparison to the general population (Coyne et al., 2000; Hailey et al., 2000). It appears that the evidence is mixed, which may be due to the differences in the recruitment strategies. For instance, Valdimarsdottir et al., (1995) recruited participants from a high-risk clinic, while Zakowski et al., (1997) recruited women from different mammography screening programs not exclusively serving women at high risk for breast cancer. It may be that individuals from high-risk clinics are more likely to experience psychological distress, which may cause variation in the findings. Although these studies in the 1980's and 1990's have revealed important findings and has been influential in guiding research, it is important to note that they may not be applicable to today's contemporary society. Changes in society (women's rights, feminism, LGBT, and equal rights movements) and industrial revolutions (social and economic changes, development of new technologies and communication systems) may impact the experiences of women and men in modern/contemporary society very differently. There is an increase in diversity and changes in gender roles in modern society. Therefore, findings from studies in the 1990's century may not be applicable to contemporary society, however replicating the research may yield interesting comparisons. This highlights the gaps in research and the need for updating research on the experiences of individuals impacted by cancer in the contemporary society.

Moreover, it was reported that daughters impacted by parental breast cancer may experience heightened levels of emotional distress like that of patients who have recently been diagnosed with breast cancer (Lindberg & Wellisch, 2004). Lindberg & Wellisch, (2004) carried out a study on well-educated, mainly Caucasian women attending a high-risk clinic for FDRs of breast cancer patients. They found that approximately one-third of this samples score on the

Center for Epidemiologic Studies Depression Scale CES-D; Radloff, 1997) was above 16 which is considered as the cut-off point for clinically significant depressive symptoms. Also, approximately half of the participants showed signs of significant symptoms of anxiety, as measured by the State-Trait Anxiety Inventory (STAI; Spielberger, 1983).

Having an FDR that has cancer can surely cause psychological distress (Wellisch et al., 1992). However, it is also clear that everyone is impacted in different ways. As a result, researchers have begun to ask what the possible predictors of psychological distress among FDRs of breast cancer patients may be. For instance, being female and having poorer family functioning were associated with increased distress (Mcdonald et al., 2016). Another predictor that was called to question was the age of FDRs. Lerman et al., (1993) found that in FDRs who were self-referred to a breast cancer screening program, higher levels of distress were reported amongst women aged 29 and younger in comparison to those over the age of 29. Nevertheless, it is possible that only younger women who experience significant distress or is at excess risk may self-refer to a breast cancer screening program. Therefore, the sample may be biased, and there is a need for further research that considers the stress levels amongst different age groups, for conclusive findings to be drawn.

Past experiences that were cancer related, such as caregiving, death, and perception of future risk to self were significant predictors of distress (Erblich et al., 2000). Erblich et al., (2000) emphasised that daughters whose experiences included maternal caregiving and maternal death from breast cancer were reported to have the highest levels of breast cancer specific distress and general depressive symptoms. Nevertheless, if one of the experiences occurred without the other, their distress levels were not higher than that of a comparison group of women without a family history of breast cancer. There is a need for further research on the possible predictors that may influence the experience and impact of parental cancer amongst young adults. Future research should consider types of medical treatments received and the type of caregiving provided. It is also important to assess whether the active treatment phase of the mother's illness is most distressing relative to the pre- and post-treatment phases. These studies highlight the importance and need for future research to focus on factors that could influence the impact of parental cancer.

However, it is important to note that all the above studies are quantitative and are therefore not designed to explore the illness experience as it is lived by the participants. Quantitative research does not delve into or explore the rich contextual details that may influence how an experience is lived or capture the complex meanings that participants may draw from their experience (Maxwell & Miller, 2013). For example, the above quantitative studies inform us that as a group there are differences among the participants or correlations among the variables under study, but do not provide insight into the unique experience of the individual adult children who participated. As Van Manen, (1990) explains, mechanistic and statistical explanations of causation and correlates cannot account for how the experience is lived and felt.

Nevertheless, McPhail et al., (2017) conducted a phenomenological study, and explored the lived experience of parental cancer amongst adult university students. They interviewed 17 university students aged between 18-27. Thematic analysis was used, and five overarching themes emerged. They reported that participants felt sad and anxious about their parent having cancer. Participants talked about recurring emotional outbursts, where they felt that they were not in control of their emotions. Most participants also reported changes in their friendships. They discussed how their friends were not able to understand what they were going through. Participants found it helpful to talk to a significant other about their problems, but also mentioned trying to avoid thinking about their parent having cancer. All participants reported feeling more health conscious since their parent was diagnosed with cancer and found themselves wanting to adopt a healthier lifestyle. Moreover, almost all participants mentioned changes in their family dynamics. These changes included changes in relationships and roles and changes in the way they viewed their ill-parent (being more appreciative of them). Most participants found that their experience made their family become closer and spend more time together. Most participants described positive outcomes of parental cancer such as greater maturity, improved ability to relate to others, and a more positive and gracious outlook on life. These findings provide rich detailed accounts from young adults who have experienced parental cancer, providing novel understanding around the areas of one’s life that can be impacted. As a result, it sheds light on areas that could be explored with future research. In this study, the sample of participants was homogeneous. This could be a limitation because the lived experiences reported on were those of mostly White university students who were all, except for two, attending the same university. There were also only three men who participated in this study and so the experiences of men were underrepresented in the sample. Research inclusive of a diverse population is needed for a more enhanced understanding of young adults experiencing parental cancer.

In addition, Almarza (2008) carried out a Thematic Analysis (TA) on the data from three adults whose parent was diagnosed with cancer. Their study was concerned specifically about what it was like to have a parent with cancer for adult children living at home. From their analysis, they reported that the experience of adult children involved intense distressful emotions, particularly feelings of anger, shock, uncertainty of the future, disbelief, frustration, apprehension, and above all intense dread: an intense fear of facing the prospect of father's early death. Furthermore, the adult children sought to control their emotions to reclaim the agency to do whatever was needed. All participants admitted that treatment was the most difficult phase in the journey, where instrumental caregiving and emotional work was demanding. All adults confided how their reality was completely altered: school, friends, work, socializing, pleasure, self-enjoyment, were left behind. There was no day off from the treatment protocols, no escape from the taxing emotions that adult children living at home experience: hopelessness, helplessness, misery, anguish, uncertainty, and death fear. Moreover, adult children described how their parents deteriorated and changed. As treatment unfolded, an altered reality emerges when a strong father figure lies down fragile, despondent, and weak on a hospital bed. These findings provide a more in-depth understanding of what it is like for adults experiencing parental cancer. It highlights novel understanding around how the phases of cancer can be a crucial factor in how difficult the experience could be. It also highlights the adult offspring perceptual change of their parent because of the treatment process. However, these findings were based on the experience of paternal cancer, and so the experiences that emerged amongst the three participants' may not be the same for adults whose mother has cancer. In other words, the parent's gender may be a significant factor that impacts the experience of parental cancer for adults. However, it appears that there is no research that has explored gender and gender roles of a parent with cancer, and how this may impact their adult child. Studies exploring maternal and paternal cancer can provide novel understanding that could be helpful to understand the difficulties and needs of this population.

Gender and Gender roles

Studies exploring the experience of parental cancer is predominantly inclusive of the daughters' experiences of maternal cancer and the male perspective is minimal. Therefore, it is crucial to scrutinise the influence of gender and gender roles on the experience of parental cancer and consider why research focus has predominantly been on the female narrative. The high prevalence of studies conducted on females can be attributed to several factors. Firstly, breast cancer is one of the most common cancers affecting women worldwide (Ferlay et al., 2012) while it is very rare amongst men (Miao et al., 2011). As a result, due to its high prevalence worldwide, parental cancer studies often focus on breast cancer and majority of participants in such studies is therefore women.

The impact of gender and gender roles on the experience of having a parent with cancer can be profound and multifaceted, affecting both the individuals directly involved and their broader networks/families. In many cultures the traditional gender roles often dictate that women take on the role of primary caretaker in families, especially in times of illness (McPhail et al., 2017). Therefore, daughters may find themselves shouldering a significant portion of the caregiving responsibilities for a parent with cancer. This can lead to increased stress and pressure, particularly if they are also managing their own families and careers simultaneously (Schrank et al, 2016). Indeed, Schrank et al, (2016) used structured questionnaires to assess 308 caregivers. It was found that burden was significantly higher in women in comparison to men. Hope was the most significant protective factor against burden in both genders, together with perceived fulfilment of support needs. Only in women emotion-oriented coping and being in employment while caring was significantly predictive of higher burden. Nevertheless, women reported to spend more hours caring, performing more intimate care duties such as toilet tasks, more often change their employment status because of caregiving responsibilities and less often draw on support by other family members or professional services (Mackinnon, 2009). These findings suggest that women are more likely to be impacted by burden while caregiving for their ill parent, and as a result are more likely to be the research focus. Therefore, psychological support interventions for family caregivers should take gender-specific risk factors into account. Women may benefit from interventions that address adaptive coping and strategies to deal with the dual demands of employment and caring. Interventions focusing on keeping up hope while caring for a terminally ill family member may be a valuable addition to palliative services to improve support for family carers.

In addition, societal norms often encourage women to be more expressive with their emotions, while men are often expected to remain stoic and composed (Gorski, 2010). As a result, daughters may feel more comfortable openly discussing their feelings and seeking emotional support, while sons may struggle to articulate their emotions or feel pressure to maintain a facade of strength. On the contrary, in many societies, men are still predominantly viewed as the primary breadwinners. Therefore, there may be added financial pressure on sons to step into the role of providing for the family. This can lead to increased stress and anxiety, particularly if they are not adequately prepared or equipped to handle such responsibilities. Based on the National Study of Caregiving (NSOC) caregivers were interviewed on the phone and were asked questions regarding their experiences. The findings were based on a random sample of 2007 caregivers in 2011 and 2204 in 2015 (spouses, partners, children, and others). It was found that all caregivers experienced burden, particularly elevated emotional stress, with sons reporting the highest emotional and financial strain levels (Lopez-Anuarbe & Kohli, 2019). It appears that the burden of caregiving and experience of parental cancer may be different amongst daughters and sons, as societal norms may put different pressures on each gender. Recognizing and addressing these gendered dynamics is essential for providing comprehensive support to individuals and families facing the challenges of cancer diagnosis and treatment.

To explore the gendered dynamics/differences in caregiving, Harrington, et al., (2023) studied the contextual complexities of the caregiving role acquisition articulated by female family caregivers of those with Alzheimer's. They employed a Critical discourse analysis (CDA) to explore the complex but subtle nuances of gender, power, and ideologies. CDA uncovered the theme of 'compulsory altruism'. *Compulsory altruism* was conceptually defined as a socially constructed assumption that caregiving duties or primary caregiving responsibilities were based on socially structured gender role criteria (e.g., oldest, female, closest geographically, unmarried) and exercised through coercion, guilt, assumed, or familial expectation. Respondents normalized family structures whereby gender roles were assigned as caregivers. Compulsory altruism was precipitated by family structures that dictated which siblings would be primary caregivers without consensus. The female caregivers assumed caregiving roles because of their expressed love, devotion to their family members, and desire to "keep the peace" with their siblings. These findings are highly valuable and can help shed light on the imbalance of studies focusing on mainly females and why caregivers tend to be females. However, the voluntary nature of sampling may have introduced selection bias; as, the represented ethnicities and female samples were congruent with the caregiving populations of the regions in Kentucky and North Carolina where data collection occurred. It is important to replicate such studies on a diverse population of caregivers, to understand their experiences and achieve generalizable findings.

Moreover, in most societies, mothers often play a significant role in caregiving and family dynamics. Therefore, understanding the impact of maternal cancer on offspring and family dynamics is of particular interest to researchers. Women have also been recorded to utilize healthcare services more frequently than men (Bertakis et al., 2000), leading to a higher likelihood of their participation in research studies. In addition, parental cancer studies often examine the psychosocial impact of cancer on families, including issues related to caregiving, family relationships, and emotional well-being. Given the societal expectations surrounding female caregivers and emotional expression addressed above (Gorski, 2010), there may be a greater focus on women's experiences in these studies. While most parental cancer studies may involve females, it's essential to recognize the importance of including diverse perspective, including those of males and non-binary individuals, to gain a comprehensive understanding of the impact of parental cancer on families. Increasing efforts to include diverse participants in research studies can provide more nuanced insights into the experiences of families affected by cancer and facilitate the development of interventions considering the specific needs of the different groups/genders affected.

The conceptualisation of illness and caregiving in families

The conceptualization of illness, caregiving, and coping varies significantly across different families, which may significantly impact the experience of parental cancer. The structure and dynamics of the family play a crucial role in caregiving and coping. In some families, caregiving responsibilities may be shared among multiple members, while in others, there may be a primary caregiver (Bagautdinova et al., 2023). Family relationships, communication patterns, and support networks all influence how illness is experienced and managed within the family unit. Edwards and Clarke, (2004) carried out a study on newly diagnosed cancer patients and their families. Family functioning was identified as a factor that might impact on the family's depression and anxiety. Families who were able to act openly, express feelings directly and solve problems effectively had lower levels of depression. Direct communication of information within the family was associated with lower levels of anxiety. These findings suggest that the experience of having a parent with cancer is influenced by the way the illness may be handled within the family. In addition, these findings suggest that researchers and clinicians need to be family-focussed as cancer affects the whole family and not just the person. However, this study employed a cross sectional design and to determine the long-term impact cancer has on the families, a long-term follow up is required.

The influence of culture and the context may also influence the conceptualisation of an illness within a family. For many families, religious and spiritual beliefs provide a framework for understanding illness and coping with its challenges. Prayer, rituals, and seeking guidance from religious leaders may be integral parts of the coping process (Thune-Boyle et al., 2006). Koerner and Shirai (2013) interviewed caregivers, and found a reliance on religious coping, religiosity/spirituality into the daily stream of life, perceived connection of religion/spirituality to family, and experience of close attachment to God, or an affirming spiritual order. Moreover, in another study they found that in Latino families, family interests are a priority over personal interests (Koerner & Shirai, 2012). Interestingly, caregivers with higher education levels had higher levels of individualism, which inversely correlated with strong caregiving beliefs associated with prioritising familial needs (Koerner & Shirai, 2012.)

Moreover, cultural and community norms shape the support available to families dealing with illness. Close-knit communities may rally around the affected family, providing practical assistance, emotional support, and guidance. Conversely, in more individualistic societies, families may rely more heavily on professional healthcare services and formal support networks. Pinquart & Sorensen, (2005) conducted a meta-analysis of 116 studies investigating the impact of ethnic differences on the caregiving experience. They reported that ethnic minority caregivers had a lower socioeconomic status and were more likely to receive informal support. They provided more care than white caregivers and had stronger filial obligation beliefs than white caregivers. Moreover, they found that white family caregivers experienced higher perceived burden while black family caregivers expressed improved wellbeing (Pinquart & Sorensen, 2005). Nevertheless, it is important to highlight that the study was on caregivers of Alzheimer's patients, and the caregiving experience may be significantly different from the caregiving of cancer patients. However, the results suggest that more specific research is needed to explain differential effects of different ethnic groups of caregivers, as intervention needs may also vary amongst different ethnic groups.

Cultural values and beliefs among different ethnic groups often affect how one may experience illnesses in a family and the caregiving that it may entail. Filial piety, duty and reciprocity are deeply ingrained in cultural values and belief systems. Filial piety, referring to one's familial devotion to, or respect for one's parents or elders, is a commonly cited motivation for assuming caregiving responsibilities (Pinquart & Sorensen, 2005). Moreover, Reciprocity was highly correlated in Black adult child family caregivers of those with Alzheimer’s AD/ADRD. In one study, Black families viewed family caregiving as an expression of love, respect, and spirituality (Powers & Whitlatch, 2016).

There is substantial evidence suggesting that Western and non-Western caregivers of patients with Alzheimer’s disease have different caregiving experiences depending on the cultural values they adopt. Ar & Karanci, (2019) investigated Turkish adult caregivers’ perceptions of Alzheimer’s disease and caregiving experience. In-depth interviews were conducted with 20 primary caregivers and data was analyzed using Interpretative phenomenological analysis. Firstly, most caregivers viewed family disharmony as the main cause of the disease. Second, although burden is evident in their accounts, caregivers reported positive changes during their caregiving experiences, as well. Third, caregivers employ religious/fatalistic coping, and they benefit from social support during their caregiving experiences. Forth, most caregivers opposed to nursing home placement because they view it as a morally improper act; they are afraid of neighbourhood pressure, and they perceive caregiving as a child’s responsibility. Findings indicated that Eastern norms and values might have differential impacts on caregiving outcomes and experiences. Consequently, it is essential for mental health professionals to integrate culturally sensitive aspects into the possible intervention programs targeting caregivers from non-Western contexts. Nevertheless, these findings were based on the caregiving experience of Alzheimer’s patients, which may entail different caregiving demands to that of cancer. Hence, research exploring the differences in how parental illness and caregiving is conceptualised in different societies and families is crucial, to develop interventions that are culturally more sensitive and applicable.

To date, study designs have not accounted for subpopulations of ethnic groups’ distinct histories, sociocultural values, and contextual experiences. In conclusion, the conceptualization of illness, caregiving, and coping within families is deeply intertwined with cultural and religious beliefs, and societal dynamics/norms. Understanding these influences is essential for providing culturally sensitive and effective support to families facing health challenges.

Parental cancer & Posttraumatic Stress symptoms

Cancer and other life-threatening illnesses have been conceptualized as possible precipitants of posttraumatic stress disorder (PTSD) symptoms in the recent Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013). People with PTSD have intense, disturbing thoughts and feelings related to their experience that last long after the traumatic event has ended. They may relive the event through flashbacks or nightmares; they may feel sadness, fear, or anger; and they may feel detached or estranged from other people. People with PTSD may avoid situations or people that remind them of the traumatic event, and they may have strong negative reactions to something as ordinary as a loud noise or an accidental touch. Symptoms of PTSD include, intrusive thoughts, avoiding reminders, negative thoughts and feelings, and arousal and reactive symptoms (American Psychiatric Association, 2013). Boyer et al., (2002) found that breast cancer patients and their daughters reported symptoms consistent with PTSD, which they measured using the PTSD Reaction Index (RI; Frederick, 1987). Other studies have also reported on the link between the experience of having a parent with cancer and PTSD (Valdimarsdottir et al., 1995).

Studies exploring the PTSD responses in young adults impacted by parental cancer have generally used the Impact of Event Scale (IES; Horowitz et al., 1979) or the Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997). The study by Compas et al., (1994) was one of them. In their study male and female preadolescent, adolescent, and young adults of a heterogeneous cancer patient sample was used. The IES scores were lower for adolescents and young adults in comparison to preadolescent children. Indeed, adult offspring of cancer patients scored well below 26 on the IES, indicating a moderate or severe impact (Horowitz et al., 1979). Their stress response symptoms on the IES were significantly correlated with the perceived seriousness and stressfulness of the parent's cancer. Young adults whose fathers had cancer reported more symptoms on the IES than those whose mothers had cancer. In addition to these findings, in an independent sample of preadolescent, adolescent, and young adults, Compas et al., (1996) found that increasing age was related to fewer intrusive thoughts about parental cancer and more avoidance of these thoughts. Although this study was inclusive of younger children and adolescents, they provided imperative findings that can direct future research for understanding the experience of parental cancer and therefore was included in this review. These findings reveal that the experience of parental cancer is created with the interplay of many factors. The factors operating to produce these demographic differences warrant further investigation.

Majority of studies exploring PTSD responses and stress reactions (IES AND IES-R scores) in individuals impacted by parental cancer, have focussed on daughters of breast cancer patients. The findings drawn from these studies emphasised that FDRs of breast cancer patients have higher levels of cancer-related intrusive thoughts and avoidance in comparison to women with no family history of cancer (Valdimarsdottir et al., 1995, Zakowski et al., 1997). Lerman et al., (1993) found that 53% of FDRs of breast cancer patients experienced intrusive thoughts, and that levels in these women were comparable to those found in studies of individuals exposed to other types of trauma (e.g., Horowitz et al., 1979). In addition, 30% of these women reported breast cancer-related worries that interfered with their daily lives (Lerman et al., 1993). Furthermore, in their study Lindberg & Wellisch, (2004) found that 4% of FDRs of breast cancer patients showed symptoms in line with a diagnosis of probable cancer-related PTSD, and another 7% of the FDRs reported symptoms consistent with potentially subclinical levels of cancer-related PTSD, according to DSM-IV criteria. However, the percentage of women impacted in this study (4% & 7%) is considerably low, and the participants in this study were attending a clinic for women at high risk for breast cancer. Thus, the findings and sample are not representative for the population of FDRs of breast cancer patients, and there may be great differences between everyone's experience. Indeed, Erblich et al., (2000) also stresses that there is great variability of distress experienced amongst FDRs of cancer patients (Erblich et al., 2000), making it imperative to assess the predictors of their stress responses. A women's current age was associated with the severity of the distress they experienced relating to their parent's cancer. For instance, Lerman et al., (1994) found that daughters of breast cancer patients aged 50 and older, experienced higher levels of intrusive thoughts when compared to younger women.

Moreover, research has highlighted that some aspects of a women's experience with familial cancer may influence their current level of stress response symptoms. Baider et al., (1999) found that compared to women who had either a mother or a sister with breast cancer, women who had a history of breast cancer in both relatives experienced greater intrusive thoughts. Another potential predictor of posttraumatic stress is a parent's death from cancer, which may be preceded by a lengthy and painful decline in the parent's health and long-term caregiving by close family members. In support of this, it was found that among FDRs of breast cancer patients, those whose parent(s) had died of cancer were found to have the highest levels of intrusive thoughts, avoidance, and perceived risk (Zakowski et al., 1997). It was also reported that perceived personal risk of breast cancer mediated the effect of parental death on intrusive thoughts and avoidance regarding breast cancer. In a cross-sectional study of healthy FDRs of breast cancer patients, all of whom had maternal breast cancer histories, women who had cared for their mothers with breast cancer had higher levels of cancer-related distress (i.e., intrusive thoughts, avoidance) than women who did not (Erblich et al., 2000). In addition, women whose experience included both caregiving and the death of their mother from breast cancer had the highest levels of cancer-related distress (Mosher et al, 2005).

Furthermore, Schwartz et al., (1995) studied 103 women who had a first-degree family member impacted by ovarian cancer. Specifically, the authors tested the relationship between the dispositional attentional style of monitoring (the tendency to scan for threat-relevant information), perceptions of risk for ovarian cancer, intrusive thoughts regarding ovarian cancer, and psychological distress. Their findings reflected that FDRs of cancer patients experience higher levels of psychological distress. Interestingly, high scores on monitoring were associated with high perceived risk for ovarian cancer and elevated levels of intrusive thoughts and psychological distress. In other words, individuals who perceived themselves at higher risk of developing cancer were more likely to tend to scan for threat relevant information, along with experiencing more unwanted thoughts and distress.

In another study, the association between social constraints and cancer related distress was studied. The social constraints were measured via the Social Constraints Scale (SCS) (Lepore et al., 1996), which is a five-item scale designed to assess the level of strain individuals experience in their relationship with the most important person in their life, and the degree to which they feel constrained with respect to expressing stressor-related thoughts and feelings to that person. It was found that higher levels of social constraints were related to higher levels of both cancer specific distress and general psychological distress. Avoidance was found to mediate the relationship between social constraints and levels of stress for both types of stress. In other words, individuals who reported higher levels of social constraints reported higher levels of avoidance; in turn, they reported higher levels of psychological distress. These findings were congruent with the social cognitive processing model, suggesting that unsupportive or negative reactions from others during disclosure of stressor-related thoughts and feelings may result in attempts to avoid such thoughts and feelings. This inadequate exposure to the stressor may prevent its cognitive processing and prolong distress. (Schnur et al., 2004). It is also in line with research showing that attempts to avoid thoughts of a topic lead to more intrusive thoughts of that topic (Gold & Wegner, 1995). Moreover, it was also reported that social constraints lead to decreased disclosure. This in turn may prevent individuals from gaining increased objectivity and insight into stressful experiences; prevent individuals from having the opportunity to elicit helpful stressor-related information from others; decrease individuals' ability to make sense of and find meaning in stressful events; and make it difficult for individuals to structure such events in their minds, which would make the events seem less overwhelming (Zakowski et al., 2001). It has also been suggested that social constraints may be related to distress by interfering with the cognitive processing of stressful events. Constraints may interfere with processing by increasing emotional arousal (Lepore et al., 1996) or by decreasing individuals' level of expo- sure to stressor-related material (Lepore et al., 2000).

Interpreting the findings of research on PTSD responses to facing cancer is complicated, as there is overlap between normal reactions to cancer and PTSD responses (Kangas, Henry & Bryant, 2002). In other words, common grief reactions to a cancer diagnosis may be confused with PTSD symptoms, as both may involve arousal, avoidance, and intrusive thoughts (Kangas et al, 2002). For instance, family members of a cancer patient may experience arousal and intrusive thoughts because avoiding reminders of the trauma may be impossible because of external cues (e.g., medical appointments, prescribed medication, visible treatment side effects) (Kangas et al., 2002). In addition, The DSM-IV-TR definition of reexperiencing symptoms is potentially problematic in the context of cancer, because intrusive thoughts may be future-oriented health concerns rather than ruminations related to past experiences (Kangas et al., 2002). Although some FDRs of breast cancer patients report having intrusive thoughts (e.g., Erblich et al., 2000, Zakowski et al., 1997), the exact nature of these thoughts has not been assessed. Clearly, further research is necessary to gain a better understanding of differences between PTSD responses after cancer and cancer related responses. This will guide the adequate identification and management of cancer-related PTSD.

The experience of caregiving for a cancer patient

Pallative care teams have become more available in the community over the last decade, and an increasing number of cancer patients have decided to die at home (Wilson, 2000). However, palliative care requires the dedicated help of caregivers alongside the support of care teams (Aranda & Hayman-White, 2001). Caregivers play a primary role in the cancer patient's symptom management, monitoring of treatment and disease progression, methods of transportation, and maintenance of medical equipment such as an IV (intravenous) fluid (Given et al., 2001). The caregiver plays an important supportive role by aiding in personal care and providing emotional, financial, and spiritual support (Given et al., 2001). The caregiver may become responsible for certain former responsibilities that the cancer patient can no longer maintain due to his/her illness, and it is common for caregivers to suffer from anxiety and/or depression during the caregiving experience (Given et al., 2001). Familial caregivers are expected to provide complex care in the home with little preparation or support (Van Ryn et al., (2011). When the demands placed on caregivers exceed their resources, caregivers feel overwhelmed and report significant distress (Siegel et al., 1991). It was reported that most of these caregivers are family members, primarily a spouse or an adult daughter (Stone & Kemper, 1989; Horowitz, 1985). Therefore, cancer may change the family's identity, roles, and daily functioning and the disease's effects may be profound and long-lasting, regardless of the medical outcome (Blanchard et al., 1997).

Caregiving is surely beneficial for patients, especially to maintain them in their own homes for longer. However, it is documented that caregiving can impact all aspects of a caregiver's life and the cumulative impact of these stresses can diminish their ability or motivation to continue as a caregiver's overtime (Seigel et al., 1991). The various challenges caregivers face can impact their health and psychological wellbeing. Caregivers who have high distress also have changes in their immune system that can lead to flare-ups in auto-immune diseases, worsened glucose control in the body, and increased vulnerability to cardiovascular diseases (Rohleder et al., 2009) These changes increase the likelihood that the caregiver's own health will suffer and, subsequently, hinder their capacity to provide care. In addition, distressed caregivers have more difficulty providing optimal patient care (Van Ryn et al., (2011) and administering medications to patients (Lau et al., 2010). Caregivers need to be understood to support them through their caregiving role, both to maintain their own wellbeing and the person they are caring for.

As well as psychological stress (depression, anxiety, and burden), caregivers of cancer patients (children or spouses) experienced negative effects to their day-to-day lives. For instance, during the caregiving period, participants had an average decrease in work productivity of 22.9% (Mazanec et al., 2011). It was found that the caregivers' feelings of depression, anxiety, burden, financial issues, and personal health problems were the mediators of decreased work productivity (Mazanec et al., 2011).

Caregiving is a very broad area, and everyone may be impacted differently, and various factors could influence this impact. Research suggests that a caregiver's individual characteristics such as their age, own health, and relationship to the patient are factors that could influence the impact of the caregiving experience (Given et al., 2004; Fried et al., 2005). Also, a sense of personal accomplishment are factors that have found to impact the experienced psychological distress positively (Hagedoorn et al., 2002). In addition, the patient's characteristics could also inform the psychological distress experienced by caregivers. For instance, the type of cancer and severity of symptoms were found to impact the level of stress experienced by caregivers (Given et al, 2004; Hodges et al., 2005). Moreover, the demands of the caregiving, such as monitoring the patient's symptoms around the clock, administering medications, and coping with treatment side effects, were factors that contributed to may be physical and emotional exhaustion for caregivers (Blanchard et al., 1997, Porter et al., 2002). Other factors such as the availability of homecare (Sharpe et al., 2005), social support (Sharpe et al., 2005; Payne et al., 1999) and financial burden (Grunfeld et al., 2004) were found to impact caregiver experiences too. Clearly, it is vital to research the experience of young adults impacted by parental cancer to get a greater understanding of the factors that moderate this experience positive and or negatively.

In a study by Kim et al., (2012) in the United States, 5-year follow-up data were collected from the Nationwide Quality of Life Survey for Caregivers and this data showed how different caregiving experiences affected the quality of life of caregivers. Caregiving experiences were assessed 2 years after the caregivers' relatives received their cancer diagnosis and then quality of life components for the caregivers, such as mental health, physical health, psychosocial adjustment, and spirituality, were assessed 5 years after their relatives received their cancer diagnosis. Caregivers were then classified as being former caregivers who's relative was in remission, former caregivers who's relative was deceased, and caregivers who were currently providing care. Older caregivers and those who had perceived the caregiving experience as less overwhelming had better mental functioning, but younger caregivers had higher physical functioning across all caregiver types. Psychological distress was associated with younger age and higher levels of caregiving stress. At 5 years post diagnosis, former caregivers whose relatives were in remission had normal levels of psychological well-being, while former caregivers who had lost their relative showed psychological distress and difficulty in spiritual adjustment. Current caregivers that were heavily involved in the care of a long-term surviving relative suffered from the lowest quality of life of all the groups of caregivers.

Dumont et al., (2006) reported that family caregivers' psychosocial distress is strongly associated with the patient's terminal disease progress and declined functioning. In other words, caregivers of cancer patients in advanced stages of cancer, experience higher levels of psychological distress, which increases significantly as the patient loses autonomy/independence. Furthermore, Funk et al., (2010) conducted a review of the literature on caregiving at the end of life, which included caregiving for cancer patients. It was found that providing end-of-life care led to caregivers experiencing decreases in their own physical health, isolation from social activities and friends, changes in lifestyle, disruptions to regular routine, time management issues, financial issues, and employment issues. The relationship between these should be further investigated to gain a more nuanced understanding. However. it may be that providing end of life care may involve physical efforts such as lifting and therefore may be related to the decline in physical health. The demands that come with providing this type of care may make it impossible to devote time to social activities, causing the caregivers to isolate themselves. Lastly, acknowledging that a loved one is at the stage of end-of-life, may be very different from the diagnosis of cancer itself. In basic terms, it is not only facing the illness it is also facing the inevitable loss of a loved one. These findings reveal that terminal cancer, and the associated caregiving is strong moderators of greater stress and burden amongst caregivers, impacting their lives from various dimensions. Further research can investigate the relationship between end-of-life caregiving and factors such as the decline in caregivers' health and isolation from social activities.

Moreover, research points out that the pain that cancer patients experience can contribute to the psychological distress amongst both the patient and their caregiver. In their study, Bonica et al., 1990) highlighted that up to 80% of cancer patients with advanced disease experience considerable pain, which caused both them and their caregivers psychological distress (Bonica et al., 1990). For instance, cancer patients who are experiencing pain report higher levels of depression and anxiety and lower quality of life relative to pain-free cancer patients (Glover et al., 1995, Miaskowski et al., 1997). And, cancer pain has been associated with higher levels of tension, depression, and overall mood disturbance for caregivers (Miaskowski et al., 1997).

However, research has found discrepancies between patients' and family caregivers' perceptions of the cancer-related pain experience, with caregivers typically overestimating patient pain Allen et al., 2002; Redinbaugh et al., 2002). In fact, differences in the assessment of pain between cancer patients and their family caregivers (13% children) have been associated with poorer psychosocial outcomes for both groups (Miaskowski et al., 1997). For example, cancer patient–caregiver dyads rated the patient's pain intensity using a visual analogue scale (VAS) (Miaskowski et al., 1997). The greater degree of discordance in perceived pain intensity between the patient and the caregiver, caused greater tension, depression, and confusion for the caregiver. In other words, when the caregiver thought the patient was experiencing greater pain than they were, it caused them to experience greater distress. These findings are very informative as it shows that a caregiver’s perception and outlook on the experience are strong moderators of their overall experience. This highlights an area that could become a focus in therapy with this population to help them achieve a more positive outlook on their overall experience. Thus, investigating factors associated to the caregivers’ characteristics and the impact this has on their experience is enlightening. Indeed, research that has explored the caregiver characteristics that may impact the caregiving experience highlight that, caregivers with medical conditions, a greater sense of filial duty, and a greater caregiving burden were found to have higher levels of anxiety and depression (Raveis et al., 1998, Raveis et al., 1999). Those who had a positive outlook on the caregiving experience, performed a greater variety of caregiving tasks, and those who had a higher level of satisfaction with the support received in providing care showed lower levels of anxiety (Raveis et al., 1999). Lower levels of depression scores were associated with having other social roles, having graduated college, having a positive outlook on the caregiving experience, and performing a greater variety of caregiving tasks (Raveis et al., 1998).

Caregivers may have varied experiences depending on their perception of their experience of parental cancer. Future longitudinal studies should incorporate characteristics of cancer patients and their caregivers (e.g., personality, coping efforts), contextual factors (e.g., disease stage, social support), and psychosocial outcomes for further understanding of this population.

It is important to stress that majority of the studies exploring the caregiver experiences have incorporated the experiences of young adults and spouses, as they are the ones who generally become the primary caregiver. However, it is also crucial to examine the caregiving experiences of young adults and spouses separately, as research has documented differential perceptions of burden and adaptational outcomes for these groups (George & Gwyther, 1986, Johnson & Catalano, 1983, Rankin, 1990). Studies exploring these two groups to date have yielded mixed findings. George & Gwyther, (1986) found that spouses were more likely to experience greater stress and lower wellbeing compared to the adult offspring. While Johnson & Catalano (1983) stressed that young adults were more likely to experience greater role strain. Further studies have indicated that young adults are less likely to experience physical and financial problems, but are equally likely to experience psychological distress (Barusch & Spaid, 1989, Hoyert & Seltzer, 1992, Lowenstein & Gilbar, 2000).

Focussing more precisely on young adults who has taken on a caregiving role, it found that the care-giving commitments that followed the diagnosis of parental cancer is linked to role strain, increased depression, anxiety (Aranda & Hayman-White, 2001) and burden (Given et al., 2004) amongst caregiver children. For example, Texeira (2014) examined psychological responses in 78 young adults caring for their parents diagnosed with cancer, compared to a matched group of 78 adults with healthy parents. All participants completed psychological measures of depression, distress, burden, and post-traumatic stress disorder (PTSD). Findings revealed that individuals experiencing parental cancer had higher levels of psychological symptoms. In other words, parental cancer and associated caregiving could have negative psychological impact on young adults. Strong conclusions may be drawn from this study, as a considerably large sample and a matched control group was used, reducing the likelihood of biased conclusions. Furthermore, in an earlier study by Texeira, (2013) 214 young adults caregiving for their parents with cancer completed psychological measures assessing depression, stress, and burden. Findings suggested that the psychological impact of caregiving is strongly influenced by perceived dependency of ill parent. Children who perceived their parents as highly dependent showed more distress, higher PTSD, greater caregiving burden and less satisfaction with social support. Earlier studies have confirmed this finding, by reporting that caregiver's depression and burden levels increase as patients' functional status declines (Grunfeld et al., 2004). Together these findings suggest that the level of impact of parental cancer and associated caregiving may vary significantly for different individuals depending on parent's level of dependency.

In addition, majority of literature investigating the impact of caregiving experiences on young adults have focussed on daughters. This may be because the caregiving literature in general indicates that adult daughters are heavily involved in the informal support and care of dependent older people (e.g., Kim et al., 2006; Brody, 1981). Caregiving daughters are referred to by researchers as the "sandwich generation" or "women in the middle" (Brody, 1981), due to the pressures that they experience trying to balance the needs of their marital, parental, and work roles with their caregiving demands. Employed caregiving daughters that face these demands do not reduce their caregiving, they eliminate their leisure time (Horowitz, 1985; Johnson, 1983), reduce their work hours or leave their jobs (Enright & Friss, 1987). If unemployed, they have chosen to defer entering employment (Soldo & Myllyluoma, 1983). Investigations of various long-term care situations have documented the increased incidence of depressive symptomatology and psychiatric morbidity among familial caregivers (Dura et al., 1991). Also, despite the recognition that these women provide critical parental support, most research on caring for adult cancer patients has studied samples comprised primarily of spouses (Raveis et al., 1999).

However, Leedham and Meyerowitz, (1999) found that female adult offspring who experienced parental cancer in their youth, had also experienced some negative outcomes regarding their family. These participants were affected psychologically because they had to face short-term effects of cancer in the family including changes in family members' roles, less quality time with their parent with cancer, their parent being debilitated from their illness, having to take on more household responsibilities, and the financial strain on the family. Participants also identified impending long-term consequences of parental cancer, such as the potential of parental death. These findings were based on retrospective self-report measures, and although such measures may have methodological limitations, the aim of the research was not to make general conclusions, rather was to discover how grown children of cancer patients reflect on their prior experiences.

In a more recent qualitative study, similar findings were reported. Puterman and Cadell, (2008) performed interviews examining the experiences of young adult women, aged 20 to 32 years, who were presently experiencing parental cancer. Participants reported that the timing of their parent's cancer shocked them as they felt they were too young to lose a parent. Participants alluded to conflicts between "what they were supposed to be doing" during young adulthood, and the compromises required because of their parents' illnesses. Moreover, participants also revealed their struggles to find balance between living in the present and anticipating the future. They feared and were saddened by the fact that their parent may not be present at important occasions in their lives. Some participants felt a desire to accelerate major life decisions such as marriage or having children so that the parent with cancer could be around for those experiences, but no participants implemented these decisions. Most daughters also were certain that they will develop cancer in the future. These findings show that parental cancer can be a life-altering experience and during young adulthood it can cause a conflict with the developmental goals of this stage. Translating these findings into clinical implications, individual counselling can provide an opportunity for young adults to acknowledge and work through these conflicts, and to continue negotiating their development in the context of family illness. The findings of this study were based on a small sample of 5 women only. Therefore, to get a better understanding of young adult's experience of parental cancer, future studies with a larger sample size, particularly including the experience of males is crucial.

On the other hand, Bagautdinova et al., (2023) explored sibling related experiences of adult child caregivers when caring for a parent diagnosed with blood cancer. Fifteen adult child caregivers who had at least 1 sibling was interviewed. Majority of the participants were in midlife (M age = 44) and were 87% white and 80% daughters. A thematic analysis was conducted, and three overarching themes emerged. Caregivers described 3 types of sibling-related experiences that centred on caregiving responsibilities*,* expectations about the caregiver role and coping together and apart*.* Firstly, caregivers described the importance of sibling involvement on the caregiving demands, however also experienced challenges due to lack of involvement and the experience of frustration towards their sibling(s). Secondly, they referred to societal expectations about caregiving such as gendered expectations about their role. Caregivers and some of their siblings associated the caregiving role with being a woman or a daughter in the family system. They also referred to family status expectations when discussing their role as primary caregiver versus other siblings. This included marital status, with those divorced or single siblings expected to take on more responsibilities. It also included child status, as those siblings with children had less expectations given their parental obligations. caregivers mentioned sibling birth order expectations in reference to caregiving. Being the oldest child in the family was associated with an assumption of being the primary caregiver within the family system. However, birth order and the primary caregiving role did not always coincide, which they remarked went against expectations though upheld others societal norms (e.g., gendered roles). Lastly, caregivers also shared sibling-related experiences that capture their coping and adjustment to their parent's disease. Some people described cooping together and some apart. Most of them described becoming closer and that the relational communication enhanced in the family system (Bagautdinova et al., 2023).

These findings illustrate how parental cancer can influence the sibling bond, as well as contribute to tension, particularly regarding the experiences of not sharing caregiving tasks. Findings also provide insight into areas in which supportive interventions or resources are needed (e.g., helping siblings talk about caregiving involvement) to promote healthy family functioning after a parent is diagnosed with cancer. It must however be noted that, most of the participants were women and white. Future research should both capture men's experiences and represent ethnically and racially diverse caregivers, given that both gender and culture inform familial expectations and caregiving experiences. Also, only one sibling within the family was interviewed. Future research should aim for a family systems approach by capturing other siblings' perspectives. Additionally, this study was focussed on caregivers whose parents had blood cancer, and future research should consider populations experiencing other forms of cancer which may differ in terms of treatment and prognosis.

Coping and support needs for caregivers of cancer patients

Caregiving for a patient is likely to be a demanding and traumatic experience. Children are impacted significantly by their caregiving roles and demands, they experience emotional distress, anxiety, and burden. Caregivers may be underprepared for their role, leading to powerful negative emotions, stress, and anxiety. Funk et al., (2010) found that the stress of caregiving was found to be due to a combination of realizing the impending loss of a loved one and seeing them suffer while also not having the support or information to provide proper care. Therefore, appropriate support from other family members, friends, and medical professionals, will increase caregiver's capacity for their caregiving responsibilities, while minimizing their personal distress (Given et al., 2001). This balance allows caregivers to improve their psychological, physical, and emotional well-being and reduce levels of stress and depression, which can lead to the caregiver providing better care (Given et al., 2001). If caregivers can understand the value of the care they provide, this can also reduce the burden of caregiving (Given et al., 2001). Health care professionals can play an important role by providing caregivers with information on how to care for their family member at home, thus easing a component of the frustration and stress of caregiving (Given et al., 2001). The health care professional can also tailor the care plan to fit both the needs of the patient and the caregiver (Given et al., 2001).

Moreover, Funk et al., (2010) also concluded from their review of caregiving at the end of life that most studies identified a need for balance between formal support, such as the healthcare team, and informal support from friends and family. These support systems can promote “coping”, “security”, “reassurance”, and the “manageability” of the experience itself (Funk et al., 2010). The caregiving experience can also have positive components, such as when caregivers discover positive or rewarding aspects of their experience (Funk et al., 2010). These positive and/or rewarding aspects have been found to be a method of coping because it helps the caregiver find personal meaning in their caregiving role (Funk et al., 2010). Caregivers can also experience post-traumatic growth from their caregiving experience because they are heavily involved in the cancer experience itself (Thornton & Perez, 2006).

Kang et al., (2013) conducted a cross-sectional survey of 501 bereaved family members who served as caregivers, to determine what the positive outcomes of caregiving for a terminal cancer patient were. Older age, being female, being a spouse, and the caregiver’s religion significantly correlated with the positive outcomes of the caregiving experience. Older caregivers experienced more meaning in their life and they also reported appreciating others in their life more after their caregiving experience. Men benefit less from the caregiving experience than women do, but if a caregiver was female, she was more likely to experience mental health issues alongside experiencing the positive outcomes of caregiving. It’s also important to note that the investigators found that the caregivers’ depression and/or experience of caregiving burden did not influence whether they perceived positive outcomes from the caregiving experience. Religious beliefs were also found to increases the chances that caregivers would perceive positive outcomes from their experience. Kang et al., (2013) indicated that the most important finding of the study was that the care the caregiver received after the death of the cancer patient significantly increased the chance that caregivers could achieve positive outcomes from their experience such as: control over their own life, appreciating others, finding life meaning, and changing attitudes and values in their life. However, the findings of this study should be interpreted in caution as it was carried out nationwide in Korea. Therefore, the experiences of individuals from other countries or cultures may vary significantly, highlighting the need for future research in this area.

Even though research has shown that caregivers of cancer patients health shows declines (Funk et al., 2010). Research examining whether family members are influenced to make their own lifestyle changes, such as eating healthier or becoming more physically active, after observing a family member experience cancer has been minimal (Kim & Given, 2008). The only one that is known so far is by Mazanec et al., (2011) who explored the health behaviour practices and work productivity of caregivers of people with an advanced form of cancer. Caregivers rated their personal health as “good” or “excellent” and they reported participating in screening, regular medical appointments, and having a healthy diet. The caregivers didn’t report meeting the recommendation of 150 minutes of moderate physical activity per week (Canadian Society for Exercise Physiology, 2012; Mazanec et al., 2011). This study suggests that behaviours such as participating in screening, regular medical appointments, and having a healthy diet may contribute to feeling “healthy” and “good”.

Interventions can reduce emotional distress in cancer patients and their caregivers. A meta-analysis on 29 randomized clinical trials that delivered psychosocial interventions to cancer patients and their family caregivers were analysed (Northouse et al., 2010). This study included a large sample of individuals from a variety of backgrounds (Caucasian, Hispanic, African, Australian, Hawaiian and other) and age groups. The findings revealed that the caregivers benefitted from these interventions in several ways. The interventions resulted in reduced caregivers' burden, increased caregivers' knowledge and perceived benefits of caregiving, enhanced caregivers' coping resources and self-efficacy, and improved many aspects of the caregiver's quality of life. These interventions were classified in to three groups: psycho-educational, skills training or therapeutic counselling. The dose of the interventions ranged from 2-16 sessions, and were offered in face-to-face (68.6%), phone (20%) or group (11.3%) format. 16 of these studies measured the effects of these interventions on caregiver burden, depression, and anxiety. Findings revealed that the interventions significantly reduced caregivers' burden (Caregiving burden was conceptualized as caring as a strain or demanding activity, an overinvestment, or a negative reaction to activities related to caring for the patient) and anxiety. However, there was no significant reduction in depression in this group. This finding must be viewed with caution because in some studies caregivers had little depression at the start of the study, and in other studies, caregivers who were more depressed dropped out of the study. Similarly, in a separate meta-analysis that examined the effect of interventions on depression in cancer patients, there was also no significant reduction in patient depression. Findings from these meta-analyses suggest that it may be more difficult to reduce depression than to reduce emotional distress and anxiety, but this needs further research. However, these findings also show that this group can benefit from interventions and gaining an understanding of their needs can help develop interventions that will prove more beneficial for them.

Another rare qualitative study exploring the experiences of young adult women impacted by parental cancer was by Patterson and Rangganadhan, (2010). They examined the unmet needs of participants with the aim to explore the difficulties they encountered on facing parental cancer. The second most prevalent unmet need was "help coping with feelings". The participants emphasised on their need for assistance in managing their negative emotions such as feelings of anger, grief, and depression. These findings together show that individuals impacted by parental cancer need help in coping with the emotional arousal that is caused on facing parental cancer.

Moreover, in the same study "support and understanding" was the most prevalent unmet need. The participants mentioned needing more support from their teachers, friends, the public, and their own family members. Friends were identified as being unable to have a full understanding of the experience of losing a parent to cancer and how this experience affected the bereaved adolescent or young adult. Conversely, participants identified the need "to talk to people who have had a similar experience" and that this could occur by communicating with other people their age, who had also lost a parent to cancer. Leedham and Meyerowitz, (1999) examined the experiences of adult women who had lost a parent to cancer and found that these women also recollected having difficulties with their relationships and friendships, while they were experiencing parental cancer. Schmidt and Welsh, (2010) explored how facing the chronic and/or terminal illness of a family member affects university students' adjustment to university life. Many students identified withdrawing from social activities and feeling strain because there wasn't enough time to spend with family and friends due to their family members' illness. Clearly, individuals impacted by parental cancer experience difficulties in various domains of their life, and they could be supported to overcome such difficulties.

Growth that comes with Parental Cancer

Parental cancer is surely a traumatic experience therefore, majority of studies have focussed on the consequent negative impacts. However, research has also documented that parental cancer can have positive impacts on young adults such as increased feelings of personal strength, appreciation of each day (Leedham & Meyerowitz, 1999) and improved family relationships (Thornton, 2002). Leedham & Meyerowitz, (1999) report that although participants reported experiencing emotional distress during the acute phase of their parents diagnoses and treatment, the vast majority (93.3%) indicated that cancer had caused at least one positive change in their lives, particularly in the interpersonal and existential domains.

Furthermore, Mosher et al., (2006) performed a quantitative study, using cross-sectional surveys to explore the possible benefits related to the experience of caregiving for a parent with cancer. In their study, the scores, and experiences of 30 women caring for their parents with breast cancer were compared to 16 women with healthy parents. Women who cared for their ill parent, and who found the diagnosis to be stressful reported a greater level of post-traumatic growth, life satisfaction and social support, which clearly contradicts the findings by Texeira (2013). However, Kim et al., (2007) found that carers who have higher levels of social support were more likely to perceive benefits. This highlights the need for further research investigating the casual relationship between social support and adult offspring's perception of positive benefits for caring for ill-parents. In sum, these findings have very important implications for counselling psychology, as it indicates that providing appropriate support for caregivers may decrease their burden and increase positive outcomes.

Moving forward, Mosher et al., (2006) also reported that women experiencing maternal cancer did not differ from women who had healthy parents in terms of psychological wellbeing. These findings imply that daughters of parents with breast cancer could experience positive growth and do not differ in regard to psychological wellbeing compared to women with healthy parents. However, the credibility of this study is questioned as the sample size in this study is relatively small for a quantitative research methodology. In addition, Mosher et al., (2006) has not provided a detailed account of the positive growth domain, therefore what he means by it remains unclear. Nevertheless, Oktay (2005) also explored the impact of maternal cancer on female young adults using a qualitative approach and collected data using interviews. In line with Mosher et al (2006) caregiver offspring reported that maternal cancer also caused positive growth for them. These findings provide rich information about the experience of parental breast cancer and indicate that parental breast cancer may impact adult offspring positively. However, the adult offspring's experience of other types of parental cancer is still to be explored as both studies were based on parental breast cancer. Undoubtedly, cancer types classed as more serious or in serious/terminal stages would cause higher distress levels and have a differing impact on young adults (Compas et al., 1996). Therefore, studies using comparable samples regarding the type of cancer, and providing a more detailed account of the positive growth domain are crucial to get a better understanding about the diverse experiences of this affected population.

On the other hand, Levesque & Mayberry (2012) performed 11 interviews with adults whose parents were diagnosed with different types of cancer, in an aim to understand the perceived benefits and consequences of parental cancer. The data was analysed using Interpretive Phenomenological Analysis (IPA), which allows gaining greater insight into how people understand their own world (Willig, 2001). It was conveyed that all the participants were able to report positive outcomes and a detailed account of these positive outcomes were provided. These benefits included improved relationships with ill parents, changes in life priorities, a greater focus on family, and personal development. These findings are important to inform practice and may suggest that a greater emphasis on the possible beneficial outcomes may help adult offspring's' impacted by parental cancer to cope. Nevertheless, the credibility of this study is called in to question as there was no criteria restricting the time gap between the experience and the interview. Therefore, recall could have been affected, and the perceived positive outcomes may have been influenced by other life events. Even though these findings are not generalizable and conclusive, they provide useful information that could guide future research and inform therapeutic practice. In addition, qualitative methods allow individuals to express their experiences more openly and without being limited to categories that may not reflect their subjective lived experiences precisely or fully (Rapley, 2004). Consequently, further research employing qualitative approaches are vital.

Research generally tends to derive negative experiences of individuals impacted by parental cancer. However, some other studies have shed light on the positive life changes or posttraumatic growth of cancer patients too (Cordova et al., 2001, Cruess et al., 2000, Katz et al., 2001, Sears et al., 2003, Stanton et al., 2002). Considering the above literature, research efforts should include an examination of both positive and negative psychosocial experiences of individuals impacted by parental cancer, to gain a more nuanced and complete understanding of the experience.

Understanding the impact of parental illness in the light of Theories

Considering the literature, young adults are impacted in various ways by their parents' illness and this impact may differ for everyone. A factor that could influence this impact can be the relationship between the parent and adult child prior to the cancer diagnosis. The attachment theory can provide a framework for understanding the experience of young adults impacted by parental cancer as it is solely concerned about the parent-child relationship. According to the attachment theory the parent–child attachment constitutes a biological need for love and caregiving that is hardwired and essential for survival (Bowlby 1982). Attachment theory proposes that threats to, or permanent breaks in, the attachment system serve as distressing and potentially traumatic events for children. A serious parental illness can be viewed as a threat to the attachment system. Children contending with a parent's cancer illness must also grapple with significant attachment-related challenges. These challenges may especially arise from the realization, upon witnessing their caregiver in the throes of a life-threatening illness, that their parent is vulnerable and may die. According to the attachment theory, the attachment style that the parent-child had formed in the first years of their life will also affect their experience when the parent becomes ill. Research shows that individuals with insecure attachment styles (dismissing avoidant, preoccupied/anxious, fearful or disorganized) were more likely to experience more grief and less post-traumatic growth (Cohen & Katz, 2015). People with dismissing/avoidant attachment styles, tended to suppress their negative feelings and converted those negative emotions into physical symptoms like headaches or abdominal distress (Wayment & Vierthaler, 2002). In contrast, those with preoccupied attachment styles almost never suppress their emotions and experience more intense prolonged grief (Lai et al., 2015; Maccallum & Bryant, 2018). Future research could take into consideration the attachment style between the parent-child when studying their experiences of facing parental illness, which may provide an explanation to why everyone may respond differently to the experience.

Another theory that can contribute to our understanding of the experience of young adults and families impacted by a parents life-threatening illness is the Family systems theory (Kerr and bowen, 1988). Family systems theory (Kerr and Bowen, 1988) is a theory of human behaviours that defines the family unit as a complex social system, in which members interact to influence each other's behaviours. Family systems theory has been applied to a wide variety of areas including psychotherapy in general and family therapy (i.e., health care (medical family therapy – tracking the emotional dynamics of illness and facilitating collaboration among patients, families, providers, and health care systems). According to a family systems perspective, an individual's functioning is determined not so much by intrapsychic factors as by a person's place in the system(s) in which he or she finds himself or herself, subject to the pushes and pulls of the system, including competing emotional demands, role definitions and expectations, boundary and hierarchy issues, coalitions and collusions, loyalty conflicts, family and institutional culture and belief systems, double binds, projective identifications, and systemic anxiety. In addition, self-correcting and self-reinforcing feedback loops in a system can either facilitate or hinder pathology or health, breakdown, or resilience (Watson, 2012; Watson & Enns, 2012). Therefore, when a family member is impacted by an illness, the positions of individuals in the family system may change, and for young adults they may find themselves in new roles, boundaries, and emotional demands.

When the family is hit by a life-threatening illness, it is like the addition of a new infant member, one with 'special needs' that will compete with those of the real children for potentially scarce family resources that are diminished by parental loss. If the illness is terminal, the inevitability of death becomes apparent and dominates family life. The family must cope with issues of separation, death, mourning and family reorganization beyond the loss (McGoldrick et al., 1991). It is how the family adapts to these changes that can govern the influence of a life-threatening illness on each individual member. Although little is known regarding what traits of a family may help the members cope through this process, the family systems approach suggests that families adapt best to this phase when they can shift their view of mastery from controlling the illness to a successful process of 'letting go' (Rolland, 1999). Further research exploring the link between the family systems and the experience of parental cancer will reveal critical information for the understanding of this population.

Rational & Aims of the present study

Overall, these findings provide important implications for counselling psychology by revealing the gaps in the current literature and stressing the importance of the following two points. Firstly, it is vital to develop programs and provide support for young adults impacted by parental cancer. Secondly, it is apparent that the impact of parental cancer is a very subjective and personal experience that may be influenced by many factors in one's life. Therefore, affected individuals may show differing presenting problems in psychiatric services/practice. Further research exploring the unique and subjective impact or experience of parental cancer and factors that influence this impact on young adults is crucial to establish rich data and an enhanced understanding of this population.

Therefore, the aim of this research is to further our understanding of the specific experience of adults who have a parent with cancer. The aim is not to draw on generalizable findings, but to gain a richer understanding of the experience as reported by the participants. In getting a deeper understanding of the participants experience of parental cancer, the aim is to identify gaps in the literature and direct literature in ways that could increase our knowledge, and in turn, help develop support and interventions for this population. The present study provides an opportunity for individuals impacted by parental cancer to express themselves freely, without their experiences being categorised into assessment tools or questionnaires. Therefore, a qualitative approach and Interpretative Phenomenological analysis (IPA) was conducted, in an aim to reveal information on "*Young Adults Experience of Parental Cancer".*

Objective:

The question this study sought to answer was: *What is it like for a young adult to have a parent diagnosed with cancer?*

CHAPTER TWO - METHODOLOGY

Conceptual Methodological

Overview

This chapter will aim to discuss qualitative research and Interpretative Phenomenological Analysis (IPA), and the epistemological standpoint in relation to the choice of methodology used in this research. Furthermore, a descriptive outline of the research procedures, sampling considerations, recruitment, data collection methods, and analytic procedure will follow. Lastly, the ethical considerations and the reflexivity process is highlighted in depth.

Use of first person

I have used first person within this section to align myself with the phenomenological approach which emphasizes the role of the researcher and the process of reflexivity throughout my study (Smith et al., 2009).

Rationale for adopting a qualitative research paradigm

The aim of this research was to further our understanding of the specific experience of adults who have a parent with cancer. To my knowledge, research carried out that relates to this topic are based predominantly on quantitative methodology, using tools such as questionnaires and scales in an aim to understand the experience of this group in general. However, it is clear from the literature that having a parent with cancer is a very subjective experience that may be influenced by various factors. It is not possible to capture the subjective, unique, and widely varying experiences of everyone with quantitative approaches. Therefore, a qualitative study was considered as a suitable methodological approach, which provides the opportunity to understand the subjective experiences of individuals, while acknowledging that different people can perceive and experience the same environment in radically different ways (Willig, 2013).

This study explores the experience of young adults who have a parent with a life-threatening illness. Qualitative research is an appropriate design as it will seek to engage with the data to gain new insights into the ways in which each individual construct meaning in their unique world. The rich quality and texture amongst the responses will help identify and embrace the similarities among and differences between the individuals (Willig, 2008) experiencing parental cancer.

The aim is not to establish generalizable findings, it is to gain an in-depth understanding of a subjective experience of young adults impacted by parental cancer. According to Husserl this is essential, as science is a second order knowledge system, dependent on first order personal experiences (Smith et al., 2009). Hence, qualitative research employing phenomenological investigations could influence both qualitative and quantitative research by eliciting previously unrecognised themes, which will in turn inform counselling psychology and therapeutic practice. The development of a coherent body of knowledge will inform and guide support for children impacted by their parents life-threatening illness and the difficulties related to it. Also, another aim was to give the participants an opportunity to express their experiences and be heard. A qualitative research design enables both aims to be achieved.

Epistemological position

The theoretical and philosophical bases of qualitative research is a significant factor in research that must be considered, as it will affect every component of a research from the research question to data collection and analysis. Therefore, it is vital for the researchers to identify and outline their epistemological position and ontology, to evaluate research in a meaningful way and to be able to state what knowledge their research is aiming to produce (Willig, 2013). Epistemology is the branch of philosophy concerned with the understanding of how we know things, whilst ontology is the branch of philosophy concerned with the nature of reality (Smith, 2015; Willig, 2013). For the purposes of clarity, I will discuss epistemology and ontology separately.

The different researchers used different typologies to categorise epistemological positions (Madill & Gough, 2008). For instance, Ponterotto (2005) uses the classification of positivism, post- positivism, constructivism-interpretivism and critical-ideological; Willig (2013) distinguishes between realism, phenomenology, and social constructionism; Madill et alk., (2000) proposed the framework of realism, contextual constructionism and radical constructionism; and Clarke & Braun (2013) use the epistemological continuum of positivism, contextualism and constructionism. After much thought, I decided to use the epistemological strands proposed by Willig (2013), as I find this one to be the most understandable framework. I will briefly discuss all three epistemological positions outlined in this typology and then discuss my chosen position in more detail.

Realist knowledge aspires to capture and reflect as truthfully as possible something that is happening in the real world and that exists independently of the researchers, and indeed the research participants', views, or knowledge about it. A researcher aiming to derive phenomenological knowledge is interested in the subjective experience of individuals, capturing their feelings, thoughts, and perception. Social constructionist knowledge is not interested in knowledge about the world or knowledge about how things are (experienced) but rather knowledge about the process by which such knowledge is constructed in the first place. It is interested in how people talk about the world and therefore how they construct versions of reality using language.

It is essential for the qualitative researcher to acknowledge their own beliefs, assumptions and experiences, as both the participants' and researchers' interpretation of events contribute to the process of making sense of the findings. However, Willig (2012) highlights that it can be challenging to acknowledge and directly express our assumptions within the range of epistemological positions that are available. Indeed, I found it challenging to understand the different epistemological positions and how they may apply to my research question. To help me become more aware of and prepared to acknowledge my own epistemological stance, I set to answer the following questions as suggested by Willig (2012): What kind of knowledge do I aim to produce? What are the assumptions I make about the world? What is the relationship between myself and the knowledge that I aim to generate?

I was interested in the experiential world of the participants and to create knowledge that explores what it is really like for the participants. The aim was to get close to their unique world and explore how their experience differs from the experience of another participant that may have experienced the same event. Therefore, this qualitative research aimed to generate phenomenological knowledge. Phenomenological knowledge ranges from 'descriptive' to 'interpretative'. Descriptive phenomenological knowledge would stay close to the participants' account as it is believed that meaning cannot be found outside the actual experience. This research intended to move beyond the experience at 'face value' and to step outside the account to reflect on the wider meanings. The knowledge produced would therefore involve a process of interpretation of the participants' experiences of their parent with cancer.

I intend to produce 'interpretative phenomenological' knowledge, as this approach believes that an understanding of the phenomena can only be made when we allow our own conceptions and standpoints to inform our analysis of the data. This enabled me to move beyond the 'descriptive' data and reflect on wider social, cultural, and psychological meanings that underpin the participants' subjective accounts (Willig, 2012). It is necessary to adopt a reflexive attitude as my experiences, expectations and assumptions become the bases of how I interpret and give meaning to each account to understand it. Therefore, according to interpretative phenomenologists, it is not in fact possible to produce pure descriptions to capture and comprehend the experience as it is inevitable that a certain amount of interpretation will have to be applied (Willig, 2012). I will later discuss how I aimed to make my own impact (e.g., experiences, attitudes, beliefs, culture, etc.) more transparent in the research.

Ontological standpoint

If the ontological positions were explained on a continuum, the realist position will be at the one end, which holds the belief that there is a reality that is independent of our thinking (Kirk, 2012) and it can be captured by research investigations (Guba & Lincoln, 1994). The critical realist position can be placed in the middle, which holds the view that data is not a direct reflection of reality but the outcome of interpretation, allowing the possibility that there are different explanations to the nature of truth (Willig, 2012). At the other end of the ontological continuum, the relativist position considers reality to be constructed by people's beliefs, thoughts and language (Guba & Lincoln, 1994).

The ontological position held by this research is a critical realist position. The critical realist position allows us to explore what may be going on in the world, while also acknowledging that data gathered may not reflect the reality (Clarke et al., 2015). This approach assumes that there is a real specific phenomenon in the wider social world that is shaped by the way an individual's constructs meaning in his or her own world (Willig, 2012a). In other words, real world exists but each person constructs their own version of it (Eatough et al., 2008). Furthermore, the critical realist position accepts the hermeneutic notion that knowledge is constructed, and that our concepts and beliefs can be challenged and are subject to change

(Wikgren, 2005). As a result, the data collected, and information gathered from a study that positions within this philosophy acknowledges that the knowledge created is a result of the participants and researchers lived worlds.

The interpretive phenomenological stance adopted by the study allowed the researcher to interpret the participants lived experiences. Also, the critical realist position adopted by this research, allowed the therapist to acknowledge that there is a specific phenomenon that we can know about, which is not experienced in a single way, rather can be experienced in many ways. In other words, there is not one truth but many truths about the specific experience of having a parent with cancer.

It is important to note that even though my ontological and epistemological viewpoints were not explicit to me. I think my epistemological and ontological views impacted this research and my decision-making from the beginning. I was not explicitly aware of what they were until I immersed myself more in my research, and after I read more on epistemology and ontology, I realised which positions expressed my beliefs.

Rational for adopting IPA as the analytical methodology

In asking how adult individuals experienced having a parent with cancer, this study aimed to understand the subjective experience of each individual and how they make sense of their experience (Willig, 2013). Therefore, Interpretative Phenomenological Analysis was deemed as the most appropriate approach to employ for this study for the following reasons. It is concerned with the detailed examination of lived experience and it enables that experience is expressed in its own terms, rather than according to predefined category systems (Smith et al., 2009). IPA is an inductive and flexible approach, which allows for new themes and ideas to be developed, which is an important advantage when the topic under investigation is under-researched, as with my research (Smith, 2004).

Another rationale for using IPA, is its close relation to Counselling Psychology which adopts a phenomenological approach as the field maintains to explore the subjectivity and idiosyncratic nature of individual accounts. In addition to drawing on a scientific approach, Counselling Psychology aims to jointly create findings between the clinician and patient from their interactive dialogue and interpretation. It does not assume there is a ‘correct’ or ‘true’ way of experiencing a phenomenon, all of which resonate within IPA and my natural way of thinking and working. Also, IPA adopts a holistic view of the person influenced by humanistic psychology. As a trainee counselling psychologist whose profession is underpinned by these humanistic values and holistic view of the individual, I was naturally drawn to IPA as my method of choice (Eatough & Smith, 2007).

However, before selecting IPA as the most suitable analytical methodology, three other approaches were carefully considered and was disregarded, as they were incompatible with the research aims. The initial approach considered was Narrative Analysis, as the focus is also on the participant's experiences, and care is given for the interview to be participants led. Like with IPA, NA also acknowledges the role of the researcher, who should always be mindful and consistently revisit their role in shaping the narratives (Murray, 2003). However, although interpretation of themes drawn from the interview does occur, the primary focus of NA is on the structure of the narrative itself (Murray, 2003), which is not what the presenting research aims to explore. Moreover, grounded theory was also considered, however, its concern with identifying social processes from data and generation of common and explanatory themes was also incompatible the research aims (Willig, 2013). Lastly, Discourse Analysis was considered, as it acknowledges the significance of language within qualitative methods (Potter & Wetherell, 1987). However, the focus of Discourse analysis is on the participant's construction of their experience through language and discourse (Willig, 2013). Surely, if the aim of the research were to explore how individuals use discursive resources to construct their experience of having a parent with cancer, DA would have been a suitable method. As the research aims to explore the experience of adults who have a parent with cancer, in depth, IPA is deemed to be the most appropriate analytical approach.

I have, so far, justified my choice of IPA as the most suitable method of data analysis in relation to my research question. In the next section I will describe IPA and examine the theoretical underpinnings of IPA.

Interpretative Phenomenological Analysis & the Philosophical underpinnings

Interpretative Phenomenological Analysis (IPA) is a qualitative methodology of data analysis articulated by Smith in 1996. IPA is a relatively new method as it was created almost 20 years ago; however, it has a long history as the theoretical underpinnings of the approach have a long tradition. These theoretical positions are phenomenology, hermeneutics, idiography and symbolic interactionism (Smith et al., 2022).

Interpretive Phenomenological Analysis (IPA) is a qualitative research approach, created by Smith in 1996 (Eatough & Smith, 2008), which aims to study how people perceive an experience, and particularly how they make sense of their lived experiences (Langdridge, 2007). IPA assumes an epistemological stance whereby, through careful and explicit interpretative engagement, it becomes possible to understand an individual's subjective experience of a specific phenomenon. In other words, IPA engages in the process of looking in detail how the person reflects on and makes sense of their experience, thus connecting phenomenology and hermeneutics, with an idiographic lens (Smith et al., 2022).

The philosophical underpinnings of IPA have been influenced by the thoughts of phenomenological Philosophers such as Husserl, (1999) and Heidegger, (1927; 1962). Husserls (1972) ideas involves the examination of human experience to identify essential qualities of that experience. The descriptive aim of IPA is influenced by this approach, in which it attempts to reflect as closely as possible the participant’s life world (Eatough & Smith, 2008). On the other hand, Heidegger (1927, 1962) emphasised that reality was based within the human individual who interpreted and made meaning from the world. The process of revealing and making sense of an experience requires interpretative engagement (Moran, & Moorey, 2002). Therefore, IPA is phenomenological in attempting to get close as possible to the personal experience of the participants and is hermeneutic as it is impossible to gain understanding without an interpretative engagement. In other terms, without phenomenology, there will be nothing to interpret, and without the hermeneutics, the phenomenon would not be seen (Smith et al., 2009).

Nevertheless, it is argued by Heidegger (1962) that it is impossible to be free of any preconceptions when looking at and making sense of someone’s lifeworld. No observation or interpretation is free from the interpreter’s experiences, presuppositions and projections, and relationship to the world operates in a “hermeneutic circle” (Eatough & Smith, 2008). Therefore, in research the hermeneutic circle requires the researcher to acknowledge their preconceptions and assumptions when they attempt to understand the others experience (Smith & Osborne, 2007). It also requires the researcher to use knowledge that they when thinking about how they approach the phenomenon (Packer & Addison, 1989). Therefore, it is vital that the researcher takes a sensitive and responsive position by acknowledging the impact of themselves on the research, in an aim to reduce it as much as it is possible (Larkin et al., 2006). However, IPA accepts that it is impossible to gain direct access to an individual's lifeworld, and the understanding is based on the interpretation of the researcher (Willig, 2013), which is referred to as the double hermeneutic (Smith & Osborn, 2008). IPA acknowledges that full bracketing of our prior assumptions is not possible as we are not fully aware of all our preconceptions (Smith & Osborn, 2008).

Moreover, IPA also recognises that access to the experience of others is dependent on what and how the other communicates, and it is the researcher that needs to interpret this account to make sense of what is shared as the experience (Smith et al., 2009). Therefore, the participant is trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world, which Smith and Osborn (2008) refer to as the "double hermeneutic". Although the interpretative side of IPA can be challenging, it is a considerably flexible analytical approach that could adapt to different research titles (Larkin et al., 2006). There are no set guidelines to how it should be conducted (Smith et al., 2009). For instance, there is no prescribed sample size, sample strategy, data collection method, analysis and how the research is written up (Eatough & Smith, 2008).

Reflexivity

Reflexivity is a significant part of qualitative research, which is referred to as the ability of recognising the different ways in which the researcher affects the research and findings (Willig, 2013). Qualitative research has argued that it is impossible for a researcher to position themselves outside of the subject matter as the researcher inevitably influences and shapes the research process (Willig, 2013). Therefore, it is crucial that the researcher acknowledges and is aware of the experiences and beliefs that could influence the research.

Willig (2013) differentiates between two types of reflexivity in qualitative research:

1. Personal reflexivity: which focuses on how the researchers, values, assumptions, characteristics can influence the research process. It also refers to consideration of the influence the research process has upon the researcher.
2. Epistemological reflexivity: which refers to the researcher's assumptions about epistemology, ontology and choice of method, and how they may have influenced the findings of the study (Willig, 2013)

I have provided my epistemological reflexivity earlier on, in the epistemological standpoint section (see above). In the next section, I will provide a brief personal reflexivity. However, throughout the research process I realised that my speaking position deserves and should be integrated throughout the research (Coyle, 2007). I did not want to restrict my reflexivity in the study thus, I have been reflexive throughout the research process and write up, when I felt it was appropriate.

Throughout the research process, I kept a reflexive journal in which I used the 'free association method'. I attempted to capture my own process not only as a researcher but also as a trainee counselling psychologist who was going through a similar experience as my participants, which I will discuss further in the personal reflexivity section.

Personal reflexivity

My interest in this topic rooted from my own personal experience of having a mother who had experienced having cancer for several years. Therefore, I am very much embedded in the research process rather than a distant observer. In qualitative research, personal reflexivity is needed to acknowledge the ways in which the researcher impacted on data collection and analysis (Willig, 2008). It is hoped that, by disclosing my connection to the topic under investigation, as much as these are accessible to consciousness, I can both prevent these from interfering with my analytic process and inform any future audience about potential biases prior to their engagement with my account. Dogson, (2019) highlights that when qualitative researchers describe the contextual identities and relationships between participants and themselves, it enhances the understanding of the research and increases trustworthiness.

Maso, (2003) states that every researcher must know what motivated the research question, which beliefs are behind it and which conceptual framework it is an expression. To do this, researchers must cross-examine themselves and unravel their involvement in the research, which I will aim to do in the next few paragraphs. Throughout the process of my mother's illness, I had experiences that I wanted to better understand. I often found myself questioning if everyone else understands how I feel, and a sense of not knowing how to cope. I became very curious about research into the experience of parental cancer. Through first person experience, it became apparent that there were major gaps in the literature, and not enough understanding around the experience of individuals who have a parent with cancer. And even when there was research, it appeared that majority of them were based on quantitative methodology, and generally on children. The unique experiences of individuals experiencing parental cancer was minimal. Therefore, my own personal experience coupled with the gaps in the literature have informed the presenting study and its choice of methodology. I am highly motivated about this research, as I strongly feel that research in this area will inform therapeutic practice, and tailored support systems could be developed for individuals that are experiencing having an ill parent.

Having experienced the phenomenon being studied, I have many similarities with the participants and therefore, consider myself as a ‘cultural insider’. Being familiar with the topic under research can come with advantages. For instance, Smith et al., (2009) states that the empathy provided by a shared humanity and common cultural understanding could be an important bridge between researcher and participant’s and a valuable analytic resource. I agree that, resonating with the participants has allowed me to approach them empathically and approach the data with a greater curiosity. Padgett, (2016) pointed out that in studying the familiar, it is easier to enter and get a head start in knowing about the topic and understanding nuanced reactions of participants. Indeed, coming from the ‘shard experience’ position, I was better equipped with insights and the ability to understand implied content, and was more sensitized to certain dimensions of the data. For instance, I was familiar with the terms used to describe ‘treatment processes’ and aware of potential sensitivities, thus I knew what to ask and how to ask it as well as understood the responses in a nuanced and multileveled way. Also, as a cultural insider I was able to hear the unsaid, probe more efficiently, and ferret out hints that others might miss, which gave opportunity to elicit further detail.

On the other hand, an insider’s position and familiarity carry the risks of blurring boundaries; imposing own values, beliefs, and perceptions by a researcher; and projection of biases (Drake, 2010). Bringing the researcher into the researched carries the danger of researcher’s self- involvement to the degree that it blocks hearing other voices (Cloke et al., 2000). And therefore, the researcher’s preoccupation with their own emotions can distort research findings in an undesirable way. Yet, it is rare if not impossible to embark on a research study without any preconceived knowledge, biases, or emotions about the topic, which is why bracketing becomes so important at all stages of the research process (Finlay, 2002).

As a daughter, of a mother who has suffered from cancer for long years I was aware that my personal standpoint could have been a threat to the meaningfulness and transferability of this research if I did not acknowledge this possibility (Dixon et al., 2004). Therefore, as the researcher I took extra care to use the skill of bracketing on my own thought processes, in an aim to reduce their impact on my interpretative engagement. However, it must be acknowledged that, Philosophers such as Heidegger has highlighted that bracketing may be imperfect (Landridge, 2007) and interpretive engagement is part of IPA. Therefore, the researcher needs to acknowledge their preconceptions and assumptions when they attempt to understand the others experience (Smith, 2007). I managed this process by keeping a self-reflective journal/diary, in an aim to acknowledge and reduce my impact as much as it is possible (King & Horrocks, 2018). Finlay, (2012) highlight the importance of the researcher to look through a critical lens at the process, context, and outcomes of research and interrogate the construction of knowledge. I tried to implement this by asking myself the following key questions: What am I trying to do? Why am I carrying out the interview this way? How is my approach affecting the research? (Finlay, 2012). By a continuous reflexivity process, I was able to ensure that I do not become too self-absorbed in the research process in that I risk overshadowing the voices of the participants (Finlay, 2012).

Being a member of the participant group does not disproportionately influence the process in a negative or positive way (Dwyer & Buckle, 2009). Researchers always need to consider their position and role in the research process. Disciplined bracketing and detailed reflection on the subjective research process, with a close awareness of one's own personal biases and perspectives, may well reduce the potential concerns associated with insider membership. Therefore, the key aspect is not insider or outsider status, but an ability to be open, authentic, honest, deeply interested in the experiences of one's research participants, and committed to accurately and adequately representing their experience (Dwyer and Buckle, 2009). According to Dwyer and Buckle et al. (2009) it is possible to occupy both insider and outsider researcher positions: using insider knowledge to help inform potential areas to investigate (e.g., the questions asked), yet holding a position of naivety during interviews. Taking this into consideration, I also feel that I had an outsider position in many ways. I had only experienced having a mother with bladder cancer and was naïve to the subjective experiences of everyone and their families who had various characteristics that were different to mine. At all times, I held the position that every experience is substantially unique in their own way, and I was genuinely curious in hearing each one as told by the participants. At times, I did find myself comparing and thinking that participants experiences resonated with mine, however, I also was able to reflect on participants experiences that were very different from mine.

Moreover, as a Trainee Counselling Psychologist, I feel that my engagement in the interviews is prone to be impacted by my practice/profession. For instance, it has been reported that being in training has been recognised as a time of creating an identity as a counsellor/psychotherapist (Grafanki, 2010). Therefore, this may influence how I interact with the participants and make me take on a role as a therapist, which could be helpful for the client to feel safe. However, Asselin, (2003) has pointed out that the dual role can result in role confusion when the researcher responds to the participants or analyses the data from a perspective other than that of researcher. Therefore, I was always mindful of my position as a researcher, to keep the interviews focussed on the phenomenon under investigation. I ensured this process by keeping a research journal to reflect on any influence I might be exerting on the process, thereby turning the hermeneutic lens on my own subjectivity to minimize the interference of personal prejudices in my representation of participant material (Langdridge, 2007). In keeping a reflexive eye, I was able to researcher understand the role I can play on the material that is uncovered (Berger, 2015). Also, I consulted my supervisor on several occasions to sense check interpretations as plausible, thereby assuring the "transparency and coherence" of my findings (Yardley, 2000).

Moreover, I am aware that through the process of the research, uncomfortable and or emotional content could be shared for both the researcher and the participants. Therefore, I utilised supervision and personal therapy consistently and frequently throughout the research process to ensure duty of care is established and maintained for both the participants and researcher.

This concludes the first section of my methodology chapter.

Procedural Methodology

In this section, I will move to discuss the procedural methods employed in the study which will include, recruitment process, data collection, analytical procedure, ethical considerations and lastly the consideration of quality and validity criteria for the evaluation of the present study.

Recruitment

Recruitment strategy

Participants were recruited via purposive criterion sampling (Polkinghorne, 2005), since the research employed an idiographic approach and the aim was to explore a specific phenomenon experienced by a specific population (Smith et al., 2009). Altogether six participants were recruited, who were selected based on meeting the inclusion criteria (See below). Six participants were deemed sufficient as there is no proposed sample size for IPA (Smith et al., 2009), and the commonly suggested sample size is 6-8 participants, given the complexity of analysing/interpreting human phenomena (Landridge, 2007). In addition, the aim of this analysis was to establish an in-depth examination of each case, cautiously exploring differences and similarities, to produce detailed accounts of patterns of meaning for participants reflecting on a shared experience (Landridge, 2007), which is more important than a large sample.

To recruit the participants, advertisement posters were put up around a London University campus (See appendix 1). Recruiting from a single university campus did have its limitations as it could have yielded participants with a particular age from a particular demographic. However, the university campus is in London, and is a campus with a diverse population of students with different demographic backgrounds. The advertisement poster contained contact details and some information about the study, in an aim to recruit participants experiencing the targeted phenomena. Also, the advertisement posters highlighted the requirement for a screening and briefing before any individual is recruited to participate in the study. Therefore, individuals interested in the study, were instructed to arrange a face-to-face meeting or a phone meeting with the researcher. This was essential to ensure that the participants met the inclusion criteria and that it was safe for them to pursue their participation in the study.

Inclusion and Exclusion criteria

Using purposive sampling, the aim was to recruit a specific population. The participants were required to have had experienced having a parent with cancer in the last 5 years. We chose to include those that experienced having a parent with cancer in the last 5 years, to avoid recall being affected by memory decay, as the possibility of forgetting is known to increase after 4 to 5 years of the experience (Cansino, 2009). In addition, as the study is aiming to gain an insight in to having a parent with cancer and not the process of bereavement, it was essential that the ill parent was still alive. In an aim to achieve a homogenous sample, individuals between the ages of 23 to 35 were recruited, as the experience of having an ill parent may vary significantly in different stages of life. For instance, adults experiencing having a parent with cancer, may be more likely to be involved in their parent's personal care (Ferrel et al., 1990), which may be an element that children and adolescence are less likely to experience. In addition, facing the possibility of losing a parent in different stages of life could also be a distinctive experience itself. Having a parent being diagnosed with cancer during young adulthood is unexpected and incongruent with social expectations of when someone may have to face the death of a parent (Puterman & Cadell, 2008). Therefore, young adults may have a different experience to an individual who is older and has an elderly parent that is ill. As a result, this research was interested in gaining the subjective experiences of young adults who has experienced having a parent with cancer at earlier stages of adult life.

There was no control regarding ethnicity, culture, religion, social background, or sexual orientation when recruiting participants. All participants were required to be able to communicate in English clearly, to ensure information was conveyed correctly. There was no control regarding type and stage of diagnosis of parent's cancer, as the research is interested in exploring the perception and experience of each individual participant, with no intent of generalising the findings to the wider population.

The exclusion criteria were carefully considered, and the following decisions were made to make sure a homogenous sample and a safe environment was always ensured. Individuals who have lost their parent from cancer were excluded from the study, as the research question is not concerned with the bereavement process and rather wants to examine in-depth the process of living with a parent who has cancer. However, if a participant was to lose a parent between recruitment and interviews, they would not have been excluded from the study, unless they requested to be. Individuals who disclosed having a neurological (brain damage potentially affecting communication or cognition) and psychiatric (e.g: Psychosis, Bipolar, Personality Disorders) difficulty and or formal diagnosis and or is currently taking centrally acting medication (prescriptions and drugs) were excluded, to ensure their safety and to obtain information that is not impacted due to these reasons. All inclusion and exclusion criteria were set out on the information sheets (See appendix 2).

Individuals excluded from the study were signposted to sources of mental health and were provided a document that contained all the help sources they could access (See appendix 3). They were also given an opportunity to discuss their feelings with the researcher.
The screening was conducted by asking the following questions:

- Is your parent currently or has been diagnosed with cancer in the last 5 years?
- Are they alive?
- Do you have any neurological or psychiatric diagnosis?
- Are you under the care of a psychiatrist?
- Are you currently on any centrally acting medication (prescriptions or drugs)?

Individuals that met the inclusion criteria were briefed and given the opportunity to ask any questions that they may have relating to the research and its process. Following this, they were provided with an information sheet. Once they were happy to participate in the study, a date for the interview was set, where informed consents were obtained, prior to engaging with the interview/research process.

Participant Characteristics

Altogether 6 participants (5 Females and 1 Male) meeting the inclusion and exclusion criteria were recruited via purposive criterion sampling and were interviewed. All participants reported having either a mother or father diagnosed with cancer in the last five years. The type of cancer diagnosis differed, and included types such as Ovarian cancer, Skin Cancer, Urethral cancer, and Stomach cancer. All participants were UK citizens and were aged between 24-33. Please see Table 1 for details of the participants.

Table 2. Characteristics of participants.

PARTICIPANT	AGE RANGE	ETHNICITY	TYPE OF CANCER	THE PARENT WITH CANCER
Shirley (F)	**18 - 24**	**Black British**	**Ovarian cancer**	**Mother**
Maria (F)	**25 - 34**	**Asian**	**Ovarian cancer**	**Mother**
Dalia (F)	**25 - 34**	**Asian**	**Breast cancer**	**Mother**
Nyla (F)	**25 - 34**	**White**	**Skin cancer**	**Father**
Harry (M)	**25 - 34**	**White other**	**Urethral cancer**	**Mother**
Grace (F)	**25 - 34**	**Asian**	**Stomach cancer**	**Father**

Data collection method: Semi structured interviews

Constructing the interview schedule

The research data was collected using semi-structured interviews, which allows interviewees to share their experiences through verbal and conscious descriptions. In addition, semi-structured interviews allow the interviewer to maintain consistency throughout the interviews while, also offering flexibility (Landridge, 2007). For the interviews, an interview schedule was used to guide and facilitate a natural flow of conversation (Pietkiewics & Smith 2012). The interview questions were in part based on findings from the literature review. The interviews consisted of open-ended questions and the researcher avoided using leading questions (Smith, 2009), which allowed participants to express their subjective experience with minimal researcher impact. The interview questions were designed to explore participant's experience of having a parent with cancer, and how they make sense of the experience. The initial questions were designed to gain information about the feelings experienced during the initial diagnosis process and the present time. In addition, questions specifically exploring experiences relating to the participants perception of their self, parent(s), family, and relationships were included (See appendix 4). The interview schedule included descriptive, narrative, analytic and evaluative questions. The topics were arranged in the most logical order and the phrasing of questions were carefully considered, to ensure participants fully understood them. The participants were asked a total of 14 questions along with prompts. The list of questions was revised multiple times as appropriate, after discussions with supervisors.

Conducting the interview

The interviews were arranged by phone and email and took place at a London University campus, depending on availability and proximity to the participants. All interviews were conducted prior to the COVID-19 pandemic. Therefore, the participants experiences, and reflections were not impacted by covid-19 or associated difficulties or safety measures. All interviews were recorded by a digital audio recorder to ensure no content was lost and was stored on a password protected home computer in accordance with data protection legislation requirements (BPS, 2010). Prior to each interview, I went over the interview schedule and ensured that I was familiar with the key questions, which permitted a more interactive interview style, allowing participants to feel more comfortable about going deeper with their experiences. The interview schedule was a guide, and I did not follow it strictly or in the same order for each of the interviews. The aim of the interview schedule was to facilitate a flowing conversation that yielded more detailed conversations. Questions addressing specific key areas allowed participants to talk at length and provide a rich account of their experiences. Also, probing questions helped gain a more detailed account of participants experiences and clarify questions when participants found them unclear or abstract. The semi structured nature of the interviews allowed flexibility in asking the questions in the most convenient order. And when novel perspectives or topics occurred, I was free to develop them with further questions. Using a semi structured interview style and a carefully devised interview schedule was appropriate for IPA research, as it allowed detailed examination of a participant's lived experience while giving enough space and flexibility for original and unexpected issues to arise (Pietkiewics & Smith, 2012). However, it is important to acknowledge that semi-structured interviews may fall short in eliciting some information too. Some interviewees may respond less or may not want to share about certain experiences. They may find it difficult to talk about or may be too ashamed to speak about some of their experiences (Nguyen, 2015).

At the beginning of the interviews, I explained to the participants that I was interested in exploring their experience of having a parent with cancer. I also added that I will not interfere inappropriately and will say very little, to make sure I offer them the space to express their experiences freely, to make sense of their experiences as best as I can. The interviews were conducted in a professional, warm, and empathetic manner, providing a safe and supportive environment. At this stage of the research, I was entering the hermeneutic circle of the participants world (Smith et al., 2012).

Transcription

I transcribed all the interviews solely, and listened to the audio files repeatedly, to ensure accuracy. There are various guidelines for how transcription could be carried out. However, I chose to follow the guidelines of Smith et al., (2009). The transcripts included all the words spoken by the participants and researcher. Line numbers were added to specify the sequence of the questions, and to ease the data analysis process, when quotes are extracted from the data to support findings. A space was left between each turn in the conversations, and “I” represented dialogues of the interviewer, while “P” represented the comments from the participant. Wide margins were added, to allow notes and comments to be added during the analysis process. All identifiable information such as names and locations were anonymised in the transcripts by using pseudonyms. Detailed transcriptions such as a precise record of non-verbal utterances and the length of pauses were not made, as IPA aims to interpret the meaning of participants accounts of their experience (Smith et al., 2012).

Analytical procedure & Reflexivity

Six interviews which were between 35-50 minutes in duration were analysed. Using the method of IPA, the data was analysed following the steps outlined in Smith and Osborn (2008). This provided a structure in analysing the data, while also offering a degree of flexibility in the way I was able to approach the data. Note that, IPA analysis is bottom-up, and there is no pre-existing theory used to identify the themes/codes (Landridge, 2007). The emergent themes are based on my interpretations as the researcher trying to make sense of the participants making sense of their experience (Smith et al., 2009).

Note that, the data was collected, and the analysis started in 2018. Therefore, the IPA guidelines used in this study is not the most recent one published in 2022. However, there is no difference in the underlying philosophy, aims and principles in either version. After reading the newer version, I can confirm that the main changes are concerned with the terminology rather than the methodology. Therefore, using either version would not have influenced the findings of my analysis or the analytical process itself.

The breakdown of the analytical process/steps is below:

Step 1: Reading and re-reading the transcripts

Reading and re-reading the data is an important step in IPA, which helped me as the researcher to familiarise with the data and what the participant was telling. Smith et al., (2012) also suggests that for a complete analysis, it is useful to listen to the audio recordings repeatedly, to assist familiarity with the data. In doing so, I found that I was able to re-immerse myself in the data, and listen out for the emotions, the pauses, the tone and volume of the participant's voice. At this stage, I found myself thinking how important it is to be able to portray a sense of the participants accounts in my findings. The primary reason for step 1 is to encourage the researcher to focus on the participant only and to begin to enter their world (Smith et al., 2012). Before making any connections and interpretations, it was very useful and important to focus on what each participant was saying.

Step 2: Initial noting

At this stage, I went through the transcripts and made notes on the left-hand side of the margin, of what seemed to be important (Smith et al., 2009). These notes involved closely examining the language and content, noting my initial thoughts (Smith et al., 2012). I made notes of any interesting keywords, phrases, and emotional responses. I also made notes of participants linguistics comments such as pauses, metaphors, repetitions, laughter, or cry (Smith et al., 2012). I also made conceptual comments, which involved becoming more interpretative and conceptual with the data (Smith et al., 2012). To distinguish between the different type of comments, I used a black pen for the descriptive comments, a blue pen for the linguistics comments and a red pen for the conceptual comments.

I continuously questioned whether I was analysing in enough detail and found it very challenging to interpret at a contextual level. I felt hesitant about adding my interpretations and attempted to stay as close to the participants own accounts, to avoid content being lost. In other words, I may have relied heavily on participants own words, to stay as close to their experience. Developing an interpretative stance was the most overwhelming and time-consuming part of the analytical procedure for me. However, through practice, closely examining and making notes of the text allowed me to gain a further insight in to how a participant is making sense of their experience and particular issues/events, which facilitated my interpretative stance.

Step 3: Developing emergent themes

In this section, I identified and labelled emergent themes that characterize each section of the text (See appendix 5). The aim was to reduce the transcripts and initial notes into emergent themes. I started this step by listing out all the possible ideas that I had developed from my initial note taking and comments. I then tried to focus on the larger parts of the narrative and grouped similar or overlapping ideas under the same theme. It was difficult to break or cluster ideas together, as there seemed to be so much information, that it was not possible to represent the participants experience in depth. This made me feel like I was missing out some of the essence of the participants accounts.

Step 4: Searching for connections across emergent themes

In this stage, I tried to look for connections between the emergent themes, which involved thinking about how they fit together (Smith et al., 2012). The aim was to establish natural clusters of concepts that share meanings. This included common links, associations, or hierarchical relationships between the themes. I tried to reflect on what the participant might be trying to tell and what the underlying meanings may be. In searching for connections between the emergent themes, Smith et al., (2012) suggests that organising themes in more than one way can be creative and push the analysis to a higher level. Therefore, I tried to use different ways to search for connections and identify patterns, which are summarised below:

Abstraction: Grouping like with like and identifying a new name for the cluster. For example, there may be several similar emergent themes which can be grouped under one title, referred to as a superordinate theme (Smith et al., 2012)

Subsumption: The superordinate theme brings out other related themes.

Polarization: The Focus on the opposite relationship within the emergent themes. For example, the focus is on the difference rather than the similarities.

Contextualization: The focus is on the contextual elements with specific references to narrative, cultural and temporal themes.

Numeration: This includes the frequency of the emergent theme appearing within the text.

Function: The focus is on the function of the emergent theme which involved interpreting further than what the participant described in the interview (Smith et al, 2009). Throughout this step, I felt extremely overwhelmed as it was difficult to feel satisfied with the interpretations that I was making. I found myself always questioning and revising my ideas, in an aim to form connections and themes that was representative of the participants accounts.

Step 5: Moving to the next case

This step involved moving on to the next participant and starting the same analytical process from steps 1- 4 again. However, before I moved on to a new participants data, in an aim to bracket my thoughts and ideas that developed from each participant's interview, I left a time gap of a week in between. This also allowed new themes to emerge from each transcript and I felt that I was able to differentiate between the ideas I developed from each of the participants transcripts.

Step 6: Looking for patterns across cases

Once all steps were completed for each participant, step 6 involved looking for patterns across all the cases. In identifying patterns, the focus was on making connections across them and identifying the most powerful themes. To start this process, I listed all the themes I came up with. I revised the list several times, as each time I wrote the list, I realised several different ways the theme could be written and the overlaps between some of them. I drew up different tables including the emergent themes, sub themes and superordinate themes to reflect the different ways in which the themes could be represented. Lastly, a final summary tables of the subthemes and superordinate themes, together with quotations that illustrate each theme were produced.

Throughout the analysis procedure I constantly rechecked if the emerging analysis is reflective of the data. The themes evolved and changed throughout the analysis (Landridge, 2007). At all times, as the researcher, I tried to suspend presuppositions and possible judgements, through the practice of bracketing (Husserl, 1999) to maintain interpretations as closely as possible to the participants own lifeworld.

Ethical considerations and permissions

This research is in line with the 'BPS Code of Human Research Ethics' (British Psychological Society (BPS), 2021) and the 'Standards of Conduct, Performance and Ethics' (Health & Care Professions Code (HCPC), 2016). Prior to commencement of data gathering, ethical approval was obtained by City University Psychology Department, Ethics committee (See appendix 6 & 7).

Informed consent

All participants were given a detailed information sheet, including the general information about the purpose of the study with information relating to their rights as a participant through the research process (See appendix 2). Additionally, all participants were informed verbally about their rights to withdraw, without facing any form of penalty. There was no pressure or an incentive that was put on individuals to take part in this study. Participation was entirely voluntary and informed consents were obtained before participation in the study. Once participants were happy to proceed with the study, after reading the information sheet fully and having an opportunity to ask clarifying questions, they were given an informed consent to read and sign (See appendix 8).

Confidentiality

All participants were allocated pseudonyms, to anonymise any personal identifying information and to establish confidentially in this regard. For instance, during the transcribing process any information or word that could identify a person or place were changed into a pseudonym. However, although all details were kept anonymous, due to the nature of qualitative studies confidentiality of experiences shared in the interviews were not promised. Those that wanted to see their data/transcripts before it is published were given the chance to see their transcripts. However, no participants made this request. All data gathered was locked in a cabinet and personal details were stored in separate a place to the audio files and transcripts, in accordance with the Data protection act (2010). All computer files (transcripts) were saved on a password protected computer to ensure they are not accessible to others.

Managing distress & Debriefing

As the researcher I was always aware of the possibility that participants could discuss issues that are emotional, and individuals may experience an understandable and expected degree of psychological distress regarding their experience of having a parent with cancer. Being a trainee counselling Psychologist, I had experience of working with clients who report emotional distress, which allowed me to manage potential situations appropriately. Participants who experienced distress were asked if they are happy to continue with the interview. Also, all participants were signposted to available support services and provided with resources outlining local charities and organisations that offer psychological support (see appendix 3). Participants were made aware that they have the right to terminate the interview at any time. Participants were offered a time to speak to me, the interviewer, before they leave. If any interview was terminated, the supervisor would have been informed immediately to ensure that appropriate help and referrals were made. I always worked closely with the supervisor, to ensure safety issues are anticipated for both the me as the researcher and the participants. Once interviews were complete, participants were given a debrief sheet (see appendix 9) and an opportunity to ask any questions that they had regarding the study. The debrief sheet contained the details of the researcher and supervisor, for the participant to contact if they had any concerns or questions in the future.

Assessing Quality and Validity in qualitative research

While, the quality of quantitative research can be demonstrated with measures of validity and reliability, this is not as straight forward in qualitative research. However, there is still a great need to demonstrate how quality has been ensured throughout the research process. Elliott, Fischer and Rennie, (1996), together with Yardley (2000) provide a widely cited set of guidelines of how to achieve and demonstrate the quality of a piece of qualitative research that has been conducted. These principles are highlighted as sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. Based on these guidelines, I will highlight the ways in which I have ensured the quality of my research.

Sensitivity to context

Sensitivity to context may be demonstrated through an understanding of the relevant literature around the topic, through providing a rationale for the use of IPA, and through demonstrating sensitivity to participants. At the earlier stages of my research, I spent significant time considering my research question. I thought about the different ways in which I could phrase it, to make sure I was not implying any expectations about the participants experiences.

Commitment and rigour

According to Yardley (2000) a researcher can demonstrate their commitment within an IPA study through the way in which they carry out the interview and the degree of attention they pay to the analysis of each. Throughout the interviewing process, I paid significant attention and was highly mindful towards the participants and their emotional wellbeing. I was aware that emotionally distressing content could be shared during the interviews and therefore, offered time at the end of the interview for a debrief, where participants were contained appropriately.

Furthermore, rigour refers to the detailed attention given to the selection of the sample, the way the interviews and analysis is carried out (Smith et al, 2009). In an aim to establish rigour and a homogenous sample, a set of inclusion and exclusion criteria was employed. My initial thought was to explore the experience of adults of all ages who is or has experienced having a parent with cancer. However, I then narrowed the sample down to young adults aged between 23-35, who have experienced having a parent cancer in the last 5 years. In addition, throughout the analysis, I paid close attention to keeping the same style of interviewing or way of being towards each participant, in an aim to establish rigour amongst the interviews and findings.

Coherence and transparency

Transparency refers to how clearly the researcher writes up the different stages of the research process. Throughout my study, I aimed to be transparent and write up each section providing as much detail as possible.

In addition, in my reflexivity I have aimed to be transparent in the ways I may have influenced the study and findings. Coherence refers to the extent to which research reflects the theoretical underpinnings of IPA and the degree to which the researcher can carry this out. I have aimed to achieve this by explaining in fine detail the rationale for using IPA and attempted to stay as close as possible to the guidelines recommended for carrying out IPA.

Reflexive consideration of researcher impact and involvement

Yardley (2000) suggests that validity can be demonstrated as the extent to which the study is informative for the reader. Counselling Psychologists works with individuals experiencing various difficulties in life, including those who have family members with health problems and illnesses. The role of counselling psychologists may be key in helping this population, and knowledge gained in this area will be vital. This study aims to contribute to the field of counselling psychology by furthering our understanding about the experience of individuals who have experienced having a parent with cancer. If the study successfully explores the phenomenon, then it will be of benefit to all professionals working in this area, contributing to their understanding of this population.

SUMMARY

The aim of this chapter was to describe and outline in fine detail the methodology for the present research. I have initially outlined my chosen paradigm and epistemological position. My research has aimed to produce interpretive phenomenological knowledge.

I have also outlined the procedural methodology in fine detail, including the recruitment process, participants/sample, data collection procedures, the analysis stages, and ethical considerations. In the following section, I will provide an IPA analysis of the findings and report the themes that emerged from the data.

CHAPTER THREE - ANALYSIS

Overview

In line with Smith et al., (2009), this chapter explores in depth the themes that emerged from my analysis of the data. The themes discussed in this section offer an insight into the subjective experiences of the participants who have a parent with cancer. The superordinate themes were common to all the participants. However, the subthemes were not necessarily present in all participants' transcripts but were selected according to salience and relevance to the research. I have compared and contrasted participants experiences where it has been appropriate to draw out similarities and differences in their expressions. As a researcher, I am aware that the following findings are based on my understanding and interpretations, and that others may interpret the data differently. By no means does my analysis suggest findings that are generalizable. However, they aim to reflect the lived experience of individuals who have experienced having a parent with cancer.

Six interviews which were between 35-50 minutes in duration were analysed.
The analysis of the data revealed material which was clustered around four superordinate themes (See table 2). I have detailed each superordinate theme in turn by exploring their subthemes using verbatim quotes from the participants transcripts. Longer quotes are presented in italics and shorter quotes that are run in the text are illustrated by quotation marks. All quotes are followed by the participants pseudonym, page, and line numbers from the original transcripts. Participants have been given pseudonyms to maintain their anonymity. A list of pseudonyms and participants demographic information is presented in table 1 in the methodology chapter.

My comments following the quotations represent my tentative interpretations of the participants own interpretations and sense making of their lived experience. In line with smith et al., (2009), I make both conceptual and linguistic comments. The linguistic comments involve observations relating to each participant's use of language, including hesitations, repetitions, and tone of voice.

Analysis - Interpretation of Results

In analysing the data from six interviews, 4 Superordinate themes were identified. These themes are: “Having to face cancer”, “A process of role transformation”, “Coping through cancer” and “The Positive growth”. Each of these superordinate themes have been broken further down in to subordinate themes. The superordinate themes that I have come up with are like an umbrella that clusters the variety of experiences about a specific phenomenon. The subordinate themes aim to give deeper insight into the experiences of the participants, while reflecting the connection between the similar and different experiences reported by the participants.

Table 3. Superordinate themes and sub-themes.

Superordinate Theme	Subthemes
1. Having to face cancer	1.1 Psychological Pain 1.2 Anxiety of uncertainty 1.2.1 Fear of losing parent 1.2.2 Fear of own risk
2. A process of role transformation	2.1 Observing parents’ deterioration 2.2 Adapting a parent mode 2.3 Putting self on hold
3. Coping through cancer	3.1 Invulnerable self 3.2 Estranged from others 3.3 A source of support for coping
4. The Positive growth	4.1 Stronger family bond 4.2 Desiring a healthier lifestyle 4.3 A better person

Superordinate theme 1: "Having to face cancer"

The first superordinate theme "Having to face cancer" aims to describe the responses and emotional changes individuals experienced on facing their parent's diagnosis of cancer. The diagnosis of a parent or a loved one with cancer was an unexpected event that stimulated various emotional changes. The participants reported experiencing changes in their feelings as well as their thinking styles and the way they relate to the world. Therefore, with particular focus on their thoughts and the associated feelings, this theme aims to provide an understanding of how the participants responded to their parent's cancer when faced with it. General negativity, burden, stress, upset, and sadness was highly common feelings amongst the participants. To describe these feelings, the subtheme 'Psychological pain' emerged. Anxiety relating to uncertainties was also highly prominent amongst the participants and appeared in the following two forms: possibility of losing parent and developing illnesses themselves. To reflect on these anxieties the subtheme 'Anxiety of uncertainty' emerged and was broken down in to the following two categories: 'Fear of losing parent', and 'Fear of own risk'.

Subtheme 1.1: 'Psychological Pain'

The diagnosis of a parent with cancer was a very distressing experience for most of the participants. Often, the participants experienced confusion and found it difficult to identify and reflect up on their deeper feelings. Reflecting their emotional response in single words was challenging. To describe their pain, some of the following terms were used; 'sad', 'upset', 'scared', 'angry' and 'heartbroken'. The subtheme 'Psychological pain' aims to reflect the participants deeper feelings experienced through the process of their parent's illness, with particular emphasis on their emotional responses.

When describing her experience and response to her father's cancer, Nyla expresses many emotions, including sadness, fear, disappointment, anger, and pain.

> ***Nyla:*** *Erm, like I said, I just remember feeling very sad. I was terrified, I was disappointed, I felt resentful. I felt pain. I felt pain in my heart, cos err I, I am the only daughter. The only girl in the family. And I, I had a very different bond with my dad, and a strong relationship with him. So having that happen to him was erm, very*

> *painful, sad erm, experience for me. I just remembered I have been very tearful. Very sad. (Page 4, 143-149).*

Nyla's use of multiple words to express her upset may suggest that a single word was not enough to express her distress and the variety of emotions she was experiencing at the same time. Additionally, the overwhelm of feelings may have made it difficult for her to distinguish between them. Moreover, Nyla refers to the strong relationship she had with her father. Her use of the past-tense word "had" as if it is now in the past, may resemble a feeling of loss and the start of a grief process. The diagnosis of cancer, which is a life-threatening illness, may have fostered the start of a grief process even before the physical loss of her father. This may also suggest a possible confusion of deeper feelings and the difficulty of understanding them. Overall, from Nyla's expressions it becomes apparent that the diagnosis of a parent with cancer is a psychologically disturbing experience, producing a variety of emotions that could cause frustration and confusion.

Experiencing a mixture of emotions on facing a parent's diagnosis of cancer was also reflected by Shirley.

> ***Shirley:*** *I was very scared, I was very ermm. I had mixed emotions, I was very angry at the fact that it's happening to my mum. I was just questioning why erm. I had mood swings, is that what you say? It's, I would cry and I would just then get angry and tell my family not to, just stay strong and then when I look at my mum. You just get so many emotions going through your mind. You get, erm, I am so sorry, it's just so hard to explain, but as I said, ermmm I was, I was very scared. Worried, anxious. (page 2, 40-47).*

Like Nyla, Shirley's expressions indicate that multiple emotional states are experienced at the same time, possibly causing a confusion and difficulty in understanding one's own feelings. Although Shirley attempted to explain her emotions, she found it very difficult. The use of words did not do justice and were not adequate expressions of her real feelings. Providing a representative reflection of her mind and feeling understood by another party was very difficult for her. For example, her saying "I am so sorry, it's so hard to explain" may reflect that she does not feel that she can explain her emotions, and even if she did attempt to explain her feelings, it was not going to be enough for her to be understood. Moreover, Shirley describes finding herself having mood swings. Although she does cry herself, when she finds others in her family crying, she gets angry and wants them to stay strong. As she expresses, '*It's, I would cry and I would just then get angry and tell my family not to, just stay strong'*. Seeing her family cry, may be making Shirley feel even more vulnerable and unsupported. Her aggressive attitude when someone in the family may be a desperate attempt to assert some control over her and her family's pain, and to achieve strength in the family during this highly stressful time of experiencing cancer. In addition, Shirley's reflections suggest that she is switching between different emotions, which may also be causing switches in the way she behaves/responds. In other words, the variety of emotions she is experiencing may be causing her confusion.

Dalia found it significantly difficult to accept her mother's diagnosis of cancer. And she used the word "Nightmare" to describe the experience of facing her mother's cancer diagnosis.

> ***Dalia:*** *Ermm, it was a nightmare the first time I heard the doctors say that know your mum is diagnosed with cancer…. Ermm (coughs), ermm, I don't know I feel a bit uncomfortable at the moment, but (sighs) yeah. Erm, shes, shes she well, it was too hard for me to accept in the beginning because obviously its not something easy for you to straight away accept. …. Therefore, oh I had to accept, I had to accept (helpless voice)… (Page 1, 17-33).*

When describing her feelings, Dalia gets very uncomfortable. She coughs, sighs and repeats words. After a few attempts of starting a sentence, she says "she's, she's, she's well" and adds that it was not easy to accept her mother's cancer in the beginning. Her repetition of the word "she's" 3 times before being able to say that her mother is well, may suggest a hesitation about her mother's current health. Later, with a helpless and low voice, Dalia says, "I had to accept" and repeats again. It appears that it is very difficult for Dalia to acknowledge and accept her mother's illness and saying the opposite (i.e. "she's well") may be a way she tackles and avoids the pain associated to her mother's illness.

Moreover, Maria describes how the bad news of her mother being diagnosed with cancer changed everything in life completely for her.

> ***Maria:*** *So, when I newly found out, its just, you know everything just changed completely. It was just, I just felt like a lot more, like I just felt really drained. You know, I felt like some sort of, like in a way a bit of my life had shattered. So, in order to pick up the pieces it took a lot for me. And, it just sort of changed my whole view on like how I was looking at, cos I had a positive mindset, interms of you know I had to make arrangements for my marriage. But then when I found out about her diagnosis, it was just like you know I don't want to think about my marriage because all I could think about is your cancer. And, how your going to, whats going to happen, you know that uncertainty of the future, that's really really hard for me. (Page 2, 51-64).*

Facing the news of her mother's cancer was significantly draining and upsetting for Maria. She had to make changes to her life, plans and whole mindset to continue with life. She describes her response to her mother's illness by saying "*in a way a bit of my life had shattered".* Cancer had taken over her life, and she did not want to engage with anything else, including her marriage planning. Concerns related to her mother's cancer diagnosis preoccupied her mind. She developed disturbing worries about the future and what may happen in terms of her mother's life. The worries were connected to the fear of losing her mother, the effectiveness of the treatment processes, the changes that the illness will bring to the family and so on. Not knowing the answer to all these concerns felt very difficult, and hard to contain.

Harry describes trying to find meaning in why it was his mother who got cancer. This was a differentiating experience to the other participants.

> ***Harry:*** *Just err, just being weak. That's the only thing that comes to my mind. Just being er, I mean, unhappy. I mean, I mean, if you're just talking just for my mum. I do sometimes feel like it's not fair, err, but it's not fair on what. Because err, I mean sometimes I pray to god and say why? Why is it my mum? Why has cancer hit my mum? When everyone's mum is so healthy. And everyone, there's a lot of people out there that don't deserve to live (laughs) and they, they just live till 80, 90. Just being evil. My mum was one of the best people in the world, and she's got cancer. (page 8, 296-304).*

Harry appears to experience a lot of resentment as he feels that cancer affecting his mother was unfair. But Harry expresses praying to God and asking him why it was his mum who got the illness. His faith and religious beliefs may be making him feel that there is a reasoning behind why God gave them this experience. A religious reasoning behind his mother's illness may be giving Harry a sense of relief that his mother's illness was beyond his and his families control.

On the other hand, on facing her parents' diagnosis of cancer, the experience of Grace was somewhat different from the other participants. She reflected that she did not understand Cancer like she understands it now. She did not think it was so serious and so her response at the time of her parent's diagnosis was very different from what it would have been now after experiencing it.

> ***Grace:*** *I didn't think, think nothing of it. It wasn't, its not the feelings I got now, for definite. It's a matter of understanding the situation. If you know the situation, you'll be upset, or you won't be upset. I wasn't, I wasn't necessarily that upset about it. Cos I knew erm, I even thought that his exaggerating things sometimes. Because he would have emotions, emotional things. And I use to think why is he acting like this? Its just, its just an illness that can be cured. (Page 3, 109-116).*

Not having prior knowledge of cancer had a significant impact on Grace's experience when faced with her parents' diagnosis of cancer. Grace thought of cancer as an illness that can be cured. As a result, she did not experience the fear and anxiety of losing her parent. However, the experience of having a parent with cancer has brought into her awareness that cancer can kill, and therefore her feelings of cancer has also changed.

Subtheme 1.2: Anxiety of Uncertainty

As well as stimulating negative emotional patterns, the experience of having a parent with cancer caused participants to experience significant anxieties. The life-threatening experience of having a parent with cancer caused participants to feel like they were living with uncertainty, and with fear associated to not knowing what the future holds. In other words, they experienced fear of not knowing how life will progress, and after facing their parent's illness they experienced a heightened consciousness about life and death. To describe this experience the subtheme 1.2: Anxiety of uncertainty has emerged. However, this anxiety of uncertainty was mainly associated to two underlying reasons. Firstly, participants all experienced anxiety about losing their parent, and secondly, most participants faced the idea of developing cancer themselves too. To differentiate between these two reasons underlying the anxiety participants experienced, the subtheme 1.2: Anxiety of uncertainty was broken down in to two categories; 1.2.1: Fear of losing parent and 1.2.2: Fear of own risk. This subtheme provides a detailed account of these two separate anxieties that is moderated by the feelings of uncertainty about the future. It is important to understand the uncertainty this population experiences, to understand the underlying mechanisms of their anxieties and emotional arousal.

1.2.1 – Fear of losing parent – “When will my parent die?”

Uncertainties about what was going to happen in the future regarding their parent’s wellbeing caused significant distress amongst young adults. Although death is inevitable, often individuals do not think of it, and it is not always in our conscious awareness. However, when an individual in the family, particularly a parent is diagnosed with cancer, it can make us more conscious about death. Having a parent diagnosed with cancer caused all participants to experience a heightened awareness of death. It made them start to think about death more often and come to terms with the inevitable truth that they will lose their parent. Participants described cancer to be an uncurable illness and were unable to avoid the thought of their parent dying. They questioned when and how their parent may die? if the treatments were going to be effective? and the possibility of relapse of cancer? These thoughts were especially unavoidable when observing a parent deteriorate from cancer. To sum up, the possibility of relapse of cancer, and concerns around losing their parent caused significant anxiety amongst young adults. The subtheme “Anxiety of uncertainty - Fear of losing parent” aims to reflects this experience.

To express her feelings and concerns about the possibility of her mother’s loss, Maria says:

> ***Maria:*** *When I found out that my mum had cancer, it was just, it was, the first that came to my mind was how long is she going to live? You know, is she going to live for long? Erm, what going to happen in terms of her life? What going to happen in terms of my life? (Maria - page 1, 23-27)*

Maria shared that when she faced her mother's cancer diagnosis, she started to get many questions in her mind about life and her mother's time left in this world. She developed worries about what life was going to be like for her mother but also for herself. Her expressions in the form of questions reveal the level of uncertainty she is feeling, and the worry this is causing for her.

Harry also states that experiencing cancer in such proximity has increased his awareness about it. He explains acknowledging that he can lose his mother to cancer.

> ***Harry:*** *But it ju, just comes like that my mums got cancer and err it could get, gradually worse for her. I mean, I could lose her in the next 5 years, in the next couple of years. I mean, I mean, I felt really vulnerable at the same time. I am 24, I mean at that time, I was in my earlier 20's. early 20's. I mean my mum use to help me out a lot at home, with the lot of tasks I do at home. And she use to be the backbone of our household. Err, seeing her like this, err it's made our family really, it's put our whole family in a different state to be honest. Mental state. (Page 5, 178-186)*

Like Maria, facing a life-threatening illness like cancer has caused Harry to question the time his mother may have left in the world. Although Harry has not lost his mother, he describes what it used to be like for him when his mother was not ill. He expresses that his mother used to help him at home and was the backbone of the house. In his description his use of the words in past tense indicates that he has already lost parts of his mother and his life that his mother catered for. This sense of loss is difficult for Harry and his family, as he feels it has put then in a different mental state. His reference to a different mental state may be an attempt to describe their upset and emotional change.

Moreover, as well as thinking about the possibility of death and questioning when it will come, Harry describes researching how cancer kills.

> ***Harry:*** *So, before it was like a sickness to us, but now two of her friends have passed away from cancer. And this has really got us to start thinking about death. And were thinking that death is nearby. Even for me, I'm just keeping thinking about death. How is. I'm actually on YouTube everyday googling, how will cancer kill someone.*

> *And just looking at that cancer will grow and take out all the nutrients from the other cells nearby and starve your body. Just that process, just makes me, just makes me feel very bad and terrified. (Page 18, 692-700)*

Harry acknowledges that his mother could die because of cancer. He has also developed a sensitivity towards his own possibility of death too. These concerns have in turn caused Harry to research how cancer kills, which in turn causes greater anxiety for him. He explains in detail how cancer leads to death, which highlights his awareness of the process his mother is currently going through. Therefore, it is also possible that having done research about the process of dying due to cancer, may have given Harry an indication that his mother is closer to death.

Dalia also expressed her fear of losing her mother and elaborated on the impact of this fear on her emotional wellbeing.

> ***Dalia:*** *But, I'm very scared, I'm very scared. Im very anxious. I just don't want to loose my mum. I want her to be healthy. I want her to have her health back, be a happy family again. But, I don't think that is going to happen. I am very scared. I have become a very weak person that I am surrounded by fear. I am always thinking of death. (Page 10, 399-404).*

The worry of losing her mother is causing Dalia significant anxiety. She explains being occupied by the thought of death. Her expressions clearly indicate that when a parent is diagnosed with cancer, death is greatly in the conscious awareness. The mind is overwhelmed by the possibility of losing a parent. This burden in turn has caused Dalia to feel weak. Her use of the term "weak" may reflect her belief that she cannot overcome the situation. In other words, not having control over death and not being able to change what is happening to her mother may be the reasons for this feeling of weakness.

Moreover, Grace's reflections highlight that when an individual in the family experiences cancer, it increases the understanding about cancer and brings into awareness that cancer can kill.

> ***Grace:*** *Because like me, he didn't even know what cancer was. We used to hear about it, but you don't know how hard or how erm unbeatable it is, unless it happens to you. (Page 4-5, 165-167)*
>
> ***Grace:*** *the situation now is he has been erm. Basically, they've they haven't, although on the back of my mind, I know that it's, his at his final stages. His dying. Erm, but erm, they haven't openly told me, and it's something that I don't wanna know, personally. Even though I know, but I don't want someone to tell me. (Page 5, 173-177).*

After experiencing a parent being affected by cancer, Grace expresses realising how "unbeatable" cancer is. Her expressions point out that she has accepted the idea that she will lose her father to cancer. She appears to be hopeless about the possibility of him recovering from cancer. Indeed, later in the interview Grace further adds that she knows her father is dying but does not wish to be told that he will die. She prefers to avoid such news and would rather not be told. This may be a way to cope with the process and avoid the emotions that will arise from accepting her father's loss. Not being told about her father's life prognosis is also allowing her to avoid the feelings that will arise from grief.

Subtheme 1.2.2: Fear of own risk – "Will I develop cancer?"

The experience of cancer through a loved one also evoked the fear of their own risk of developing illnesses and mortality amongst all the participants. They all expressed a fear of developing cancer in the future themselves. For some this fear was associated to their belief that cancer runs in families and is genetic. On the other hand, for some of the participants experiencing cancer in such proximity increased their awareness of the possibility of developing an illness, and in turn increased their concerns about getting it themselves. The uncertainty of what the future holds regarding one's own health, brought together a lot of anxiety.

After her father's diagnosis of cancer, Grace developed concerns around getting cancer herself too.

> ***Grace:*** *Definitely, cos erm. It makes you worry about yourself as well. So psychologically it affects you, ermmm. When my father was diagnosed, I then ermm, with any slight problem that I had myself. I use to think is it cancer? Ermm, like for example, I use to have stomach pains, and my father had stomach cancer. I thought I got the same thing. Or if I have any other pains somewhere, I use to think is it cancer. Ermm, yeah. (Grace, Page 1, 31-37)*

When grace experiences pain in her body, she gets worried that it is cancer related. It may be that experiencing cancer in such proximity brings into the awareness that health difficulties are always a possibility. And small pains around the body could point towards bigger health problems such as cancer. For instance, Grace observing that her father's stomach pains turned out to be stomach cancer, increases this fear that small pains in her body could be associated to cancer too.

Likewise, Maria also expresses the fear of developing cancer herself. She explains believing that cancer runs in the genes.

> ***Maria:*** *And there is a lot of uncertainty of the future, if I am honest. You know, I don't know if I am going to be completely healthy because cancer does tend to run in the genes. And it's just, ok if she had it, what if I get it. And if I get it, how am I going to cope. Because I feel like my mum is a lot more stronger than me. So yeah, its that constant fear of getting it myself. (Maria - Page 10, 408-419)"*

She expresses her worries with various questions regarding what the future holds for her health. From her expressions, it is clear that Maria is experiencing significant anxiety regarding the future and concerns related to uncertainties. The experience of having a parent with cancer appears to make individuals question the possibility of developing illnesses and heightens their awareness of their own mortality. Likewise, Harry also expresses experiencing significant fear of developing cancer.

> ***Harry:*** *I use to think this will never happen to us. But it's made me feel much more again vulnerable. Anything could happen to me at any time. I should always be careful. This happened to my mum, why can't it happen to me. I mean, this is also*

> *made me a bit anxious as well. And gives me some anxiety, anxious. And sometimes I do feel depressed, just waking up in the morning. And I feel like were going to get cancer one day. What if it is genetical and my whole family gets cancer, and we all die. What if there's something wrong with our genes, and stuff like that. (Harry - Page 9, 344-352)*
>
> **Harry:** *.... And actually, even if I don't have cancer, this stress level and anxiety could actually. Actually, I believe, it could lead me on to having cancer one day. (Page 11, 399 - 406)*

Harry experiencing cancer through his mother has made cancer feel closer, and as a possibility that is more likely. In addition, he expresses feeling concerned about the possibility of cancer being genetic. His concerns cause him to question the possibility of him and or his family members dying because of cancer. Clearly, the uncertainties that the future may hold, is underlying these anxieties. Harry also expresses that the anxiety he is experiencing is so great that it could cause cancer. His expressions indicate that he is experiencing a significant amount of anxiety which he believes can impact his health.

Superordinate theme 2: A Process of role transformation

The second superordinate theme "A process of role transformation" aims to capture the experience amongst the participants about the process of change that occurred after their parents' diagnosis of cancer. It describes and reflects how the ill parent, the roles, responsibilities, and dynamics in the family have changed. Furthermore, this theme explores the changes and feelings the participants have experienced in their role as a child of a cancer patient, with particular focus on changes they have made in their lives, decisions, and responsibilities.

Having a parent with cancer brought together a lot of changes to the family, as well as the ill-parent. Often, the ill parent became needy due to their illness, and the adult child became involved fully or partially in their care. Depending on the parent's cancer severity and treatment needs involved, sometimes this involvement was physical and sometimes it was emotional. It also emerged that along with these changes and due to the care-giving responsibilities, young adults reported sacrificing from their own life and duties. They felt the need to make changes to their own priorities and day to day lives. This cycle was common amongst the participants and there was a domino effect. The parent's deteriorating change was leading to changes in the roles and responsibilities in the family and consequently the adult child became the caregiver. To reflect on this cycle experienced, the following three subthemes emerged: 'observing parent's deterioration', 'Adapting a parent mode, and 'putting self on hold'.

Subtheme 2.1: 'Observing parent's deterioration'

Changes in parents after the cancer diagnosis was a common topic that was expressed during the interviews. While some participants reflected seeing physical changes occurring due to cancer and the treatment process involved, other participants reflected on the changes in their own perception about their parents. Participants expressed that their parents after cancer became more vulnerable, needy, and weak. Observing these changes was highly distressing for the young adults. The subtheme: "Observing parent's deterioration" aims to reflect this experience.

When describing the changes in her father, Grace cries. She uses the term “deteriorating” to describe the changes in her father after his cancer diagnosis, and explains:

> ***Grace:*** *It's basically you can see that person like deteriorating, in to like a little person. Like, a strong man, he was very like tall and built, he just turned in to like a little, like shrunk (Continues to cry while she speaks). (Page 9, 336 – 339.*

Grace’s emphasis on her father’s changes indicates that these changes that occurred in her father is visible and therefore, watching the impact cancer has on her parent is unavoidable. Cancer has taken away these traits from her father and has made him weak, causing her great upset.

Maria also describes a similar experience. She emphasises that cancer has turned a strong person in to a vulnerable person.

> ***Maria:*** *So, I’ve always seen her as a very dominant figure and someone who’s, who’s really brave. And, who always takes a stand for her family, for herself. I strongly admire that trait in her. And, to see her go through that process and she became really fragile at the time, and really vulnerable was really shocking for me because I have never seen her like that before. And for me to see that, it was just so confusing. And I felt like, but mum I have always seen you as someone who just fights. You’re a fighter…. look what cancer did to her. In terms of made such a strong person into a vulnerable person. (Maria - page 7, 279-290).*

Maria adds that she always saw her mother as a fighter, who is now very fragile, suggesting that her mother’s change may resemble a losing position, bringing her mother closer to death. Maria feels that cancer is changing her mother, taking her mother away, which is difficult to accept for a daughter. She perceived her mother as a hero and someone that was always going to maintain a strong stance for the family. Seeing her mother’s unexpected change due to cancer came down as a shock for Maria and may have felt like taking her hero away. This left her in a state of confusion as she was not familiar with the feeling of seeing her mother in a vulnerable state. Realising and visibly observing this change because of cancer, was hurtful and hard to acknowledge.

Likewise, Shirley described the traits her mother held before cancer, and described her mother as a “strong lady”.

> ***Shirley:*** *Its, it’s very ermm, I, my mum she’s a very strong lady. She’s very strong and seeing her, melting. It’s very heart-breaking. Its, it’s very scary, it’s horrible……(Shirley - page 4, 117-122).*

She used the term “melting” to describe her mother’s change after cancer. This expression may reflect her experience of observing her mother gradually loose against cancer. She described her feelings of this experience as horrible and heart-breaking. As the changes in a parent with cancer can be physical, it may make the process feel unavoidable to think about. The physical changes in a parent that occurs after cancer means it keeps the experience at the forefront of the eye and therefore the mind. They are faced with having to watch cancer diminish their parent.

From a differing perspective, Harry also reflects up on the changes that his mother had in her attitudes and behaviour.

> ***Harry:*** *She doesn’t look the same, that’s the main thing. She looks different. Err physically. Secondly her actions are different, she’s always either sleeping or. I mean even when she’s with us, she doesn’t have the same energy no more. She doesn’t go out as much as before. I mean, she just spends a lot of time with her family, doesn’t do that. At the same time err, I think she craves more attention and love and caring. So, she’s always expecting for people to err, think about her and look after her. And she does get upset quiet easily than before. (Page 6, 221-229)*

Harry highlights that his mother’s actions have also changed after her cancer diagnosis. She has lost energy and is spending more time resting. He also reflects on the changes of her expectations and desire for attention and care. Cancer may be tiring her out and making her more needy. Being needy and having expectations from others may resemble a weaker or more vulnerable person for Harry. Therefore, cancer not only changes parents physically but the impact it has on their stance/ability as a parent also changes. Consequently, a parent becoming more needy, may take away the strong parent model that their children perceive of them.

However, Harry feels the need to express that he still thinks of his mother as a strong woman with a special character. There is clearly a dilemma in his expressions with regards to whether he sees his mother as weaker or not.

> ***Harry:*** *I mean my mum has never changed in my eyes. She's always the same lady, because my mum is actually a very strong woman. And, she is still really strong and there. She still has the same place for me, like, as before. And this, this, this weakness, this illness has taken you know err, her strength away. But even though my mum is, really really. She has got a really strong and special character. (Page 6, 235-241)*

It appears that Harry struggles to complete sentences when describing his mother and appears to have a desire to describe his mother as someone that is very strong. It comes across to me that Harry feels guilty when describing his mother as needy or weak. Each time he thinks of her in this way, he aims to reverse it by emphasising that she has not changed in his perception and refers to her as the same strong lady. It may be that he struggles to face the changes in his mother and tries to keep a perception of her that is less painful for him. Or Harry may feel that he is shaming his mother if he describes her as someone weak. Perhaps, describing her as "stronger" makes him believe she is stronger and is a way of honouring her battle against cancer.

Like all the other participants, Nyla and Dalia also expressed observing the changes in their parents and reflected on their feelings about these changes.

> ***Dalia:*** *My mum was a strong character and now seeing her very weak is making me feel very weak. (Page 8, 305-306).*
>
> ***Nyla:*** *Who would want to see their parents suffer or look upset, when they've always been the stronger ones. And seeing my dad was up there and kind of going down there, was very, very ermm. What's the word? Hard and is very disappointing for me as well. (Page 11, 422-426).*

Dalia described feeling weaker when her mother is weaker. Nyla described feeling upset seeing that her father is no longer the stronger one. This change in strength in parents was commonly mentioned amongst the participants and was clearly upsetting for the young adults. Parents are often the carer and the stronger parties, and this change within the family dynamics is unexpected and unfamiliar. For instance, Nyla describes her experience as "disappointing". The changes that cancer has bought to their families has resulted in shifts in the normative roles/positions held by the family members. This may have been a threat to both participants, as they now had to cater for new roles that they were not made for (i.e., engaging in parent like behaviours and responsibilities).

Subtheme 2.2: 'Adapting a Parent mode'

Most participants reported the multiple roles and added responsibilities they have had to take on since their parent's diagnosis. The subtheme 'Adapting a parent mode' aims to reflect what the experience of caregiving for a parent with cancer was like. Furthermore, this theme explores how the added parent-like duties and responsibilities were experienced by the young adults and how they catered for it.

An interesting similarity between some participants was that they used very similar sentences to reflect their experience. Shirley, Maria & Nyla reflected feeling like they became the new parent, like the new mum of their ill parent.

> ***Shirley:*** *At home, ermm, well, ermm. I'm the one who's caring for my mum. So erm, whenever she needs to, I am the one who erm cleans her, I'm the one who, dresses her, I am the one who cooks, I'm the one who cleans. So, erm it's like, it feels like I am the new mum. So, I, it ooh (tired voice). Its erm, I am the caregiver basically, I am the one who makes sure that the families all supported, all, they feel ok. I make sure that, their all ok. It's hard for me as well, cos having everything on your shoulders is very difficult, it's very tiering, it's very stressful. (Shirley - page 8, 286-294)*

The added responsibility and caregiving duties that Shirley has had to take on since her mother's cancer diagnosis has made her feel like she is the "new mum". She lists the duties she has had to take on and reflects that this is putting her under stress. Her mother's cancer has taken away her mother's role as a parent, and Shirley is feeling the need to replace that figure in the house, to maintain the family home. It comes across that replacing her mother is somewhat providing herself and the family with comfort, achieving normality and making them feel supported through the process.

Maria also emphasises that she is being her mother's parent and explains the changes she has had to make to cater for this parent like role.

> ***Maria:*** *So, in order to encourage her further, I have changed my diet as well. So, just so that it could erm, so I could support her with it as well. Yeah so, I guess because I was there for her as a supportive figure, its made me more responsible. So, my responsibilities in that sense have increased. I feel like although she's my parent, in a way, I have to be her parent. So yeah, caregiving in term of me being her parent. I do play that caregiver role isn't it. (Maria - page 12, 483- 495)*

Maria feels the need to make changes to her life such as changing her diet, in an aim to change her mother's diet too. She says that the added responsibilities that came with having to be the supportive figure for her mum, has made her feel like she must be the parent. The experience of having a parent with cancer changed the roles, adding more caregiving responsibilities to Maria. This change felt unavoidable for Maria, as she say's "*I feel like although she's my parent, in a way, I have to be her parent.*". It is almost like Maria's new role is set out for her and she must cater for it.

Similarly, Nyla also expresses feeling like the mum. She explains that her new role is connected to the changes in her father and her knowledge that emotional support is very important for patients diagnosed with cancer.

> ***Nyla:*** *Yeah, I didn't have to take care of him before that. He was my father, he would take care of me. But, it went the other way around, where I had to take care of him. And, I just felt like they're vulnerable, like a little baby. So you know, show them love, show them care, show them physical support, be around for them. So yeah, even*

> *showing them that you're there, I am sure they do say, you know emotional support is very important for patients who are diagnosed with cancer. So yeah, trying to give that to them, when you actually have nothing to give, because of what you're feeling and what your experiencing, just drains you out even more. You feel really drained. (Page 10, 363-373)*

Observing the deteriorations in her father has caused her to perceive her father as weaker, more fragile, and vulnerable like a baby. And therefore, she is feeling responsibility like a parent and is adapting the role of a parental figure to provide a climate that is safe for her father. Also, she emphasises on her knowledge that emotional support is very crucial for cancer patients. It becomes clear that her urge to support her father and become a parent like figure may be a way to help her father overcome cancer. However, this urge and change in roles comes with a lot of emotional difficulties for Nyla too, as she expresses feeling tired and drained.

Grace's description of her change was very interesting. She referred to herself as a little girl, who became mature after her father's diagnosis of cancer.

> ***Grace:*** *I think before all this happened; I use to think be like a little girl. Even though in age I was very old (laughs). I was, but you mature very quickly. When he told me that I didn't know it was something very serious like I said. I just thoughts its something that can be cured. (page 3, 95-99)*

Grace felt that although she was an adult before her father's cancer diagnosis, she was not mature. When she was hit with the news of her father's diagnosis, she did not know what that was going to mean in terms of their future. However, this direct experience of the process of cancer has made her learn the toughness of the illness, making her grow. When Grace refers to this maturity/growth, it came across to me that she was referring to the ability and readiness of adapting the parent like role, to cater for the difficulties that cancer can bring for her ill parent and members of the family.

In fact, later in the interview, Grace reflects on the changes to her life and how she adapted to her new role after her father's cancer. She also shares the societal expectations that people hold, and the frustrating impact this has had on her.

> ***Grace****: Erm, now, although I've got an older brother, I kind of stepped in to keep all the family together…. Ill cook for him and take it, take it over there. Erm, I would want him to be at home and go through his final stages at home but I know that erm, (pause) medically we can't look after him at home properly. Because his erm, all of his like, poo and urine and everything is like there's a erm a bag put on him….. So, we can't actually look after him like that at home. So, he has to be in the hospice. Now ah, it's very bad, like we get people, especially erm like my aunties and uncles on my dads' side, they talk as if like we don't want to look after our dad. Like as if we have kind of put him aside, but that's not the case. And it, there's a lot of things that hurt. Erm, there's a lot of, apart from the illness being so difficult, people make it difficult for you as well. (page 5, 185-204)*

From Graces experience it appears that the judgements and expectations that come from people and society can be a significant factor that impacts the experience of having a parent with cancer. Individuals may feel a greater sense of burden and a need to become a caregiver due to the expectations that is implied on them by the society. And when caregiving is not possible at home due to the nature of the illness, it may cause further feelings of upset and feelings of guilt.

Dalia's expressions reveal burden due to the caregiving commitments.

> ***Dalia:*** *like I said I have responsibilities for myself and I cant even take care of myself cos of her. I have to be always there for her, care for her, speak for her, cook for her, clean for her. It's just really difficult for me at times. But then again, I cant do anything about it. I have to just accept the way she is. (Page 7, 284-288).*

Dalia is frustrated and expresses not being able to take care of herself. The role demands and the duties she must cater for appears to have taken over all of Dalia's time. She feels helpless and feels that her new role is unavoidable. She says, *"I have to just accept the way she is".* Her use of tone and language suggests a possible degree of blame and frustration towards her mother for being needy and relying on Dalia. Her mother's neediness is taking over Dalia's life and impairing her ability to function as she normally would. Even though Dalia is an adult, she is not the parent, and may not be equipped to handle the psychological burden that this role brings.

Subtheme 2.3: 'Putting self on hold'

Other than taking on responsibilities, it appears that the experience of having a parent with cancer has led the participants to priorities their ill parent and put themselves on hold. In other words, to cater for their new caregiving role, participants may have had to neglect their own needs. Some participants explained that they have put certain events or parts of their life on hold/pause due to their parent's illness. They prioritised their ill parent and avoided doing chores or progress for themselves. For some, engaging in activities for themselves felt wrong and made them feel guilty. It just felt right and safer to devote their time and energy to their ill parent. And for some, the caregiving duties took over all their time and capacity. The subtheme 'Putting self on hold' aims to reflect this experience.

For instance, Maria expresses having to put her marriage planning on hold:

> ***Maria:*** *And I had to put all my plans on hold as well because I just couldn't go through with it, like planning my marriage and stuff at the time. (Maria - Page 3, 105-113)*

"I couldn't go through with it" is the words Maria chose to use to reflect her feelings about getting married while her mother was experiencing cancer. Her use of language and tone of voice reflected feelings of upset, burden and guilt. It appeared that engaging in positive events such as marriage while her mother was suffering with cancer, made Maria feel like it was not feasible to go ahead with the marriage planning. In addition, it may have been an additional burden for Maria at a time that she was also not enjoying herself. Therefore, putting her own plans on hold may have been an easier decision to take both to avoid additional stress and feelings of guilt.

Furthermore, Shirley reflects sacrificing from her own plans and relationships in an aim to support her mother.

> ***Shirley:*** *It has, I've, I've ermm, basically I've put that at the centre of my life, I don't know if that makes sense. Its I've isolated myself from my friends. If I want to go shopping, I just first make sure that my mum is ok. Or I just ignore doing what I have to do. Ermm, at work sometimes I call in sick, to make sure my mum is ok, or I go to my mums appointments. Ermm, I've, I, though of applying for my masters, I've at the moment, I've decided not to, I've just put that. I wanted to ermm, I had so much stuff that I wanted to do. But now I, I don't, I, my mum is what's more important, so I want to make sure she is Ok, ermm. And then, yeah. (Shirley - page 7, 235-244)*

Shirley has isolated herself from social relationships, has taken time off work, and decided not to pursue her education, as she prioritised her mother and the caregiving duties. Shirley says "*I had so much stuff that I wanted to do. But now I, I don't, I, my mum is what's more important, so I want to make sure she is Ok".* These expressions confirm that the experience of having a parent with cancer is very demanding and may change one's responsibilities, forcing them to priorities their parent and causing them to give up on some areas of their own life. They may lose their own desires and focus solely on their parent's wellbeing.

Nyla also expresses that the commitments that come with her father's cancer has taken away from her own life.

> ***Nyla****: Erm, if you know what I mean. I was just breathing, walking around like a robot. With not, I was not aware of anything. Erm, you also become very antisocial as well. You lose out on friends; you do not have time for anything. Erm, it's just the commitments you give, it takes away from your own life. (Page 14-15, 558-562)*

A major impact of having a parent with cancer for Nyla appears to be the impact it has had on her social life and relationships with friends. Due to the commitments and because of prioritising her father, Nyla does not get a chance to socialise or do something for herself. Similarly, Dalia also expresses that she had to sacrifice a lot from her life to give more to her mum.

> ***Dalia:*** *So at home, it's her. Like, I am living her life. It's not me again. At home, at work, when Im with family and friends I am always thinking of her. I feel like that is not my life, like I am living the life of my mum. I feel responsible for her. I feel like*

> *maybe it's, it's not maybe, I always think that what if she's not going to be there tomorrow. What if something happens to her and I am not there for her. I feel like I have to be there for her all the time. Yeah, so I had to sacrifice a lot from my life to be able to give more to my mum. (Page 11, 442-450).*

From Dalia's tone of voice and pace it came across that she felt anger when describing the process of having a parent with cancer. She explains feeling that her life was taken over by her mother's life. She also adds that the worry of not being around when something may happen to her mum, prevents her from going out. This fear makes her devote her life to her mother.

Harry reports finding a balance in socialising. This is different from how most other participants explained the changes that occurred in their lives.

> ***Harry:*** *Yeah, I spend. I try to spend more time with my parents, my mum. So, I do spend less time socialising with friends and going out and etc. But, I do believe I have found the right balance. There is no point of me always being next to her, cos I got such a big family. I do try to spend as much time as I can with her, but at the same time yeah, I do go out and stuff as well. With my friends and like university and work and stuff. I do remember though, during my university times, at one point I did miss out on 2 to 3 weeks because my mum was in hospital for a long period of time. And it may have affected my exams… (page 12, 432 - 446)*

It is interesting that Harry refers to a balance that he aims to achieve between spending time with his family and socialising. His need to find this balance is rooted in the experience of having a parent with cancer. He is making conscious decisions and considers trying to achieve a balance between his family and social life, which may have not been a priority if his mother did not have cancer. In addition, Harry did not refer to any caregiving duties. Nonetheless, Harry does report the impact of his mother's illness on his coursework and exams. However, he later adds that he has never applied to get extra time or re-sit any components of his course.

> ***Harry:*** *I never erm, I never used any of that. Because I just didn't wana feel guilty. I didn't want to seem like using her situation in my favour like. Err, that's, she's in a*

> *bad situation and I'm taking that and trying to make something else easier for myself. I never wanted to do that. (page 12, 454-462)*

Although Harry believes that his performance at university may have been affected by his mother's condition, he made the conscious choice not to get support. Obtaining some sort of benefit made him feel guilty. Although he probably would have been eligible to re-sit another time, he did not want to obtain any advantage from his mother's cancer. Therefore, having a parent with cancer has also caused harry to deprioritise his exams and success at university. This also shows that when a parent is ill, they become the centre and like the main character, that everything else forms around.

Superordinate theme 3: 'Coping through cancer'

Through the interviews, participants described struggling significantly when trying to cope through the process of their parents' cancer, especially with the demands that comes along with the illness. The participants had both similarities and differences in the ways that they coped. The third superordinate theme 'Coping through cancer' describes the young adults's lived experience of how each of them managed and coped with the experience of having a parent with cancer, and everyday life challenges, such as stressors and strains. More specifically, it describes the ways in which the participants tried to get through the experience. Although each participant described various ways in which they felt that they coped, 'Invulnerable self', 'Estranged from others' and 'A source of support" was amongst the most reported.

Subtheme 3.1: "Invulnerable self"

When a parent has cancer, many things change within the family home and roles, as discussed in superordinate theme 2. The ill parent may have many hospital admissions, require care and their duties within the home may be picked up by other family members such as their young adults. In addition, they need moral and emotional support through the process of their illness. To cope with all these changes participants reported a need to appear strong. In other words, despite feeling pain and weakness within, they portrayed an invulnerable self. The subtheme 'Invulnerable self' aims to reflect the participants experience of feeling the need to appear strong, while experiencing significant upset and weakness within.

For example, Shirley reflects that she felt a need to be strong, particularly after seeing the fear experienced by her mother.

> ***Shirley:*** *Ermm I remember having to ermm, I had to translate ermm my mum what was going on, and looking in to her eyes, and seeing that fear, me trying being strong but inside me I am very heartbroken, very worried, very scared ermm it was a very hard day. (Shirley - Page 1, 29-35)*

The words Shirley chose to use were, "*me trying to be strong, but inside me I am very heartbroken, very worried, very scared"*. Clearly, she reveals the upset and sadness she was experiencing when faced with her parent's diagnosis of cancer. However, she had to keep a position that appeared strong. Her awareness of the difficult and hurtful procedures that her mother is going through as part of her treatment of cancer, made her develop this need to stay strong. Her need to respond in this was a result of the responsibility she feels to take care or her mother.

Grace also felt that when a family member is ill, you must put on a fake smile, and pretend to be strong.

> ***Grace:*** *I think having a family member that's got an illness like that, on one side although you know it's something serious, something serious is going on. But on the other hand, you got to pretend as it's something normal and it's somethings that you can get over, for their moral……. Erm, but you just have to pretend. Like you just have to put a fake smile on yourself, even though inside you know that this person is dying. But you still have to pretend as if everything is ok, and they are going to get better. (Page 4-5, 154-165).*

Grace put on a fake smile and pretended to be strong with the desire to provide moral support to her father. She reflects feeling the need to respond in this way despite knowing the seriousness off the situation. Despite the possibility of her father dying, she chose to act in a way to imply that everything is going to be ok in an aim to support her father.

Dalia also expresses having to pretend she is strong. However, Dalia also reflects on some of the consequences this has had on her emotional wellbeing.

> ***Dalia:*** *I feel very anxious all the time. I feel that, I can see that I am not me anymore because I have to change my mood, change my, I have to just like you know pretend that someone that, that I am strong. I have to pretend that, I have to think positive all the time. I have to just put a smile on my face when I am with her, even though I am crying deep down, and that is just making me feel depressed. It's making me become an angry person. Like my relationship, it, it for the past one year I had to you know, break up with my boyfriend because he couldn't handle it. (Page 9, 337-346)*

Dalia feels anxious and reflects that acting in a way that is not congruent with how she feels is very distressing for her. In other words, pretending to be strong for her mother has impacted Dalia's emotional wellbeing negatively. She expresses feeling angry and depressed, which has in turn impacted her relationship with her boyfriend. Her state of pretending led to an unauthentic relationship, causing distances and in turn estrangement.

Subtheme 3.2: "Estranged from others"

An interesting commonality that came up amongst the participants was their expressions about feeling discomfort when around others and a need to estrange themselves. They felt vulnerability when in social settings, especially when the topic became their parent's cancer. Firstly, talking about their parent's illness evoked anxiety and upset, and most participants wanted to avoid the topic to avoid the feelings it evokes. It was worrying for them to be in a social setting and then to randomly be triggered into a low mood by questions. Also, they found the conversations pointless, as they believed that it was not possible for people to understand them. On the other hand, for some this vulnerability was associated to the feeling of being perceived as weak. When individuals asked them about their parent's cancer, they interpreted that as the other feeling sorry for them. Consequently, they became estranged from others to avoid such feelings. It appeared that being estranged from others was a way to cope with this feeling and survive through the process of having a parent with cancer.

For example, Grace expresses not wanting people to talk about her father's illness as this can trigger negative feelings and be hurtful.

> ***Grace:*** *I don't want people to talk about it around, it makes me angry. Because I don't think that they understand. Because they don't understand, they say things to hurt you. So, I don't, erm, I just don't feel comfortable when people talk to me about it. Or ask me questions or talk about it around me. Erm, I wouldn't, know I wouldn't do it, that to someone else. Because I feel vulnerable, when people talk about it………… erm, now that my dad is at a stage where he doesn't talk anymore. And he just, he, they just like, his breathing. Nothing else. Erm, and when people ask you what is he, what did he say, what did he, it hurts. (Page 7, 273-287).*

Grace openly shares that she does not like people talking to her about her father's illness, because she does not believe they can understand her. In fact, she believes that people can make comments that are hurtful. Therefore, she feels uncomfortable in social settings where her fathers' illness is the topic of conversation. Grace also adds that such settings make her feel vulnerable. Being reminded of her father's current suffering is upsetting and she does not want to talk about it.

Similarly, Dalia expresses feeling a need to cut her contact with people due to the stress she experienced when they asked her questions about her mother's cancer.

> ***Dalia****: I've cut my contact with a lot of people. I had to just stop talking to people because, people use to just stress me out. They would end up asking me questions about my mum, you know how she is, what shes doing, how the treatments are going. And that, it's just, it was not helping me with the way I think. So, I had to cut contact with a lot of people, all my friends. Right now, I feel better that I am speaking to the therapist. (Page 16, 674-680)*

She explains that talking about her mother's cancer stresses her out and impacts her mood negatively. Therefore, it may be that she desires to avoid such questions to avoid the negative feelings that comes with them. For instance, Dalia says "I just breakdown" when she gets questions about her mother's illness. And avoiding questions on this topic is a safety measure for Dalia. To achieve this safety, she estranges herself from others. By doing so, Dalia aimed to cope by not being triggered into feelings of weakness or disadvantage.

Harry also expresses feeling annoyed when people ask him about his mother's illness, as this also makes him feel in a position of lowness.

> ***Harry****: it's just that feeling that people are feeling sorry for my mum, and just getting that like who. It just makes me feel like, these people now think err. Now think that there in a position to feel sorry for me. And they ask me if they could do anything for me. But at the same time, before this. We would be like; do you know what I mean. They wouldn't ask us these questions. (Harry: Page 16, 615-620)*

Harry feels uncomfortable around others when the topic of conversation is his mother's illness. He feels that people may be feeling sorry for him when they ask him about his mothers' illness. This experience suggests feelings of vulnerability and an attempt to avoid this vulnerability. On the other hand, Nyla describes becoming antisocial and estranged from others due to the commitments that have arisen because of her father's cancer.

> ***Nyla:*** *You become very antisocial because you're always committing. And you can't really form friendships or even main, maintain them. Err, a lot of my friends that I was very very close with at the time, err I had to kind of put a bridge and you know, distance myself from everyone. Because I cant commit to having friends around as well as having a family that I have to run around for. So, it has affected my social life, like my social life has gone down to 0, from 100. That's been a major impact on my life. (Page 18, 695-703).*

She says, "my social life has gone down to 0, from 100". Her reasoning behind this withdrawal from others was the feeling that she cannot commit to having friends while also having a family being impacted by cancer. Nyla expresses having to put a bridge and distance herself from her friends. From this it appears that it is Nyla's choice that her social life has gone down to 0. This choice is made because her ill parent and the family have become her priority, and to cater for them she is withdrawing herself from society.

Subtheme 3.3: 'A source of support'

Most participants were able to highlight a source of support during their experience with cancer. Each participant found different activities or the presence of different people supportive during this process. For instance, for some of the participants a health professional was their source of support, while for some individuals it was their family or religion that provided support. These participants also expressed that they did seek support and emotional presence. The subtheme 'a source of support' aims to describe the different sources of support experienced by participants as helpful during their experience of having a parent with cancer.

Maria described the support she received from a Nurse:

> ***Maria:*** *Ok, so at the time I was withdrawn from everyone. And I thought that no matter who I talk to, they are not going to help me. But then I, so there was this nurse that came to me. She was the nurse that was there all throughout. And I think, just talking to her about it, because she was so compassionate. She had so much care and love inside her, and the way she spoke, it just. Because she was, you know you can tell she was there not just physically, but she was emotionally present. And for her to, for her to just give that, for her to just lend that ear to us and to give us that you know, erm, presence that we could talk to was so supportive…. (Maria, Page 13, 532-544)*

Despite her belief that talking to someone will not be helpful, Maria found talking to a specific nurse very supportive. She emphasised that the nurse was in the picture from the beginning of the process of her mother's fight with cancer. The nurse being in the process throughout appears to make Maria feel that the nurse can understand and show real compassion. In her relationship with the Nurse, Maria was able to feel the compassion, love, and emotional presence. These qualities coupled with the Nurses ability to listen was experienced by Maria as helpful. These expressions point out that emotional presence coming from a loving and caring individual could be significantly supportive for individuals experiencing significant stress from having a parent diagnosed with cancer. Dalia also describes feeling better after seeing a professional therapist.

> ***Dalia:*** *Omg, everyday. I think of it everyday. Its like a nightmare. I sometimes like in my sleep, I just wake up, and I just like have bad dreams of the whole thing. I cant get to sleep, I, I, even see a therapist about this because, psychologically it just drained me out aswell. I had to speak to someone about this, I don't feel comfortable talking to my friends, talking to my family, or, or anyone around me. So, I seek help from a therapist. In the beginning, I was ok but now I just feel like, as I said, what is things get worse? So, I, I mean, its, when I see the therapist I feel better. (Dalia: Page 5, 169 - 177).*

After her mother's cancer, Dalia is experiencing disturbed sleep and has bad dreams. She specifically adds that seeing a therapist is different from talking to family or friends. Dalia expresses not feeling comfortable speaking to people around her, such as family or friends. It may be that she does not feel understood or does not experience the level of compassion that she may be seeking. Once again, it comes across that speaking to a health professional for support is more helpful for some individuals.

Another source of support Maria identifies as a very powerful strategy in the process of dealing with her mother's cancer was Mindfulness.

> ***Maria:*** *So, like I said, I am coping. What I do now, is after. So, one thing I came across, when I was with my mum and she was going through the whole cancer treatment and everything was mindfulness. So, I think mindfulness is a very powerful strategy, in my experience. Because it really helps someone sync into the present. And it really helps gage with what is around. Because if you think about it, on a day-to-day basis there's so much stuff that we tend to ignore. And its those little things that could be a lot of value, value. I think mindfulness has given me that value of life. You know has given me that meaning. Just the simple breathing exercises has made me in touch with my body, something that I was neglecting and ignoring. So yeah (page 12-13, 500 - 511).*

Maria feels that focussing on the present is very helpful and Mindfulness makes that possible. In practicing mindfulness, Maria has gained a greater awareness about the value of her life and is able to re-connect with her body. Maria feels that she has been ignoring and neglecting her body unconsciously. This may have many reasons, such as change in priorities or even to avoid painful feelings connected to her mother's process of cancer.

Religion was also another source of support that was highlighted by Harry.

> ***Harry:*** *We are really religious, so we do pray a lot. And that really helps us. That really supports my mother. Her prayers, and her friends from the mosque. And the community, they really support and yeah. (page 13, 502-505)*

Harry believes that he and his mother finds strength from their religion and prayers. He is referring to their spirituality as a source that is helping them through the process of their mother’s cancer. Moreover, the community and friends they have from the mosque is also supportive. This highlights that holy centres and communities that individuals feel that they have commonalities with, may be very helpful in providing support during difficult times.

Grace was not able to identify a source of support for herself. However, she reflects on her viewpoint that there is not enough knowledge and support out there for individuals and families impacted by cancer and terminal illnesses.

> ***Grace:*** *I think people with family. I know it's like the NHS and everything is erm, under very much erm, pressure. But people with serious illnesses like cancer, they should be like dealt with a psych, with a erm, a psychologist basically. Like how if someone has been shot dead and that family has erm, they children and the whole family get dealt with a psychologist, it should be the same thing. Cos it's like, your hit with an illness and your going to die with that illness, not knowing how long you’ve got to live. So we should also have psychologists with us. Erm, cos were just left to deal with it in your own. (Page 13-14, 531-540).*

Grace believes that individuals impacted by an illness such as cancer, especially when it is known that the illness will be terminal, should be entitled to professional help. She also says, “were just left to deal with it on your own”. Her expression suggests that she felt very lonely and unsupported through the process. It’s possible that she did not know where and who to get support from. This raises concerns as it is possible that many other individuals experiencing parental cancer may have a similar experience. They may benefit from support as reflected amongst the other participants. However, if they do not have this access, not only will they not have support, but we will also not know whether any support will be helpful for them.

Superordinate theme 4: The positive growth

As one would expect, having a parent with cancer is certainly a highly distressing experience for both the ill patient and their families, as seen in the previous themes. However, a common thread that was also revealed through the interviews was the growth outcomes of having a parent with cancer. In other words, the experience of having a parent with cancer also resulted in experiences that can be labelled as positive or more constructive. The fourth superordinate theme "The positive growth" describes the participants expressions of benefits or perceived outcomes of the difficult and highly stressful experience of having a parent with cancer. This theme explores the constructive changes experienced in the participants families, attitudes, and lifestyle after their parent's cancer diagnosis.

Subtheme 4.1: Stronger family bond

A common theme that emerged was that the negative experience of having a parent with cancer had a positive impact on family communication and the relationship bond. Since the cancer diagnosis of their parents, majority of the participants have experienced that their family bond and communication have gained strength. Most participants reported that their families have started to spend more time together and became more caring towards each other. This suggests that for some individuals the experience of having a parent with cancer may have a positive contribution to their family relationships and attitudes. Why this occurs is an area for future research to explore. It may be that facing the fear of losing a family member, makes individuals gain the desire to spend more time and be more caring to one another. It may be that individuals become more aware and conscious of their behaviours and attitudes towards their family and aim to maintain an environment that is more loving and positive. The following extracts from the participants contribute to our understanding of this experience.

To reflect the positive changes in her family, Maria says "*our bond is a lot stronger with one and another":*

> ***Maria:*** *So now all of us. Since my mum's cancer we like I said, we, our bonds are a lot more stronger with one and another……….. Because we just think that life is so unexpected and anything could happen. And that constant fear, although fear you can*

> *associate with a negative term. But it's, it's become positive for us. So, in terms of positivity, it's made us more, erm, stronger together as a family. (Maria - Page 14, 578-588)*

The fear of losing a loved one is surely a negative and anxiety provoking feeling, as Maria expresses. She says, *"life is so unexpected, and anything can happen"*. It appears that the acknowledgment that life is unexpected coupled with the fear of losing a loved one has led Maria and her family to appreciate the current moment that they have together. It has brought them together, not only making their relationship stronger, but also making them feel stronger together. She highlights that this fear of losing each other, has had a positive impact on her family. She says "*although fear you can associate with a negative term. But it's, it's become positive for us*". This shows that a difficult experience such as a life-threatening illness can promote secondary Positive growth for families.

Likewise, Shirley reflects how the "horrible" experience of having a parent with cancer has positively impacted their family relationships at home:

> ***Shirley:*** *we've, realised that we've came together. Were very strong together, we ermm, spend more time together. Err, we its, it's horrible but, that this kind of situation lead to this, but we more often tell each other that we love each other. We call each other more often, we ermm, I don't know, have more, more (silence). We spend more erm, time. (Shirley - Page 10, 360-366)*

As well as coming together, Shirley describes that her family has been sharing feelings with one another and the expression of love towards each other is more prevalent. The awareness of the possibility of losing a parent and being left with the guilt of not having shared love and affection may be a disturbing fear. Therefore, taking every opportunity to express love and show care may be her response to this fear of loss.

Indeed, Harry reflects on his desire to spend more time with his family and his feeling that spending time away from his mother is a wrong decision:

> ***Harry:*** *I'm much more closer with my parents. Initially I had the thought of going to campus at university. However, I did then think that, that would be a wrong move.*

> *Because I did then want to spend more time with my family. So that, I just stayed at my house, my families house. (562-571)*

Harry says it would have been wrong to go to campus at university while his mother has Cancer. Doing something on his own, and for himself felt like a mistake. He took on a more collective approach and stayed within the family home. The possibility of losing his mother while he is not at home or when she is upset may be an overwhelming thought that he does not wish to carry. Nevertheless, due to this awareness it appears that Harry is trying to cater for anytime they may not get to have together with his mum in the future.

> ***Harry:*** *I mean obviously were evolving and were growing into something new. We're becoming a different family than we were before. I mean before we were a really good family as well but err, err everyone was just you know err. We didn't have this much err; we weren't this sensitive towards each other. And now, we just much more closer to each other. And we just spend way more time with each other than before (Page 17, 646-652)*

Harry identifies that the family is changing. He describes this change by saying, *"were evolving and were growing into something new".* His expressions point to a positive change in the family and his use of the word "growing" highlights that he can identify these changes to be positive. His family has become stronger, spending more time with each other. Nyla also expressed her experience of changes in her family in a very similar way. She explains that the family bond is much stronger, particularly after realising that life is unpredictable and can be short-lived.

> ***Nyla:*** *It's made it stronger, definitely. We were communicating quite well. But I think it just made it a lot stronger. We were able to tell each other how we feel more often. And that's what it changed. It just made our bond, our emotional bond a lot stronger than it was. And realising that life is short and that we should take care of one and other. And not feel resentful towards one another. And that we are a family. Being a family mean being a whole, being one, being together. (Page 17, 635-641).*

The experience of having a parent with cancer makes individuals face the possibility of losing their parent and develop concerns related to not doing enough while the parent or loved one is still alive and able. For instance, Nyla says, *"And realising that life is short and that we should take care of one and other"* highlights this concern. She further adds what the meaning of family means for her. It comes across that she feels that they are together and are united through the process of their father's cancer.

Moreover, another interesting reflection that came from Maria, Shirley and Dalia was that their relationships with their fathers, who was not the parent diagnosed with cancer (also the spouse of the parent that is ill) was impacted positively too.

> ***Maria:*** *Another positive change it's had, a very big positive change actually is that, er, my father and I always had a reserved relationship. But now since, like we went through this together with my mum, we have become close………… we got to know one another more as well. We, we opened up to one another. (Maria - Page 15, 592-602)*

> ***Shirley:*** *he was a person that very strong, very strict person that you would be scared to talk to, now I realised actually, it's not that hard, its, its, he's more understanding, he's more soft …………. I think this experience has built my relationship with my dad a bit more, stronger. Yeah. (Shirley - Page 11, 387-395)*

Maria identified the relationship as closer, while Shirley referred to it as stronger. Both participants described having a reserved and strict relationship with their fathers before their mothers were diagnosed with cancer. They did not feel close or able to speak to their fathers. However, the experience of having a family member getting diagnosed with cancer changed their relationship dynamics. It may be that prior to their mother's cancer diagnosis, there was little opportunity to spend time with their fathers. Therefore, when their mothers were diagnosed with cancer, it brought the family together and changed the priorities. The caring and sensitive side of their fathers may have also nurtured through this process and became more visible. As well as impacting the whole family relationships, the experience of having a parent with cancer may also improve one's relationships with their non-ill parent.

Dalia also describes becoming closer with her father and explains his supportive role through her mother's experience of cancer.

> ***Dalia:*** *my relationship with my dad has become more close…. And erm, yeah he was being very supportive to me, in order for me to be supportive to my mum. Hes been encouraging me to feel stronger so that I could support my mum, and he made me be closer to my mum….. (page 15, 6016-634).*

Dalia identifies her father to be the person providing her with support and strength, especially around her mother's illness. Her father not only gives her emotional strength, but he also directs her in ways she could be helpful for her ill mother, which she believes has fostered a closer relationship with her mother too. It becomes clear that when family members support each other and provide informative guidance through the highly distressing experience of having a parent with cancer, the experience could also evoke constructive/positive effects in the family relationships. It can also be helpful to cope through the highly stressful process of fighting with cancer.

On the other hand, Grace was the only participant who has a differentiating experience in their family relationships. She reports a breakage in their family bond since her father's diagnosis of cancer. This may be a different experience as the role of the father in the family may differ.

> ***Grace:*** *Before we use to be like together and talk. But now, I don't speak to my brother for example because of this situation. Because you would expect for an older brother to step in, and take ownership of the daughter, of being like involved with her family and her husband. Because my dads not going to be around and ok I am a strong woman, but I am a woman. Im not a man, I cant be a man. No matter how much I try I cant be a man. So if I have problems with my husband I need to know that I have a brother. And I need to know that even if I don't have a dad soon, I need to know that there is a man figure. (page 15, 578-587).*

After her father's diagnosis, Grace reflects the expectations she held from her older brother. It appears that she felt a need to replace her father and feel like she was owned by a paternal figure. Although she identifies herself as a strong woman, she explains she is not a man. She feels a strong desire to have a man figure in her life, for protection and support. She feels resentful and disappointed with her brother for not being able to provide her with that sense of security and feelings of belonging. Her father's cancer diagnosis has made Grace feel like she has lost him, and the sense of security he was able to provide, even before his physical death. It comes across that when a father has cancer, it may leave their children to feel very vulnerable and insecure. The expectations and loss that comes along with the loss of a mother and a father may be different. It may be that the experience of Grace is different from the other participants because it is her father that has cancer. Either way, parents look after and provide care for their children, losing that sense of belongingness and security is very upsetting and anxiety provoking.

Subtheme 4.2: 'Desiring a healthy Lifestyle'

As discussed earlier, the experience of having a parent with cancer made the participants experience anxieties relating to their own health and develop concerns about getting cancer themselves. Some individuals believed cancer was genetic and felt a heightened vulnerability. Mainly for this reason, changes in lifestyle and daily eating habits appeared to be a common topic amongst the participants. Majority of the participants reported wanting to make changes to their lifestyle in an aim to maintain a healthy life. They made changes to their diets, daily activities, and habits such as smoking. The subtheme 'Desiring a healthy lifestyle' aims to reflect this experience and the changes the participants have reflected on.

The process of having a parent with cancer led the participants to develop an urge to maintain a healthy lifestyle. One-way individuals felt that they could maintain a healthier lifestyle was by changing their eating habits.

> ***Shirley:*** *Ermm, I've, I've changed the way I eat. Ermm, what I mean by that is I started to eat healthily, I fear that I might experience that as well. I am trying to change everything around me, the way my family eats as well, I am trying to make sure everything is good. (Shirley - Page 8, 300-304)*

Shirley expressed that she changed the way she ate, particularly because she worries about developing cancer herself. She also highlights changing the way her family eats too, in an aim to make sure everything goes well. My tentative interpretation of this is that gaining some level of control over her, and her family's diet may be giving her a sense of control over cancer. For her, having this control may be a way to battle her mother's cancer and or reduce the risk of future occurrences of cancer in the family. Therefore, it may be that eating a healthier diet is seen as a preventative measure as well as a form of treatment to tackle cancer.

Moreover, Nyla and Dalia made lifestyle changes after their experience of parental cancer. As well as eating a healthier diet, Nyla and her father started exercising and have quit smoking.

> ***Nyla:*** *The awareness, the importance of health. Erm, trying to avoid such things happening to us… we both stopped smoking because of the fear that we might be diagnosed with cancer…. (Nyla – Page 13, 500-511)*

> ***Dalia:*** *what if something happens to me? What if I have cancer? what would I do? I don't want to obviously think about all this but, it's making me think twice. I appreciate my health. It made me, this whole thing made me appreciate what I have, my health and everything. I use to smoke and then, now I stopped smoking because I take more care of myself even though I feel more depressed. (Page 10, 406-412) – repeated in section above, try to bring together*

Both participants highlight that the awareness of the importance of health has led them to change their lifestyle in an aim to avoid illnesses. From Dalia's expression *"This whole thing made me appreciate what I have, my health and everything"* it becomes clear that the awareness of the importance of our health can increase the desire of individuals to take care of it.

On the other hand, although Harry appears to experience the fear of developing cancer himself too, he still continues to smoke:

> ***Harry:*** *I just drink way more water now. And err, and yeah. I mean I, I do still smoke. I did smoke before as well. But I do smoke a bit less now. I don't smoke less, I do smoke. But its just more on my mind. When I look at that packet and it says lung cancer, on the packet. It just comes to me like "oh shit". (Harry – Page 11, 412-416)*

From his hesitation during his speech about whether he smokes or not, it appears that he is experiencing guilt for continuing to smoke. Or it may be that he is unable to decide about quitting or not. Therefore, although he has not made changes to his behaviours now, his guilt when continuing to smoke may indicate a greater awareness of the consequences of his smoking. This awareness may in the future cause him to make decisions to maintain a healthier life (i.e., by quitting to smoke).

Grace revealed on her viewpoint that was very different from the other participants. She reflected that even if you are healthy and engage in only healthy behaviours this is not a guarantee that you will stay healthy.

> ***Grace**: ... Because even if you are very healthy, which my dad was. He wouldn't eat anything more than what he can take, he was not overweight person, he wasn't drinking or wouldn't smoke. But its still a fact that the illness got, found him. It's not necessarily about being healthy or not. It has, no matter how much you watch yourself, you, if its, if it's going to happen, it will happen to you. (Page 11, 415-422)*

In her explanations, Grace points out that her father was not overweight, he didn't drink or smoke, but he still got cancer. Her father's example was like a reference for her. She believes that no matter how much you try to maintain a healthy life, if it's meant to be then cancer will find you. Here we can see that she believes in fate. Believing in fate also means that you believe that you have no impact or control over what happens in life. This may be a coping tool and a way to take away any responsibility that may arise from the occurrence of an illness in the future. And therefore, the person will not need to do anything, as they cannot have any impact on what is or will happen anyway.

Subtheme 4.3: 'A better person'

Changes in character towards the outer world was another constructive impact of the experience of having a parent with cancer. From the participants accounts it occurs that the experience of having a parent with a life-threatening illness has led them to re-evaluate what is important for them in their life. Areas of self-reflection were around changing their attitudes towards others and appreciating their health and life, after realising how fragile it can be. The subtheme 'A better person' aims to reflect this growth the participants have experienced in their way of being, thinking and behaving. It describes the positive ways in which the participants believe they have changed after their parent's illness.

Three out of the six participants reflected experiencing positive changes in their attitudes and behaviours towards the outer world.

For example, Shirley expresses that she is nicer to people.

> ***Shirley****: Ermm, well, ermn, I tend to be more nicer to people. I try not to break their hearts. I, I'm more aware of, or if they are acting in a way, why they may act that way, instead of assuming that it is to do with me or them. It's just, it made me feel more caring. It has changed me a lot. I've yeah. (Page 11, 411-415)*

She describes being more aware that people's behaviours may be impacted by difficulties they are experiencing in life. She responds in a more caring way and tries to interpret situations from a positive window, rather than jumping to negative conclusions. From Shirley's expressions, it appears that observing the changes in her mother has made her more aware that health difficulties such as cancer can make people change and impact their behaviours or attitudes. Therefore, when people behave in a certain way, she reflects that she no longer takes it personally. This shows that she is responding in a more thoughtful and caring manner, which can be categorised as a positive development.

Furthermore, Shirley was able to acknowledge and reflect the changes that occurred in her way of being since her mother's diagnosis, and how it differentiated from before:

> ***Shirley****: it's different from before, as like for example, I realised after my mum ermm was diagnosed, that how common it was. It's erm, im more caring and more aware, I try to ermm do my best to help society erm, ermm. I try to help others as well, support others, then before I would just I don't know, maybe see someone and feel sorry. But now, I, it feels like that my person is my family as well. So I try, do what I can do to help that person. (Page 12, 419-425).*

Shirley feels more connected and closer to people that may be in need for help since her experience of parental cancer. Rather than just feeling sad for them and not doing anything practically, she has experienced changes in her behaviours and reflects that she tries to help society. Helping individuals in ways that she can, may be a way to tackle her feelings of helplessness regarding her mother's illness, which she does not have much control over. Also, her caring manner may be highly beneficial and supportive for people around her and may help them through their suffering. Shirley's experience shows that for some individuals the experience of parental cancer may increase awareness and facilitate positive change towards the society and others.

Similarly, Maria reflects wanting to give to the community and explains the volunteering roles she has engaged in, to help people that are more vulnerable.

> ***Maria****: I am always thinking that I could die anytime. And I don't want to leave this world without giving the good to it. You know, so I feel like I want to really strengthen my relationships. Really show people that although there's this world, its full of crapy people. But there is good people out there. I really want to give in that sense…. I committed to volunteering roles, erm. I was actually working in a cancer department as a volunteer. So, I use to help the elderly go from their like houses to their appointments and stuff. But you know that caregiving, I think that is a very strong value for me. So, it's made me more positive in that sense. (page 17, 687-699).*

Maria emphasises on finding the caregiving aspect to be a very strong value for her. From Maria's expressions, it occurs that a reason for her desire to engage in such activities and carry the aspiration to give to the community or people is rooted in her fear of death. She says *"I am always thinking that I could die anytime. And, I don't want to leave this world without giving the good to it".* Her experience of having a parent with cancer has increased her desire to give to the community, which is a constructive impact of this experience.

Like Maria, Nyla also appears to think about death, causing her to have a desire to engage with people in a more positive manner too.

> ***Nyla:*** *Life is short. Take care of your loved ones. Don't be afraid to apologies. Erm you know, the little things like saying thank you, saying sorry, and opening the door for someone, helping an old lady across the road. These things are very important cos life is short. Who knows what will happen tomorrow? I might die tomorrow. Or somebody close to me dying or something bad happening to people. It's just trying to be a good human. (Page 12, 469-475)*

Nyla is choosing to *"be a good human"* by helping others, being apologetic and taking care of loved ones. All these behaviours/characteristics are positive attributes. Experiencing parental cancer increased death awareness. This heightened consciousness of death then increases individuals desire to be a better person and engage in a manner that supports the community.

Summary of Preliminary findings

Overall, as the data from the six participants were analysed, the process revealed similarities and patterns in experience, which gave rise to the superordinate and subthemes outlined above. It appears that individuals who have a parent with cancer experience significant psychological pain, anxiety of losing parent and fear of developing illnesses themselves. Moreover, participants reflected changes and transformation of roles between them and their ill-parent. Participants observed their parent become vulnerable and felt like they had to become the new parent, suggesting a change in roles and the need to become the caregiver. They also felt a need to put their own life on hold and make their parent the priority. These findings suggest that the experience of having a parent with cancer has a strong impact on the responsibilities the young adults may take on. Individuals identified some ways in which they coped through the process of their parents' illness. They expressed a heightened need to be stronger, despite not feeling that way, mainly due to a need to contain parent. They also estranged themselves from others in an aim to avoid talking about their parents' illness and feel weak or upset in situations. However, most participants were able to find some sort of support helpful such as talking to a health professional, mindfulness, religion, which can be labelled as problem-focussed forms of coping. Lastly, despite the negative experience of having a parent with cancer, participants reported Positive growth from the experience too. They reflected that the family bond and communication became much stronger, and everyone became more caring and engaging in the family. Additionally, this experience led participants to make changes in their eating habits, trying to implement a healthier lifestyle. They also experienced changes in their way of being and expressed becoming a better person towards the outer world. It appears that the experience of having a parent with cancer can be similar amongst individuals, particularly in relation to the themes described in this research.

CHAPTER FOUR – DISCUSSION

Chapter Overview

In this chapter, my aim is to address the findings identified during the data analysis in relation to the wider theoretical and empirical context. I move from the ‘hermeneutics of empathy’, employed in the Findings chapter, and embrace the data from a more interrogative position (Smith, 2004). Thus, the findings will be approached in a questioning way, and I will adopt the ‘hermeneutics of suspicion’ stance (Ricoeur, 1970). I will try to make sense of the findings and establish any connections between participants experiences. Where possible I use existing empirical research and theoretical perspectives to ground the identified findings. I will draw on them to highlight points of convergence and divergence between their findings and those of this study. However, no claims regarding the generalizability of the findings are made. Instead, the aim of this research and the comparison with existing literature is to gain a greater understanding about the phenomenon; “Young Adults experience of Parental cancer”.

In gaining a deeper understanding of this experience, our aim was to

1. Further our understanding about this populations experience as explained by them
2. To identify the gaps in the literature and direct future research in ways that could increase our knowledge
3. And in turn, to help develop support for this population in the best ways possible, by developing interventions and treatment approaches or moderating psychological services.

The analysis revealed 4 superordinate themes, and 11 subthemes. On facing their parents’ cancer, all participants reported psychological pain, and anxiety about uncertainty regarding their parents’ mortality and their own risk of developing illnesses (Superordinate theme 1). Most participants described a process of role transformation, in which they observed their parent deteriorate, leading them to take on caregiving roles and put their own lives on hold (Superordinate theme 2). To cope with the difficulties in their experience, participants chose to portray an invulnerable self, and estranged themselves from others. Participants also reported on sources of support that they found helpful, such as therapy, mindfulness, and religion (Superordinate theme 3). Most participants also experienced positive benefits from their experience of parental cancer. Their family bonds become stronger, they developed a desire to become a better person and have a healthy lifestyle (Superordinate theme 4). These findings are further discussed in this chapter in relation to existing literature and theoretical perspectives. The structure of the discussion will be presented in sections that outline the main substantive themes identified during the data analysis, a discussion of the findings in relation to existing literature, followed by the study critique, implications for counselling psychology and recommendations for future research.

Main substantive findings

The findings from this study not only further supported findings from previous literature, the richness in the accounts of the participants have also yielded further understanding into the experience of having a parent with cancer. The analysis revealed 4 superordinate themes, and 11 subthemes. In this section, the main substantive findings will be laid out, and the novel findings will be highlighted.

Facing a parent’s diagnosis of cancer came down with significant impact on the minds of young adults. They experienced various emotional states as well as difficulty in identifying these feelings. In addition, young adults experienced changes in the way they relate to the world and gained a greater awareness about life and death, which led to anxieties. They became highly conscious of the possibility of losing their parent and the possibility of developing life-threatening illnesses themselves. I chose to refer to these psychological experiences amongst the young adults facing their parents’ cancer as “Having to face cancer”. This theme was broken down further into the following subthemes: “Psychological Pain” and “Anxiety of uncertainty: Fear of losing parent & Fear of own risk”. In this theme the aim was to reflect on the changes that occurred in the participants emotions and thought patterns on facing their parents’ cancer.

On facing their parents’ cancer, all participants reported psychological pain. Having to face parents’ cancer was a psychologically painful experience that was described by participants in similar ways. Previous literature has also well-documented that having a parent with cancer can yield psychological difficulties such as depression, anxiety, and burden. Nevertheless, specific experiences of individuals experiencing parental cancer and their emotions has not been the research focus. The current study however has provided a novel understanding of the experience of parental cancer as explained by the individuals with their own explanations and understanding of their thought patterns and feelings. The participants in this study expressed a lot of confusion and struggled to identify and differentiate between their different feelings. They experienced many emotions at the same time, and some referred to this as having "mixed emotions" which left them feeling very overwhelmed ("Psychological pain"). Categorising their emotions as simply anxiety or depression was not reflective of their feelings. This has important implications as it points out the importance of qualitative research and individuality of experience.

At the root of these painful emotions often lied the worries about losing their parent, and the uncertainties that came with the prognosis and treatment of cancer ("Anxiety of uncertainty: Fear of losing parent"). The feeling of hopelessness was heightened for most participants, as they described feeling stuck. It was not clear if anything was going to be back to normal, or what the future held. It also appeared that when describing their parents some participants used past-tense words with a sense of loss or uncertainty regarding their parents' life-status. The experience of cancer even at the earlier stages, fostered the start of a grief process even before the physical loss of a parent. This suggests that the emotional burden experienced when a parent is diagnosed with cancer may be comparable to bereavement. Furthermore, participants also experienced a lot of anxiety and stress relating to their own mortality and own risk of developing life-threatening illnesses. Experiencing cancer through their parents led individuals to experience a heightened awareness and therefore anxiety about their own prognosis in life ("Anxiety of uncertainty: Fear of own risk").

In Superordinate theme "A process of role transformation" we have explored the changes that has occurred within the family, mainly for the ill parent and the adult child after cancer. I chose to refer to this theme as a process of role transformation, as the experiences that occurred was related to the changes that occurred in the shift of the roles and responsibilities between the ill parent and adult child. This theme was broken further down into the following subthemes to reflect the process of transformation: "Observing parents' deterioration", "Adapting a parent mode" and "Putting self on hold". The findings revealed that the process started with the physical, emotional, and behavioural changes that occurred in the ill parent ("Observing parents' deterioration"). The ill parent became weak, vulnerable, and needy. They required help with their day-to-day lives and someone to replace them within the home. Consequently, the adult offspring found themselves having to step in to cater for these needs and replace their parents' role ("Adapting a parent mode"). It appears that these changes occurred automatically and unavoidably. The adult offspring found themselves trying to provide care for their ill parent both physically and emotionally, as well as stepping in to keep the family and home running as usual. However, in picking up these responsibilities and catering for the role of their parent, the adult offspring often neglected their own lives ("Putting self on hold"). They had to deprioritise their day-to-day tasks and or commitments, to cater for their parents one's. This sometimes made them feel like they were living someone else's life and resulted in feelings of burden and frustration.

The changes in roles and responsibilities in families after someone is diagnosed with a life-threatening illness in the family was well-documented by literature. However, a novel understanding around these role changes was in the way in which the process unfolded. Participants described how they observed their parent to gradually deteriorate, leaving their parent incapable of fulfilling their usual activities or duties within the family. As a result, most participants felt an obligation to adapt to a parent mode and put their own lives on hold. Some participants explained that they just did not have the choice and therefore, may have not felt that they could express their struggles or own needs. This involuntary responsibility that came suddenly led to a lot of pressure and burden. Participants found themselves prioritising their ill parent and putting their own lives on hold. For some this meant not going out with friends, and for one participant it meant not pursuing with education while for another it meant delaying their marriage planning. In fact, participants emphasised on the need to appear strong to cope with the process, and to be a supportive figure for their parent.

Another theme that was highly prominent in the interviews was the topic of managing through the battle with parental cancer. Participants reflected on various ways they tried to cope. Some of these strategies were deliberate attempts of the participants to cope. I labelled this theme as 'coping through cancer' to explain how the participants got through this process. This theme was broken further into the subthemes: "Invulnerable self", "Estranged from others" and "A source of support". An interesting commonality amongst the participants was that they tended to feel a need to appear strong, and act in a way that was not congruent with their inner self. They put on a fake smile and pretended to be strong. They did not want to show signs of weakness ("Invulnerable self"). This was to provide their parent with support and moral. Secondly, they also avoided social contexts, withdrew, and estranged themselves from others, to avoid psychological arousal and feelings of vulnerability that may occur from cancer related questions that may arise in social settings (“Estranged from others”). Lastly, most participants were able to find some sort of support helpful. Although this source of support was different for all participants, they all served the same purpose and were described similarly. These were the presence of a health professional, mindfulness, and religion (“A source of support”).

Participants found talking to a professional who understood the situation therapeutic and helpful. Whereas, talking to others who does not understand the experience of parental cancer was not helpful, and sometimes made individuals feel vulnerable. The feeling of thinking others feel sorry for them was very disturbing and did not feel comfortable. These findings are novel that they highlight how difficult it may be for adults experiencing parental cancer to seek comfort and help from people around them. It also shows that even if family and friends offered this space for support and help, it may not be as useful/therapeutic as a clinician or professional who has more understanding and clinical experience. This novel understanding has important clinical implications, as it indicates the difference in help that could be offered by family/friends and professionals. Help from trained and informed professionals/clinicians can be very effective at supporting this population. These findings also show the importance of feeling understood by individuals experiencing parental cancer. When the participants did not feel understood, they simply did not find interaction helpful.

Surely, watching your parent deteriorate from cancer is an extremely disturbing and upsetting experience. However, from the participants reflections it emerged that this negative experience brought together positive growth too. Parental cancer led to stronger family bonds and improved relationships amongst the members (“Stronger family bond”). In addition, parental cancer caused individuals to develop a desire to maintain a healthy life (“Desiring a healthy lifestyle”). And lastly, individuals experienced an urge or desire to be a nice person and leave good to the world (“A better person”). These experiences were grouped under the theme ‘The positive growth, as they were positive gains from the process of a parent’s cancer. To include the different positive gains participants have reflected on, participants experiences were broken further into the following subthemes: “Stronger family bond”, “Desiring a healthy lifestyle”, and “A better person”.

Nevertheless, it is important to acknowledge that these experiences highlighted as positive growth is not in isolation, they are rather in conjunction with the difficult experiences highlighted in the previous themes. Majority of previous literature have either studied the negative or positive experiences of having a parent with cancer. However, a novel understanding that could arise from this study is that difficult experiences can also foster change or effect that could be seen as positive. And, both negative and positive experiences could occur simultaneously. The most important clinical implication of this finding is that therapists could encourage or guide individuals to search for the positive. Acknowledging any positive growth from a highly distressing experience could help cope with the experience.

Discussion of the findings in Relation to Existing Literature and Theoretical perspectives

Having to face cancer

The present study reflected that the experience of having a parent with cancer evoked significant psychological arousal amongst young adults. Participants used a list of words with the aim to reflect on their psychological burden. Often participants experienced confusion and difficulty in identifying their feelings. They struggled to express their deeper feelings and felt that they cannot be understood. Words did not provide an adequate reflection of participants deeper feelings, which also reflects their minds confusion. Some of the words used to describe the participants feelings were sadness and anxiety. These findings were like findings from previous literature. Phillips & Lewise, (2015) also highlighted that parental cancer impacted young adults by provoking distress and psychological problems such as anxiety, depression, and feelings of burden. Nevertheless, in the current study it appeared that simply categorising feelings into terms like anxiety, depression and burden was not always reflective of the participants feelings. The qualitative nature of the study revealed that participants experienced confusion and a mix of emotions that did not feel representable by single words. In a similar qualitative study by McPhail et al., (2017) university students who had a parent with cancer reported feeling sad and anxious about their parent having cancer. However, they also talked about emotional outburst, and not feeling in control of their feelings. Similarly, they also expressed not feeling understood regarding their feelings by others. The consistency amongst previous literature and findings from this study point out that having a parent with cancer is a highly distressing illness that can leave individuals in significant sadness. Nevertheless, it also implies that qualitative research exploring the specificity of this experience is imperative for a better understanding of this subjective experience. As Van Manen, (1990) explains, mechanistic and statistical explanations of causation and correlates cannot account for how the experience is lived and felt.

On the other hand, there was a differing experience amongst the participants. When explaining her response to her father's cancer diagnosis, a participant reflected feelings that was very different from the other participants. She emphasised that she did not feel upset, as she did not know what cancer was and did not perceive it to be a life-threatening illness. Not having prior knowledge of cancer was the reason that caused her differentiating experience. She thought of cancer as an illness that can be cured and did not experience the fear and anxiety of losing her parent. She reported that her feelings about cancer only changed after experiencing the process of parental cancer and developing knowledge about it. Interestingly, Compas et al., (1996) reported that individuals who perceive their parent's cancer as more serious, are more likely to experience greater distress. The finding by Compas et al., (1996) suggests that the experience of this participant may be more common than that it was in the cohort of participants within this research. Together these findings show that the emotional burden that comes with having a parent with cancer is greater when the parental illness is perceived as serious. The perception of seriousness may be affected by many factors. From the present study it became apparent that lack of knowledge about cancer was a factor that impacted individuals' perception of seriousness. From the study by Compas et al., (1996) it became apparent that perception of seriousness was impacted by the stage and type of cancer. Therefore, when assessing the experience of this population future research should consider factors such as previous knowledge of cancer, stage, and type of cancer for an enriched understanding of this population.

Although being a rare finding, Wellisch et al., (1991) opposed the findings from the present study and claimed that parental cancer does not impact young adults' psychological symptoms. However, they reflected that parental cancer does have other substantial effects on the lives of young adults. They provided a detailed account of the effects that parental cancer had on their cohort. It was reported that daughters of breast cancer patients reported significantly less sexual intercourse, lower sexual satisfaction, and greater feelings of vulnerability to breast cancer. Although there was no significant link between parental cancer and psychological symptoms amongst this group, the effects that were reported are highly likely to cause psychological distress themselves. For instance, greater feelings of vulnerability to developing cancer is highly likely to cause elevated levels of psychological distress and anxiety (Schwartz et al., 1995). The findings from the present study supported this claim. All participants reported feeling greater vulnerability about developing cancer themselves and reflected that this caused them great anxiety. Participants expressed having disturbing thoughts and fear associated to the possibility of their parent's cancer being genetic. Research documents that 5-10% of cancer types are genetic (Anand et al., 2008), and those who have a parent with cancer are more likely to develop cancer themselves. These findings together show that parental cancer can impact young adults by causing increased psychological distress directly but also indirectly by increasing fear associated to their own risk of developing cancer.

Moreover, as well as the fear of developing cancer, individuals experienced significant anxiety and uncertainty regarding their parents' prognosis and mortality. There was always a fear of relapse, and the worry of not knowing what to expect. The uncertainty that came with cancer and its process was extremely frustrating and worrying. Together with a diagnosis of cancer comes the inevitable realisation that death is always a possibility that is nearby. The human nature avoids thinking about death or does not keep it at the forefront of the mind (Becker, 1997). However, based on the participants experience from this study it appears that individuals who have a parent with cancer have a heightened awareness of death. The diagnosis of their parent moved the idea of death from the unconscious into their conscious awareness (Becker, 1997). They think of death and the possible loss of their loved one more often and as a possibility that is now closer, which causes further emotional burden. In a study in 2010, Funk et al., found that the stress of caregiving was found to be due to a combination of realizing the impending loss of a loved one and seeing them suffer while also not having the support or information to provide proper care. In considering these findings together, it becomes apparent that the inevitable death of a loved one takes over the mind, causing more emotional pain and fear. And this process may be even more demanding if the young adults do not receive the appropriate support.

In addition, in the present study and a previous study (Leedham & Meyerowitz, 1999) similar expressions were used regarding the fear of losing a parent. In both studies, participants reported a fear about losing their parent, which reflects that a parent's illness brings death to the forefront of the mind. According to Ernest Becker's (1973) theory the denial of death, the terror of death is so overwhelming, that man conspires to keep it buried in the unconscious network of defence mechanisms where it is repressed. However, the experience of a life-threatening illness confronts an individual, and brings this repressed anxiety in to the consciousness. In addition to that, it is difficult for individuals affected by parental cancer to avoid the thoughts of death, as there are various external cues that will act as daily reminders of the experience. The patients' medical appointments, medication, and the visible effects of cancer will constantly remind their family of the threat of death (Kangas et al., 2002). Therefore, it is crucial to help these individuals understand their anxieties and the cues that evoke them to develop ways in which they can cope with the emotional burden.

A Process of role Transformation

Cancer can affect the ill person physically and psychologically. All participants reflected on the changes that they observed in their parents' post-cancer. Cancer took away their strong parent, and terms such as 'deteriorating' and 'melting' were used to express this change. In addition, observing changes in a parent with cancer was inevitable because the treatment side effects and physical changes was physically visible (Kangas et al., 2002). Therefore, it was a highly distressing and upsetting experience. In an earlier study by Texeira, (2013) findings suggested that children who perceived their parents as highly dependent showed more distress, higher PTSD, greater caregiving burden and less satisfaction with social support. Other studies have confirmed this finding, by reporting that depression and burden levels increase as patient's functional status declines (Grunfeld et al., 2004). It occurs that the higher levels of distress reported in some participants may be associated to their parents' level of functioning. Findings in this study have reflected that as cancer took away their parent's strength and ability, the young adults found themselves stepping in to cater for the gaps. In other words, there level of responsibility and related difficulties increased as their parents' health declined.

Moreover, observing changes in their parents was extremely upsetting for patients and inconsistent with the perspective they held of their parent. The changes that occurred in the parent caused participants to experience a battle against their own perceptions. They experienced contrasting views about their mother/father. For instance, their parent was both the "ill" and "weak" women, and the "strong" and "brave" lady. Participants did not to want to change their perception of their parent. It was often difficult to accept that their parent had lost their strength and physically became weak because of cancer. It may be that accepting that cancer has changed their mother, was like accepting that their parent was dying, causing emotional disturbance. In addition, according to the attachment theory (Bowlby, 1982) seeing a parent become weak and needy is a threat to the attachment bond and the perceived secure base. The participants had a desire to continue describing their ill parent as strong, which may be a desperate attempt to avoid facing the loss of this secure base.

The contrasting views of the mother may be difficult to contain for their daughters as it may be contributing to their own self-representation. The theoretical perspective by Wellisch et al., (1992) suggests that the image of a sick and potentially dying mother might be integrated by the daughter into her own sense of self, along with the pre-existing image of an intact and well mother. These contrasting views of the mother, when fused with a daughter's nascent self-concept, may form the basis for the daughter's ultimate self-representation. In other words, individuals impacted by parental cancer may struggle to differentiate between themselves and their ill-parent. Therefore, the way they perceive their parent may also form the basis of how they perceive themselves. The findings from the present study contributes to this theoretical perspective. A participant reported feeling like she was living the life of her mother. She found it difficult to differentiate between her life and her mothers. The fusion of an ill parents and her healthy daughter's life implies that a daughter's self-image or self-concept may be impacted by her experience of her parent's cancer. This is a concern as it may lead young adults to develop a self-concept that is ill, vulnerable, or weak. This may also provide an explanation to why young adults feel weak or vulnerable when the topic of conversation in a social context is about their ill-parent. For example, some participants reported feeling vulnerable and weak in social contexts when the topic of conversation was their mother's illness. Questions on this topic makes them feel weak as they may have adapted this self-concept/image as being ill. In their world, the ill parent may also reflect them as ill, and they may therefore feel that others perceive them in that way too. This theoretical perspective has great clinical implications and can be useful when working with individuals who report similar feelings to that of the cohort in this study. Working with individuals by helping them differentiate between themselves and their parents may be a useful way to foster some level of independence and remove the ill and vulnerable self-concept.

Moreover, in the study by Almarza (2008), adult children also described how their parents deteriorated and changed. As treatment unfolded, an altered reality emerges when a strong father figure lies down fragile, despondent, and weak on a hospital bed. Their findings were based on experience of paternal cancer, and so the experiences that emerged amongst the three participants' may not be the same for adults whose mother has cancer. In other words, the parent's gender may be a significant factor that impacts the experience of parental cancer for adults. In our study, the experiences of parental cancer related mainly to maternal cancer, and similar accounts were shared. Together these findings provide a more in-depth understanding of what it is like for adults experiencing parental cancer. It highlights novel understanding around how the phases of cancer can be a crucial factor in how difficult the experience could be. It also highlights that adult children will experience a perceptual change of their parent because of the treatment process. It appears that there is no research that has explored gender and gender roles of a parent with cancer, and how this may impact their adult child. Evidently, studies exploring maternal and paternal cancer can provide novel understanding that could be helpful to understand the difficulties and needs of this population.

Moreover, the changes that occurred in the ill parents led all female participants to become involved significantly in the care of the ill parent. They reported having to provide care physically, emotionally and became the source of support. They perceived this to be unavoidable and a duty that was essential for the wellbeing of their parents. They reported feeling the urge to become their parents' caregiver, and support them in all ways possible, to improve their health and moral. Sociological explanations have emphasised expectations of traditional roles, in which women are expected to adopt the role of a caregiver. This is ingrained in females through their social and cultural experiences starting from childhood and leads to a different approach to caregiving compared to men (Papastavrou et al., 2009). Additionally, in a recent study by Bagautdinova et al., (2023) participants referred to societal expectations about caregiving such as gendered expectations about their role. Caregivers and some of their siblings associated the caregiving role with being a woman or a daughter in the family system. These findings suggest that adult daughters may be more likely to become their parents' caregiver and in turn may experience a greater burden from becoming the caregiver. Indeed, Schrank et al., (2016) used structured questionnaires to assess 308 caregivers. It was found that burden was significantly higher in women in comparison to men. In this current study there was only 1 male participant, which may be because females are more likely to become the caregiver and experience burden. However, it is also important to acknowledge that societal norms often encourage women to be more expressive with their emotions, while men are often expected to remain stoic and composed (Gorski, 2010). Daughters may feel more comfortable openly discussing their feelings and seeking emotional support. While sons may struggle to articulate their emotions or feel pressure to maintain a facade of strength. Therefore, male participants involvement in research may simply be less likely. Indeed, research has shown that women are more likely to engage with health care services than men (Bertakis et al., 2000). Clearly, the experience of parental cancer may vary significantly for males and females and is an area for future research to explore further to understand if there are any differences. And if so, then why these differences occur.

Another common experience between the participants was their tendency to give up on their lives and priorities their ill parent. Participants gave up on their marriage planning, university plans and working life to cater for the needs of their new caregiving role. Some of the feelings associated with these choices was the feeling of guilt about continuing with their own lives while their parent was suffering. This was also a pattern reported in previous literature. Employed caregiving daughters that face these demands do not reduce their caregiving, they eliminate their leisure time (Horowitz, 1985; Johnson, 1983), reduce their work hours or leave their jobs (Enright & Friss,1987). If unemployed, they have chosen to defer entering employment (Soldo & Myllyluoma, 1983). Dura et al., (1991) point out that various long-term care situations have documented the increased incidence of depressive symptomatology and psychiatric morbidity among familial caregivers. Together these findings show that parental cancer is a very demanding experience and may alter an adult child’s life and priorities completely, causing psychological burden. Some individuals may be equipped and ready for this change, while for some this may be extremely difficult. They may need support through their adjustments and to cope with the long-term consequences.

On the other hand, a different experience emerged from Harry. He reported finding a balance in socialising. This is different from how most other participants explained the changes that occurred in their lives. Harry does admit that he spends more time with his family, but he also says that he feels he found the right balance and continues to socialise with others too. It is interesting that Harry refers to a balance that he aims to achieve between spending time with his family and socialising. His need to find this balance is rooted in the experience of having a parent with cancer. He is making conscious decisions and considers trying to achieve a balance between his family and social life, which may have not been a priority if his mother did not have cancer. However, Harry does not refer to any caregiving duties or commitments he feels. He was the only male participant, and at this moment it makes me feel that his experience of changes in family roles and responsibilities may have differentiated from the other participants due to gender. Unfortunately, research exploring the experience of male participants impacted by parental cancer is non-existent, as adult daughters usually become the primary caregivers for ill parents (Wellisch et al., 1992). However, Harry does report on the impact his parents' cancer had on his university life, coursework, and exams. It is important to stress that Harry was the only male participant, and it is worth engaging with research incorporating the experiences of more men impacted by parental cancer to shed light on the possible variations in their experiences.

In discussing the findings and the previous literature it becomes clear that on facing a parent's diagnosis of cancer, various changes occur within the family. The family finds themselves in a process in which they are forced to make shifts in their roles and adapt to their new lives. This process can be understood by the family systems model, which was developed by Rolland, (2005) with the aim to evaluate how families deal with chronic illnesses. The family systems model highlights that During the acute phase of the disease, shortly after diagnosis and while the patient is undergoing treatment, the family is challenged with reorganizing in the short term and becoming flexible so that they can deal with treatment and the psychosocial demands of the illness (Rolland, 2005). Later, during the chronic phase, a key task is to try to maintain a normal life. In families coping with a terminal illness, family members are faced with the process of letting go and, eventually, family reorganization. Therefore, the effect that the cancer has on the family may be affected by the phase the family is currently in. This provides an explanation to why the experience of parental cancer may differentiate based on the stage of cancer a parent is experiencing.

Coping through cancer

A need to appear strong and not show any signs of pain or weakness was a way individuals chose to face their parents' cancer. They had an urge to put on a fake smile and not reflect their feelings or struggles. This incongruency was in an aim to keep the ill parent and family stay strong, as well as avoid other people feeling sorry for them. Although this seemed to be a coping strategy that had positive aims at first, it did have consequences eventually. A participant reflected feeling tired from acting and losing relationships because of her lack of authentic engagement. Indeed, a meta-analysis by Boehmer & Clark (2001) highlighted that family caregivers were likely to supress their emotions and not seek support even when they need it. However, participants from previous research stated that a lack of honesty in the family regarding the cancer and lack of communication about the emotions relating to cancer had hindered their ability to cope effectively with it (Leedham & Meyerowitz, 1999). These individuals added that communicating openly was crucial to coping well through the process. Together these findings suggest that although the participants do not communicate their feelings honestly or openly in an aim to cope, they may unintentionally be impacting the process more negatively. Research exploring the potential positive and negative effects of this form of coping is essential. In clinical practice, it may serve helpful to understand and help individuals weigh the benefits and consequences of this form of coping.

Moreover, according to attachment theory people with dismissing/avoidant attachment styles, tended to suppress their negative feelings and converted those negative emotions into physical symptoms like headaches or abdominal distress (Wayment & Vierthaler, 2002). This may provide an explanation to the common theme "Invulnerable self" in the present study. Participants often supressed their feelings and pretended to be strong. In contrast, those with preoccupied attachment styles almost never suppress their emotions and experience more intense prolonged grief (Lai et al., 2015; Maccallum & Bryant, 2018). Future research could take into consideration the attachment style between the parent-child when studying their experiences of facing parental illness, which may provide an explanation to why individuals may choose to cope in different ways. Understanding their coping mechanisms may help govern treatment protocols that are more suitable for their needs.

Furthermore, in this study it became apparent that individuals estranging themselves from others to avoid the topic of their parents' cancer. Avoiding this topic also meant they avoided all the feelings and upset that came with it. In addition, the participants experienced a vulnerability when speaking to others about their parent's cancer. Participants experienced feeling weak when people asked them about their parent's illness, because often their reactions were making them feel at a lower position. In other words, the feeling of being felt sorry for was extremely disturbing. Therefore, participants explained withdrawing themselves from other people and becoming estranged. This could be explained with the social cognitive processing model, suggesting that unsupportive or negative reactions from others during disclosure of stressor-related thoughts and feelings may result in attempts to avoid such thoughts and feelings; this inadequate exposure to the stressor may prevent its cognitive processing and prolong distress. (Schnur et al., 2004). In other words, if individuals are approached in a way that is not pleasant for them, it may increase their desire to avoid such situations. It was also reported that individuals who reported higher levels of negative social responses, re-ported higher levels of avoidance and in turn, they reported higher levels of psychological distress (Schnur et al., 2004). In the present study it appeared that individuals felt weak or not understood in social contexts where their parents' illness was the topic of conversation. These feelings were not pleasant, and to avoid them, they withdrew from social contexts, which may in turn cause long-term distress.

This pattern is also reflective of Post-Traumatic Stress Disorder symptoms. PTSD research highlights that an individual may withdraw and become estranged from people and or places that remind them of the traumatic experience. This is with the aim to avoid emotional arousal and being triggered into intrusive thoughts. Taking these findings in to consideration, it appears that individuals may choose to become estranged from people in an aim to avoid situations that remind them of the upsetting experience of having a parent suffer from a life-threatening illness such as cancer. However, the following question arises from this supposition; Do people become estranged from others because it's a response to cancer or is it a PTSD symptom? There are various overlaps between PTSD responses and the natural responses to cancer. Further research should investigate the links between the experience of parental cancer and PTSD. It may be that individuals who choose to estrange themselves from others are also individuals that have developed PTSD from their experience of parental cancer. Clarification of this would help govern a treatment protocol that is most suitable for targeting people wo have a relative with cancer.

Indeed, The Diagnostic and Statistical Manual of Mental Disorders (DSM 5-TR) (American Psychiatric Association, 2002) now includes learning about the threat of death in a family member as a potential trigger of PTSD. It is likely that some individuals impacted by parental cancer may develop PTSD, and therefore their experiences may show differentiation to those that do not have PTSD. Research evidence also supports the notion that PTSD can arise in family members of cancer patients. It was found that cases of PTSD were present in the parents of childhood cancer patients, which supports the suggestion that, in some circumstances, the stress of having a family member with cancer might give rise to clinical

PTSD. Furthermore, research evidence suggests that the risk of PTSD is higher for individuals who perceive themselves at higher risk of cancer because of a possible genetic heritability (Lindberg and Wellisch, 2004). Although we did not examine the clinical symptoms of PTSD in the present study, the language used by the participants provided some insight into the magnitude of the impact that this experience had on them. All participants reported experiencing fear associated to their own risk of developing cancer. Furthermore, the reported emotional upheavals, and the studies cited above, strengthen the argument that we must increase our understanding of how parental cancer impacts young adults to ensure that we meet both the short- and long-term adjustment needs of all family members.

Moreover, the two forms of coping that appeared in this research, portraying an invulnerable self, and estranging from social contexts can both be seen as a form of avoidance, and may be maladaptive forms of coping. They are not concerned with addressing the problems. Rather they are both ways to supress feelings and not process them. Previous literature has referred to avoidance as a maladaptive form of coping, as it is supressing inner problems and not processing them (Schnur et al., 2004). Avoidance may feel helpful for individuals in the short-term but may cause further psychological difficulties and life changes in the long run. Compass et al, (1996) also found that individuals who perceived their parents' cancer as more serious and stressful were more likely to engage in avoidant behaviour. This avoidant behaviour was related to emotion focused coping and higher levels of depression and anxiety. More specifically, young adults used emotion- focused coping by avoiding or attempting to be distracted from their parent's cancer or the feelings they were experiencing because of their parent's cancer. This finding has a major implication for counselling psychology, as it has demonstrated that avoidant behaviour and emotion-focussed coping may be common ways children try to cope with parental cancer. However, individuals using these forms of coping do also present with higher levels of depressions and anxiety. The casual link between this form of coping and the psychological distress is vital for future research to uncover.

On the other hand, all the participants were able to identify a source of support during their attempts of coping. Majority of these sources were focussed on dealing with the psychological burden caused by parental cancer. Therefore, they were adaptive, and problem focussed forms of targeting the difficulties that arise from a painful experience. These sources of support deserve great attention, as it could lead to the discovery of ways to help support adult offspring affected by parental illness. For the participants in this study, it occurred that support from a health professional such as a therapist or nurse was useful. The compassion provided by another party who was aware of the situation was significantly supportive and pleasant. Another source of support identified was their religious beliefs. A participant found his religion as helpful both for him and his parent during the time they were affected by cancer, by giving them meaning in their experience. This was supported by literature who also discovered that religious beliefs were a factor that contributed to perceiving the caregiving experience during a parent's illness as positive (Kang et al., 2013). Additionally, Koerner et al., (2013) interviewed caregivers, and found a reliance on religious coping amongst Latino caregivers. Together these findings imply that religion can be a source that impacts an individual's thinking style and can help them perceive the experience in a more positive light. This also brings into awareness that culture and the context may also influence the conceptualisation of an illness within a family more broadly. Therefore, it is crucial to consider the impact of culture, religion and context when studying the experience of parental cancer. Clearly different populations may be impacted in different ways. Further research needs to investigate the impact of contextual differences and how this may impact the experience of parental cancer.

Another source of support identified to be beneficial was the practice of Mindfulness. Mindfulness is the process of bringing non-judgmental awareness to present the moment – paying attention on purpose in a particular way (Kabat-Zinn, 1990). Through practicing mindfulness people can concentrate on the mind, leading to increased awareness of the present moment, including to awareness of one's emotional states (Guendelman, et al., 2017; Roemer et al., 2015). Therefore, as mindfulness may lead to a heightened awareness in a person of their own experiences, they may be able to identify what would be supportive to them, more so than a person who is not mindful and, therefore, not aware of their own emotions. Indeed, research has revealed that Mindfulness based interventions has led to beneficial outcomes in patients experiencing stress, chronic pain, and disease. The participants reported lower stress, reduction in physical pain and reduction in judgments of self and others (Kabat-Zinn, 2013). Similar findings were reported for family caregivers, and it was found that they experienced reduced stress and reactivity, while at the same time they experienced increased acceptance of the illness as well as a greater sense of presence and peace. These are important findings as they suggest that mindfulness-based interventions can have positive and supportive outcomes for both the family caregivers and patient. (Jaffray et al., 2016). Therefore, efforts to offer Mindfulness for adults impacted by parental cancer may be helpful.

Problem focussed forms of coping have been found to be effective at targeting adult offspring emotional distress and anxiety (Northouse et al., 2012). A meta-analysis on 29 randomized clinical trials that delivered psychosocial interventions to cancer patients and their family caregivers were analysed (Northouse et al., 2012). The interventions that were used were labelled as: psycho-educational, skills training and therapeutic counselling. The dose of the interventions ranged from 2-16 sessions, and were offered in face-to-face (68.6%), phone (20%) or group (11.3%) format. 16 of these studies measured the effects of these interventions on emotional distress, depression, and anxiety. Findings revealed that the interventions significantly reduced caregivers' emotional distress and anxiety. In the present study, how individuals benefitted from any support they received was not addressed in detail. This opens a gap for future research. Investigating what forms of support is beneficial and in what way they provide benefits will provide valuable insights to help individuals impacted by parental cancer.

The Positive growth

The main positive effect that the participants experienced was that the family bond gained strength. There was more connection between the family members, everyone was open to spending more time together, they shared more care towards each other and were able to show more affection. Commonly, the desire to spend the time that they do have together coupled with the fear of losing a parent, caused individuals to show more effort in establishing stronger family relationships and spend positive time. These findings were parallel to the study by Levesque & Mayberry (2012) who studied solely the perceived benefits of the experience of parental cancer. They also conducted the analysis using IPA. It was found that parental cancer caused improved relationships with the ill parent, changes in life priorities, a greater focus on family and personal development. Together these findings show that when a parent is diagnosed with cancer, it leads to various changes in the family which can be classified as positive growth from the experience.

However, there was an exception and one of the participants reflected experiencing a breakup in their family bond. She experienced that her father's illness took away the family environment that he was holding together. There may be many reasons underlying this differentiating experience. Firstly, although she stepped in to care for her father, she was not the eldest child. Research does indicate that being female and having poorer family functioning were associated with increased distress (Mcdonald et al., 2016). Also, Grace expressed having expectations from her brother, who she believed had failed to replace the male figure in the house. Her reflections point out that she desired the male figure to be replaced by someone and it is possible that as she is a female, she may have not felt equipped/able to step in for her father. For example, all other female participants who had a mother with cancer reported taking on the role of their mother and taking care of the home. Taking on the role of a father however may have been a different experience that came with responsibilities that Grace may have not been ready for. She was frustrated that her brother who was the eldest sibling did not take on the primary caregiving role. This may suggest that both the ill-parent's gender and the adult child's gender can be significant factors influencing the experience.

Interestingly, Bagautdinova et al., (2023) explored sibling related experiences of adult child caregivers when caring for a parent diagnosed with cancer. In their study, caregivers described the importance of sharing the caregiving responsibilities amongst the siblings, and the frustration they experienced towards their siblings when there was a lack of involvement. They also referred to societal expectations. The caregivers and their siblings associated the caregiving role with being a woman or a daughter in the family system. Harrington et al., (2023) also suggested that caregiving duties or primary caregiving responsibilities were based on socially structured gender role criteria (e.g., oldest, female, closest geographically, unmarried) and exercised through coercion, guilt, assumed, or familial expectation. These findings may help understand Grace's experience, as it may be that although she was not the eldest child, she was expected to take on the caregiving duties as the female/daughter in the family system. In other words, even if Grace was not the eldest child, being female may have dictated that she was the main person to become the caregiver. Clearly, both the ill parents and the adult child's gender can be crucial factors that impact the lived experience of parental cancer and is an area where further research is needed to address these differences. Together the findings from the current study and previous literature illustrates how parental cancer can influence the sibling bond, as well as contribute to tension, particularly regarding the experiences of not sharing caregiving tasks. Findings also provide insight into areas in which supportive interventions or resources are needed (e.g., helping siblings talk about caregiving involvement) to promote healthy family functioning after a parent is diagnosed with cancer.

Future research should capture men's experiences and represent ethnically and racially diverse caregivers, given that both gender and culture inform familial expectations and caregiving experiences.

In addition, these findings highlight the importance of societal expectation and the context on the experience of caregiving for a parent with cancer. The findings from the current study were based on Participants from a northern European society with societal norms/expectations that may be different to a different context/culture/society. Indeed, there is substantial evidence suggesting that Western and non-Western caregivers of patients with Alzheimer's disease have different caregiving experiences depending on the cultural values they adopt. Pinquart & Sorensen, (2005) found that in more individualistic societies, families may rely more heavily on professional healthcare services and formal support networks. Ethnic minority caregivers were more likely to provide more care than white caregivers and had stronger filial obligation beliefs than white caregivers. Moreover, they found that white family caregivers experienced higher perceived burden while black family caregivers expressed improved wellbeing (Pinquart & Sorensen, 2005). Moreover, Ar & Karanci, (2019) reported that most caregivers in an Eastern society opposed to nursing home placement because they view it as a morally improper act; they are afraid of neighbourhood pressure, and they perceive caregiving as a child's responsibility. Together these findings imply that different societies/cultures might have differential values impacting on caregiving outcomes and experiences. Nevertheless, these findings were based on the caregiving experience of Alzheimer's patients, which may entail different caregiving demands to that of cancer. Hence, research exploring the differences in how parental illness and caregiving is conceptualised in different societies and families is crucial, to develop interventions that are culturally more sensitive and applicable.

In addition, the families' prior characteristics may have moderated the negative impact on Grace and her family bond on facing an illness. For instance, the resilience model of family stress, suggests that whether a family can successfully cope with stress is determined by each family members ability to cope with the stress (McCubbin, 1993). This shows that each family member and their way of being can have a significant impact on the overall impact and experience of parental cancer on the family. In addition, a father being impacted by cancer may be different from a mother being impacted by cancer, due to the societal roles and norms. Fathers have traditionally been the breadwinners and the person that caters for the needs of the family. The loss of that may feel more difficult to adjust to and even harder to replace by a female/daughter.

Moreover, the experience of parental cancer increased individuals' appreciation of their health, and therefore increased their desire for a healthier lifestyle. The main change participants reported making was changes to their diet, to maintain a healthier life. Levesque and Mayberry (2012) also found that individuals impacted by parental cancer were more aware of their own cancer risk and mentioned changed to their behaviours. Specifically, participants described being more aware of preventive measures for sun exposure (e.g., hat, sunscreen), the need for regular medical checks, dietary changes, and changes to their medication usage. Most of these areas were absent from the interviews in the present study. However, the study by Levesque and Mayberry (2012) was focussed solely on positive experiences of parental cancer, and the interviews were more likely to be expansive on this topic.

Nevertheless, the present study, coupled with the study by Levesque & Mayberry, (2012) show that the experience of parental cancer can foster a desire for a healthier lifestyle. This is a constructive gain, as research has shown that caregivers of cancer patients health declines overtime (Funk et al., 2010). According to research, acknowledging one's own risk of developing cancer and taking action to reduce potential risks could prove highly beneficial and lifesaving. 90-95% of cancers occur due to a combination of environmental and lifestyle factors (Anand et al., 2008). Avoiding the use of tobacco products and exposure to second-hand smoke, maintaining a healthy weight, staying physically active throughout life, and consuming a healthy diet can substantially reduce a person's lifetime risk of developing or dying from cancer (Doll & Peto, 1981). The interviews revealed that all participants experienced anxiety about their own risk of developing cancer and developed a desire for a healthier lifestyle. If this anxiety causes greater awareness and leads individuals to avoid factors that could cause risk, possible occurrences of cancer could be avoided. In clinical/therapeutic practice, efforts to increase this desire and the associated healthy behaviours may be helpful and preventative for future occurrences of health-related difficulties.

However, research examining whether family members are influenced to make their own lifestyle changes, such as eating healthier or becoming more physically active, after observing a family member experience cancer is still minimal (Kim & Given, 2008). One that is known by Mazanec et al., (2011) explored the health behaviour practices and work productivity of caregivers of people with an advanced form of cancer. Caregivers rated their personal health as “good” or “excellent” and they reported participating in screening, regular medical appointments, and having a healthy diet. The caregivers didn’t report meeting the recommendation of 150 minutes of moderate physical activity per week (Canadian Society for Exercise Physiology, 2012; Mazanec et al., 2011). This study suggests that behaviours such as participating in screening, regular medical appointments, and having a healthy diet may contribute to feeling “healthy” and “good”, which may be a helpful and supportive idea for this population.

A desire and urge to becoming a better person were another positive attribute that occurred post a parent’s cancer. Participants expressed being more caring and aware of individuals that may need help. This was parallel to some of the participants experiences reported by Levesque and Mayberry, (2012). They also found that parental cancer led to increased levels of compassion. In the present study, a participant reflected being more aware that individuals may be upset for reasons that are related to illnesses. An identical reflection was reported by a participant in the study by Levesque and Mayberry, (2012), who said “I think probably a much greater awareness of what it means to other people when someone dies”. These reflections show that the experience of parental cancer increases individuals’ levels of compassion and empathy. Why the positive growth occurs and how we can increase these positive experiences amongst individuals impacted by parental cancer is a crucial area for future research.

However, the emergence of positive outcomes from seemingly negative and traumatic events can be explained by the ‘Trauma- or stress-related growth theory’. Affleck and Tennen (1996) have suggested that negative events trigger the need for psychological restructuring, or a reinterpretation of the traumatic event, so that it can be perceived as “beneficial” for the individual. On the other side, Janoff-Bulman, (1992) suggest that highly stressful events may lead individuals to question his or her core beliefs about the world, giving rise to an opportunity for change and growth. Similarly, Tedeschi and Calhoun (1995, 2004) proposed that growth occurs when the individual recognizes that a new reality has arisen from the stressful event. Therefore, posttraumatic growth is not simply a return to pre-trauma functioning, but rather is an improvement in some area of the individual’s life (Tedeschi & Calhoun, 2004). In the present study, we can emphasise that individuals were aware of the changes within their family relationships. Some individuals also questioned their way of being and engaged in attempts to become a better person. These findings show that the negative experience of parental cancer can foster personal development and improvement in some areas of an individual's life. For individuals that may not be able to develop this perspective at first sight, it may be therapeutic to help them develop this recognition within clinical practice.

Why individuals experience post traumatic growth is an area for future research to explore, as it is unclear why an individual may be more likely to experience positive gains from a seemingly negative experience. However, according to the attachment theory, the attachment style that the parent-child had formed in the first years of their life will also affect their experience when the parent becomes ill. Research shows that individuals with insecure attachment styles (dismissing avoidant, preoccupied/anxious, fearful or disorganized) were more likely to experience more grief and less post-traumatic growth (Cohen & Katz, 2015). This can provide an explanation to why some individuals are more likely to experience a positive gain from the upsetting experience of their parents' cancer. For instance, most participants experienced stronger family relationships and a few participants reported a desire to become a better person.

Clinical implications

In researching the experience of adult individuals impacted by parental cancer, a fundamental gap in the literature was covered. Findings provided important clinical implications. In this section, I will highlight the clinical and wider implications of the present research. (Note that, some clinical implications were addressed in the previous section, where it has been relevant).

When a parent is ill, majority of young adults become a crucial figure, providing psychological and practical care, which in turn could impact their parent's mortality (De Boer et al., 1999). However, it also causes emotional turmoil for their adult children. Appropriate emotional and informational support to assist this group through this difficult period is essential. Counsellors and professionals working in hospital settings, need to be aware that support and /or interventions must include all members of the family, not only the spousal caregiver, as typically has been the current focus of counselling practices (Thastum et al., 2006). Increased understanding and heightened awareness about young adults' full participation in their parent's cancer journey may help counsellors assist young adults.

In addition, the role of counselling psychologists is to improve the quality of life for their clients, which should be welcomed and possible for this client group too. Therefore, the first and most important clinical implication of this study is the importance of providing support for this group. However, to provide appropriate support, it is very important for practitioners to develop an insight into the difficulties that young adults who have a parent with cancer may face. When developing an individual case formulation, it is important to consider the unique aspects of the experience and help clients understand the factors mediating their psychological distress. The findings from this study can help practitioners develop an insight into what participants may be experiencing, as findings revealed commonly occurring themes amongst this group. For instance, some participants experienced a difficulty in accepting their parents' illness and tried to avoid the associated feelings. Individuals could be offered a space to be heard, and process the feelings associated to their parents' illness through therapeutic acceptance interventions. Although research has not explored the impact of acceptance therapy on adults experiencing parental cancer, research has found that cancer-patients have benefitted from Acceptance and Commitment therapy (Hulbert-Williams et al., 2015). Therefore, future research should explore the efficacy of therapeutic interventions in relation to the experiences of young adults experiencing parental cancer.

The present study has also offered novel understanding into the experience of parental cancer that could inform health professionals/therapists. Experiencing the sudden onset of an illness such as cancer, may call in to question beliefs, assumptions, and expectations about the world. For instance, the participants accounts revealed that the unfolding of a new parental identity that is weak and vulnerable, defied the belief that their parent was strong and invincible. Likewise, cancer crashed the assumption that parents are supposed to take care of their child, rather than the other way around. Cancer made real the possibility that someone strong, young, and good can also die. Thus, counsellors may help adult children search for answers to potential existential concerns that might arise during and after the process of parental cancer.

Another novel finding from this research highlighted that individuals experiencing parental cancer feel an involuntarily responsible for taking on caregiving duties. In other words, they often experience the role changes as an obligation and therefore may not seek support or help.

They simply may not believe they have the right to help and support. This has important clinical implications. Firstly, it is important for services involved in the ill parents care to highlight the care needs and increase awareness amongst the whole family regarding the changes that may occur. Consultation sessions and educative programs for family members or carers could be helpful in allowing young adults to prepare in advance and learn ways in which they can be supported. Therefore, I suggest that a clinical implication from this study is that policies in health settings can be updated to include care, consultation, and teaching for familial caregivers. Based on the findings from this study it occurs that this will be helpful for family members and in turn may foster better/informed care for the ill patient too. Future research would also be helpful to govern the efficacy of such changes by examining the differences in familial caregivers that have received support compared to those that have not.

Furthermore, previous literature has reported that problem focussed forms of coping such as psychoeducation, skills training or therapeutic counselling of coping are effective in reducing psychological distress (Northouse et al., 2012). Mindfulness and professional therapeutic help were amongst the ones reported in the present study. Participants explained finding support from professionals and clinicians effective and helpful. They explained that they felt understood when they were talking to a professional that had experience. However, participant often did not feel that support or care from friends or family was helpful. When friends asked about their parent, this was often experienced as unpleasant. It made them feel more vulnerable, and sometimes not understood. These findings highlight the importance of feeling understood for individuals experiencing parental cancer. Therefore, an important implication arising from this study was that health professionals/therapists should be encouraged to learn about and better understand the experience of parental cancer. For professionals working in health settings that will involve families being affected by cancer, it may be imperative for it to become a necessary part of their training. In doing so, they would be able to provide a space that feels more helpful and therapeutic for this population.

Moreover, considering the positive growth that occurred from the participants experience of parental cancer can also be useful for therapy. Bringing into awareness potential benefits from an experience may alter the way in which the participants view their experience. It could also reinforce the positive growth and they can potentially become protective factors for them too. Protective factors support resilience, help individuals manage stress more effectively, and strengthen characteristics that minimize the risk of mental health. These factors could include individuals, families, or communities. Individuals could learn to benefit from these protective factors at times that they feel in distress and need support. Using a participants own sources as a protective factor could be very helpful and provide them with a sense of security and resilience. For instance, if an individual reports a strengthened familial bond after their experience of parental cancer, using this experience as a protective factor could be highly effective.

As well as thinking about possible forms of effective interventions when working with young adults who have a parent with cancer, it is important to acknowledge the possible obstacles that could impact their adjustment to their parents' cancer. For example, a potential obstacle that would be helpful for Counselling psychologists to be mindful of is the way young adults guarded their own vulnerable emotions to appear 'strong' and 'adapt a parent role'. As participants in this study were so familiar with suppressing their emotions from their parents and society, it's possible that they may reproduce this within the therapeutic relationship to protect their self- identity and maintain their inner strength. As a result, healthcare professionals may fail to recognise their needs and therefore it will be important for practitioners to foster a warm, empathic, safe, and supportive therapeutic environment to enable these young adults to be expressive and open about their feelings. This may serve to help these adults fulfil their caregiving roles and will help normalise the idea that seeking support and being expressive is acceptable rather than interpreted as undermining the strong self.

Moreover, the anxiety caused by a parent's cancer and the fear of developing cancer was so great that, a participant believed that this anxiety could lead to cancer. Indeed, research shows that caregivers who have high distress also have changes in their immune system. Although it is unknown what this may mean regarding the possibility of developing cancer, it was found that stress can lead to flare-ups in auto-immune diseases, worsened glucose control in the body, and increased vulnerability to cardiovascular diseases (Rohleder et al., *2009*). The anxiety experienced by adults impacted by parental cancer can have long-term consequences and lead to health problems. This contributes further to the importance of studying this population and developing ways that they could be supported. It is important for clinicians to acknowledge that their fears may not solely be intrusive thoughts but do have a rational underlying base. Therefore, they not only need help with addressing their fears but may also need help in understanding and preventing the possibility of them developing cancer.

Furthermore, this study can be beneficial for therapy courses and counselling/clinical psychology doctorates as there is limited information and training given on what it is like for adult offspring or carers of a parent suffering from a life-threatening illness. Training courses could facilitate experiential learning and encourage students to take on placements at services that support children of parents with cancer. In addition, training courses could invite adult offspring impacted by parental cancer to discuss and share their experiences, as it is not possible for the entire cohort to undertake placements in settings workings with individuals impacted by parental cancer. This will increase awareness and confidence among trainees when working with this client population. This type of exposure will help Counselling Psychologists to feel at ease and focus on building an empathic rapport within a therapeutic environment, as working with this client group can seem to be a somewhat overwhelming and distressing task.

The findings and clinical implications addressed are not only relevant for families impacted by cancer but can also be used in an aim to make sense of individuals who may be impacted by the illness of other family members (i.e., spouse). Or it can be useful to help understand individuals who may have parents that are experiencing other life-threatening conditions/illnesses (i.e., kidney failure, heart defects). The findings above have shown that family members can become second-order patients when a family member is ill. Therefore, it is crucial to take into consideration the ill person and their families when tailoring support for them.

As addressed above, this research could have a significant impact on practice, policies, and research regarding the experience of parental cancer, and the experience of parental illness in general. However, it is crucial that these findings and the clinical implications are shared widely and in a way that will be accessible to families, clinicians and specifically adult children impacted by parental cancer. Firstly, considering the developments in technology and social media in the modern society, I will make a short film for YouTube or TikTok that discusses the findings with the aim to reach adults and families impacted by parental illness. Moreover, I will aim to reach clinicians and health professionals that work with families impacted by cancer, by proposing to deliver the research through a short workshop/seminar. In addition, reaching the clinicians could be possible by publishing the findings in an oncology and nursing journal.

Critique of the present research

In this section, I will aim to provide a critique of the present research, and carefully consider the strengths and limitations of the study.

Strengths

Interpretative phenomenological analysis allowed a chance to examine more personal perspectives on the experience of parental cancer. This approach did not just look at the experiences at a surface level, instead it encouraged a way to understand how an experience is experienced by individuals. It provided rich and unique data, which came from first person experience. The data was not based on pre-defined categories or broader terms. It was reflections of participants experiences, as they chose to reflect it. Therefore, the findings from the analysis were as close as it was possible to the narratives of the participants (Willig, 2013).

Also, the use of IPA allowed the participants the opportunity to share their stories and feel heard. Counselling psychology is grounded in humanistic values and appreciates the subjective experience of individuals. Counselling psychologists are committed to understanding the unique inner worlds of their clients through shared exploration and "a process of mutual discovery" (Barkham et al., 2003). Participants talked about the personal value of taking part in the current study. They described being able to reflect on and communicate their experiences as helpful. Therefore, one potential benefit of the study is that it afforded the participants the opportunity to share their stories and feel heard. In addition, the participants were from different backgrounds, and their experiences may have been influenced by their society and culture. Therefore, a qualitative approach that allowed them to express their experiences freely has allowed us to capture the richness of the variations in experience amongst this group.

Another point worth considering, when reflecting on the current project, is the researcher's dual role. From the start to finish, I was always mindful of my insider status as a daughter of an individual experiencing cancer; I was exploring a phenomenon that I was also experiencing at the same time. One of the strengths of my 'insider status' was that, given our common experience, it allowed me to approach my participants in a more empathetic manner. Smith et al., (2009) states that the empathy provided by a shared humanity and common cultural understanding could be an important bridge between researcher and participant's and a valuable analytic resource. Also, researchers have suggested that insiders to participants experience can provide meaningful insights that can be overlooked by outsiders (Hamnett, et al., 1984; Hamdan, 2010).

Limitations

A common limitation of IPA research studies is the small sample sizes (Pringle et al., 2011). However, I do not consider a small sample size as a limitation, as my research did not adopt a nomothetic stance that is commonly associated with psychology which aims to create general claims and laws (Smith et al., 2009). Smith et al (2009) recommends a sample size of six to ten participants or interviews for a professional doctorate IPA thesis, and the present research employed a sample size of six participants which is within this recommendation. Generalisability of the data is not possible from a sample of six participants. However, I do not feel that this can be accepted as a limitation for the present research, as the aim of this research was to explore the individual experiences of participants experiencing a specific phenomenon. IPA is an approach committed to idiography, which is the study of the particular. One of the defining characteristics of IPA is the fact that it advocates the illumination of individual experience, which can also be seen as a strength.

However, the possibility of generalisation is not dismissed in the approach, and a concept that can be employed to explain how this fits with IPA is that of 'theoretical transferability' rather than 'empirical generalisability' (Smith et al., 2009). 'Theoretical transferability' means that if the researcher provides a "rich, transparent and contextualised analysis of the participants' accounts this in turn can allow the reader to evaluate its transferability to persons in contexts which are more, or less similar" (Smith et al., 2009, p. 51). Smith et al., (2009) also state that "The effectiveness of the IPA study is judged by the light it sheds within the broader context". Thus, echoing the above statements, my aim from the present study was not to make general claims about the experience of having a parent with cancer but rather it was to illuminate the experience of having a parent with cancer for a particular group of young adults impacted by parental cancer. The present study can help contribute to the overall understanding of young adults' experience of having a parent with cancer by providing a nuanced understanding of a particular group of adult offspring. Smith et al. (2009) point out that IPA studies can offer nuanced understandings of a phenomenon which, in turn, can start building a mosaic of an overall nuanced nomothetic understanding.

IPA studies usually advise obtaining a fairly homogenous sample (Smith et al., 2009). In terms of sample homogeneity in the present study, this was not without limitations. The characteristics of the participants of this study are homogenous in terms of the fact that they all experienced having a parent with cancer in the last 5 years. However, there was no control over the stage, type of cancer or the treatments the parents were impacted by. It is known that different kinds of cancer may have different physical impact and may differ significantly in terms of the treatment process and chances of heredity. For instance, it is documented that FDR's of breast cancer patients are at a higher risk of developing the illness, in comparison to the general population (Wellisch & collegues, 1992). However, although these factors were not controlled for, the researcher did make a note of these details. Throughout the research process and in carrying out the literature review, it became apparent that the lived experience of having a parent with cancer differed vastly, based on factors such as type, stage and even the perceived seriousness of one's parent's cancer (Compas et al., 1996). While this research cannot give us a detailed understanding of the lived experience of having a parent with specific types and stages of cancer, it does set the ground for further research. It highlights the need for research aiming to explore how the stage of one's parents' cancer, or the type of cancer they have can influence there lived experience.

Additionally, despite efforts to recruit a roughly equal balance of males and females to the study, it appeared that more females volunteered to take part. While it is acknowledged that IPA seeks a small and homogenous sample which was achieved by this research, five of the six participants identified as female, meaning findings offer predominantly female perspectives. However, reflecting on the data obtained from the 5 female participants and the 1 male participant, it became apparent that the male participant had a shorter interview. The female participants reflected that they had more duties and responsibilities and became the carer for their parent. The male participant however did not mention any caregiving duties he had to take on. These are just reflections of the data obtained from the 6 participants, and do not claim to be general or exhaustive findings. However, there may be a differentiating response to parental illness amongst the two genders, and further research exploring this phenomenon may produce imperative findings.

Also, it is important to note that the participants were self-selected, they were all volunteers, and no incentives were put on individuals to take in this research. Rozmarits and Ziebland (2004) highlight that volunteer participants may differ from broader samples in their motivation to be involved. Volunteers may have a desire to take part due to a particular positive experience, or conversely a particularly difficult one. It may be that those who choose not to participate in the study would have different stories to share. It is certainly difficult for the researcher to know the reasons for the participation drive, and it is an inherent critique in any research that is not possible to overcome. However, in the conversations that occurred during debriefing, some participants reflected that they took part in the research to raise awareness, encourage further research in the field, to better understand self, to have an opportunity to speak, and to aid support programs and interventions to be developed.

A limitation identified by Willig, (2013) in relation to IPA is the use of language. Just as other phenomenological approaches, IPA relies heavily on language. It requires rich data which in turn require that participants are articulate and able to express their experiences and perspectives in detail. I believe the individuals impacted by parental cancer that participated in this study were able to provide rich accounts of their experiences however, another researcher may have a differing view. Given the interpretative nature of IPA, it is possible that a different researcher could reach different interpretations of the data, which is another well-cited critique of IPA. I have aimed to be reflexive and was transparent regarding my own role in the research throughout the process.

I chose to conduct single point interviews for this study. Considering the contextualist position that underpins this project, that “knowledge is local, provisional and situation-dependent” (Madill et al., 2000), one could argue that the findings of this study represent the young adults’s experiences of parental cancer in a specific phase of the illness. Therefore, if the participants were interviewed at a different point of their parents’ illness process it can be expected that their experiences as communicated in their interviews would differ. Indeed, it was reported by previous literature that the stage of a parent’s cancer and its prognosis may be crucial moderators of the associated psychological distress experienced by adult offspring’s (Given et al., 2004; Dumont et al., 2006).

Lastly, although IPA analysis and its idiographic emphasis aims to capture everyone’s subjective experiences, during the abstraction phase when the analysis moved from the individual cases to the super-ordinate themes it became challenging to maintain this stance (Wagstaff et al., 2014). Trying to identify and phrase themes that was reflective of the individuality of the participants experiences was extremely difficult and required careful consideration. I attempted as much as possible to maintain the nuanced differences between cases, but I acknowledge that some of the idiographic details have been lost during the analytical process.

A final limitation of this research lies in the interpretative process. Elliot et al., (1999) suggest that using multiple researchers offers qualitative research a way to check the credibility of analysis and findings. Due to the nature of this research as part of my doctoral portfolio, it was not possible to include other researchers. Instead, I relied on attempting to rigorously adhere to IPA guidelines, often checking that I was addressing my original research question and liaising with my research supervisor on a regular basis.

Directions for future research

After carefully examining the literature and the findings from the present research it becomes clear that there are various methodological shortcoming and gaps in the literature. The experience of parental cancer is a highly unique and subjective experience, that may be impacted by various factors. This section will aim to outline and discuss the methodological limitations and gaps in the literature. In turn, I will provide directions for future research.

Most studies exploring the experience of parental cancer have incorporated homogenous samples with regards to gender, race/ethnicity, and socioeconomic status. More specifically, middle, and upper class, white women experiencing maternal cancer has generally been the focus of research. Meyerowitz & Hart (1995) suggest that this may be based on the assumption that “women feel, and men act”. The experience of men impacted by parental cancer is ignored in the literature. The present research also only incorporated a single male participant. It occurs that the females were more willing to take part in the research and share their experiences. However, more effort is needed to explore men’s experience of parental cancer and unravel their unique, subjective experiences. Their experiences may show significant differentiation, and their support needs may therefore differ significantly as well.

In addition, research generally focuses on the experience of individuals impacted by maternal cancer. Most studies carried out on the impact of parental cancer have generally focussed on daughters of breast cancer patients, and a few studies exploring the daughters of ovarian cancer patients. The reason for this may be the knowledge that, the risk of developing cancer is two to three times higher in women with first degree relatives (FDR) of breast cancer patients compared to women with no family history of the disease (Sattin et al., 1985).

Likewise, women are three to four times more at risk of developing cancer if they have a FDR with ovarian cancer (Schildkraut & Thompson, 1988). The perception of ones heightened future risk of developing cancer coupled with memories of coping with parental cancer or the death of their parent may certainly cause significant emotional distress for daughters of women with breast or ovarian cancer (Erblich et al., 2000). Therefore, it is crucial for research to continue exploring the experiences of this population, without neglecting individuals who may be impacted in different ways by other types of cancer.

Studies have failed to include comparisons groups as well as longitudinal designs. One cannot assume that the source of a participant's distress is related to their parent's cancer, without comparing to control groups. Literature is generally based on cross-sectional approaches which do not firmly establish predictors of adjustment throughout the experience of parental cancer. Future studies need to explore the changes between contextual and individual difference variables and psychosocial outcomes from the time of parent's cancer diagnosis, during adjuvant treatment, and during recovery. Longitudinal studies will provide an extensive insight into the variables that may moderate the association between a parent's cancer and psychological distress.

The study focus has always been the symptoms of psychopathology without examining the psychological strengths in the face of a parents life-threatening illness. This traditional emphasis on psychological distress reinforces a vulnerability/deficit model of women and does not acknowledge their strengths when faced with difficulties. Whereas, positive psychology shifts from focussing on pathology towards one that understand, explains and promotes wellness (Seligman & Csikzentmihalyi, 2000). This perspective does not deny human suffering, but instead complements the extant literature on psychopathology by examining human growth and resiliency. Personal strengths can act as a protective factor and contribute to individuals' resilience in coping with stressful situations. Although a few studies have explored the positive outcomes or perspectives of adult's offspring impacted by parental cancer, the strengths of individuals and their ability to achieve deeper meaning in life is yet to be explored. It is possible that certain personal strengths may contribute to an individual's resilience and ability to cope with parental cancer.

Closing Reflections

As I approached the end of this research project, I found myself reflecting on the whole process. The process was an enormous and often daunting challenge for me. There were times I felt that it was impossible to complete my portfolio. During the years it has taken me to come this far, significant changes occurred in my life. However, as I write this, I feel a great sense of achievement and confidence that I am close to closure.

In this research, young adults experience of parental cancer was addressed. I commenced in every effort to analyse the data obtained from the 6 participants in much detail as possible. On completing my analysis and discussion of the findings, I developed a desire to bring my project to a closure with my own personal reflections of the process and my journey of parental cancer.

I was an insider to the experience of parental cancer from the onset of the project. In fact, my interest in the project raised from my own personal experience of having a mother with cancer. I often felt that I was not understood, and that there was little support out there for individuals like me. This gave rise to my motivation to study this population and make us adult offspring's battling along with their parent, feel heard. I often experienced difficulties in balancing between the demands of my mother's illness and the demands of my own life. My aim was to reveal gaps in the literature and direct research in ways that could be most beneficial for people like me, to help them in areas of struggle.

During the process of my project, right after I had completed my interviews of the participants, my insider status reformed. Unfortunately, I lost my mother and my experience had changed in to 'losing a parent to cancer'. The pain was significant, and so I took a break from pursuing the data analysis. Separating myself and my journey to my research was fundamental at this point, as I had to make sure my interpretations were not influenced by my feelings. I spent months reflecting on myself and bracketing myself from the project. The participants experiences were separate to mine, and I developed the awareness that each individual experience about the process of parental cancer was going to differ based on their unique ride and what happens on that journey. My journey was simply a proof that every journey was going to vary with what happens on that journey, as my experiences were different from my siblings. This awareness allowed me to bracket the feelings and thoughts that I may have because of my experiences and engage with each participants unique data in a very passionate way. I was extremely drawn to the points of similarities and differences. This curiosity allowed me to indulge with data and try to develop my interpretations as accurately as possible. the

After my mother's loss, my analysis and write up has taken much longer than initially anticipated. My experience gave me a stronger desire to engage with the analysis and findings in a way that was very close to the participants own reflections. I felt a great responsibility to do this analysis well. Therefore, my passion to hear the participants and interpret their data in a way that was most reflective of their experiences, made me spend more time reading the interviews. Indeed, the longer exposure to the participants transcripts and analysis has made me feel much more familiar with the data. I developed a greater insight into each participant process of parental cancer. This contributed to my ability to identify connections and discuss the findings in relation to the existing literature in finer detail.

In discussing the findings to the existing literature, I felt a great sense of reward. Being able to see that my study was contributing to what we already know about parental cancer was extremely satisfying. Points of convergence and divergence in my findings and those that of previous literature was important to reveal. This allowed me to identify some gaps in the literature and show directions for potential future research. I believe I have completed a successful project that will give rise to further understanding of this population.

Moreover, in relation to the findings of the analysis, I would like to highlight the points of similarities and differences to my experiences. In doing so, I would like to reflect my own voice and illustrate that the analysis was independent of my own experiences. On facing my parents' diagnosis with cancer, I also experienced significant pain and sadness. However, this sadness grew as I realised how serious and life-threatening cancer can be. Grace also reflected that her feelings of sadness and fear changed as her understanding of cancer changed. She was the only participants who referred to this experience which was very similar to mine. Moreover, although I also experienced significant worries relating to the loss of my mother, my experience differentiated in that I did not experience similar worries about my own health and risk of developing cancer. All participants in the present research however reflected on their fear of developing cancer.

Like most of the participants, my mother's cancer also changed the roles and dynamics in the family. As my mother deteriorated, the caregiving commitments increased, and her life became the priority. However, I cannot say that it changed the relationships in our family and did not have a notable effect on our family bond. Nevertheless, we were a very connected family from the onset but, my mother's cancer did cause everyone to become more reserved and less sharing of their emotions. This was a different experience to those of the participants as some participants reported more sharing of emotions. Another differing experience was that I did not develop a desire to have a healthier lifestyle. Yet, I did develop a stronger urge to be helpful to others. This reflection once again show that the experience of parental cancer is a unique experience and will vary based on many factors. Acknowledging the variations in experiences, increases my passion to study the experience of parental cancer in finer detail.

Lastly, I would like to stress that during the process of my project, particularly after my mother's loss, I engaged in every effort to manage a self-care routine. I took regular breaks from my write up, especially at times I felt overwhelmed. I kept a reflexive journal documenting my thoughts and feelings, which allowed me to employ bracketing thoroughly. For instance, at times of any form of emotional arousal (i.e., sadness) I avoided to engage with my analysis. I also used personal therapy as a source to process my feelings and contain them. Having a different space to share and reflect my own feelings and experiences was a great way to separate them from my project.

Overall, my main sense at this stage in the research is one of relief. Seeing the biggest part of my portfolio take form was pleasing. This was by far my most difficult academic endeavour to date; however, it was also the most enlightening, enjoyable, and rewarding. I feel a sense of pride for having taken on this sensitive and complex topic, and for being able to contribute something to the body of existing research around the experiences of individuals impacted by parental cancer. The opportunity to hear the voice of other individuals impacted by parental cancer was great. I hope that this research will resonate with people and support them in their journey by making them have a sense of belonging.

Synthesis of the findings

In conclusion, in this research it was apparent that the experience of having a parent with cancer was a significantly upsetting and distressing event for young adults. They experienced various emotional disturbances such as sadness and fear. Experiencing an illness in such proximity caused individuals to become wary of death and develop a heightened awareness of the possibility of loss. They became more conscious and aware of the possibility of losing their parent. Young adults also developed concerns in relation to their own risk of developing cancer and losing their own health.

Cancer not only changed the parent, but it also had a significant impact on the family dynamics, and roles adapted by the family members. A process of role changes occurred. The initial step of this process can be described as the parents' deterioration because of cancer and the treatment process it entails. The parent starts to change both physically and emotionally. They become unable to function as they would and may not be able to complete the task and house chores they once did. As a result, the adult offspring starts to take on more responsibilities, which may include caring for the ill parent and the family. In other terms, the adult offspring becomes the new parent in some ways. In addition, they may put their own life on hold to cater for the caregiving roles. For example, some young adults may give up on their social life, while some may not continue with their education.

To cope with this process and manage through the experience of parental cancer, young adults tried to appear strong to support their parent both practically and mentally. Moreover, they also withdrew from socialising and became estranged from others. In doing so, they prioritised their ill parent, used their time to cater for the demands at home, and avoid situations that made them feel weak because of their parents' illness. All participants were also able to identify a source of support they found that was helpful. Some of these were professional help, mindfulness, and religion.

Young adults also found the experience of having a parent with cancer to cause positive growth too. Having a deadly illness impact a family member, caused individuals to develop more sensitivity towards each other. They became more caring, and their family bonds became much stronger. Not only towards each other at home, but individuals also explained becoming a better person towards others and the community too. Lastly, the concerns relating to developing illnesses and realising the unescapable nature of death, led individuals to develop a desire to live a healthier lifestyle.

Overall, this research has revealed that having a parent with cancer can be a life changing experience for a young adult in various ways. While it can cause psychological difficulties, emotional burden, and changes in responsibilities, it can also lead to positive development for themselves and their families.

References

Act, D. P. (2010). Legislation. gov. uk. National Archives of HM Government.

Affleck, G., & Tennen, H. (1996). Construing benefits from adversity: Adaptotional significance and disposltional underpinnings. Journal of personality, 64(4), 899-922.

Akpınar, B., Küçükgüçlü, Ö., & Yener, G. (2011). Effects of gender on burden among caregivers of Alzheimer's patients. Journal of nursing scholarship, 43(3), 248-254.

Allen, R. S., Haley, W. E., Small, B. J., & McMillan, S. C. (2002). Pain reports by older hospice cancer patients and family caregivers: the role of cognitive functioning. The Gerontologist, 42(4), 507-514.

Almarza, C. C. (2008). When a parent has cancer: An examination of the lived experience of adult children living at home.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders. BMC Med, 17, 133-137.

American Cancer Society. (2015). Cancer facts & figures 2015. American Cancer Society.

Anand, P., Kunnumakara, A. B., Sundaram, C., Harikumar, K. B., Tharakan, S. T., Lai, O. S., ... & Aggarwal, B. B. (2008). Cancer is a preventable disease that requires major lifestyle changes. Pharmaceutical research, 25(9), 2097-2116.

Ar, Y., & Karanci, A. N. (2019). Turkish adult children as caregivers of parents with Alzheimer’s disease: Perceptions and caregiving experiences. *Dementia*, *18*(3), 882-902.

Aranda, S. K., & Hayman-White, K. (2001). Home caregivers of the person with advanced cancer: an Australian perspective. Cancer nursing, 24(4), 300-307.

Arnaert, A., Gabos, T., Ballenas, V., & Rutledge, R. D. (2010). Contributions of a retreat weekend to the healing and coping of cancer patients’ relatives. Qualitative health research, 20(2), 197-208.

Armstrong, T. L., & Swartzman, L. C. (2001). Cross-cultural differences in illness models and expectations for the health care provider-client/patient interaction. In Handbook of cultural health psychology (pp. 63-84). Academic Press.

Asselin, M. E. (2003). Insider research: Issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Professional Development*, *19*(2), 99-103.

Bagautdinova, D., Bylund, C. L., Kastrinos, A., Hampton, C. N., Vasquez, T. S., Weiss, E. S., ... & Fisher, C. L. (2023). Adult sibling-related experiences while caring for a parent diagnosed with a blood cancer. *Families, Systems, & Health*, *41*(2), 140.

Baider, L., Ever-Hadani, P., & De-Nour, A. K. (1999). Psychological distress in healthy women with familial breast cancer: like mother, like daughter?. The International Journal of Psychiatry in Medicine, 29(4), 411-420.

Barkham, M. I. C. H. A. E. L., Woolfe, R., Dryden, W., & Strawbridge, S. (2003). Quantitative research on psychotherapeutic interventions: methods and findings across four research generations. Handbook of counselling psychology, 25, 73.

Barusch, A. S., & Spaid, W. M. (1989). Gender differences in caregiving: why do wives report greater burden?. The Gerontologist, 29(5), 667-676.

Becker, E. (1997). The denial of death. Simon and Schuster.

Berger, R. (2015). Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative research*, *15*(2), 219-234.

Bertakis, K. D., Azari, R., Helms, L. J., Callahan, E. J., & Robbins, J. A. (2000). Gender differences in the utilization of health care services. *Journal of family practice*, *49*(2).

Bettany-Saltikov, J. (2016). EBOOK: How to do a Systematic Literature Review in Nursing: A step-by-step guide.

Blanchard, C. G., Albrecht, T. L., & Ruckdeschel, J. C. (1997). The crisis of cancer: psychological impact on family caregivers. Oncology (Williston Park, NY), 11(2), 189-94.

Boehmer, U., & Clark, J. A. (2001). Communication about prostate cancer between men and their wives. *Journal of family practice*, *50*(3), 226-226.

Bonica, J. J. (1984). Management of cancer pain. In Pain in the Cancer Patient: Pathogenesis, Diagnosis and Therapy (pp. 13-27). Springer Berlin Heidelberg.

Bowlby, J. (1979). The bowlby-ainsworth attachment theory. Behavioral and Brain Sciences, 2(4), 637-638.

Bowlby, J. (1982). Attachment and loss: retrospect and prospect. American journal of Orthopsychiatry, 52(4), 664.

Boyer, B. A., Bubel, D., Jacobs, S. R., Knolls, M. L., Harwell, V. D., Goscicka, M., & Keegan, A. (2002). Posttraumatic stress in women with breast cancer and their daughters. American Journal of Family Therapy, 30(4), 323-338.

British Psychological Society. (2021). *BPS Code of Human Research Ethics*

Brody, E. M. (1981). "Women in the middle" and family help to older people. The Gerontologist, 21(5), 471-480.

Cancer Research UK (2014) Cancer statistics for the UK: Cancer incidence. Retrieved from http://www.cancerresearchuk.org/health-professional/cancer-statistics

Cancer Research UK (2018) Cancer statistics for the UK: Cancer incidence. Retrieved from http://www.cancerresearchuk.org/health-professional/cancer-statistics

Cansino, S. (2009). Episodic memory decay along the adult lifespan: a review of behavioral and neurophysiological evidence. International Journal of Psychophysiology, 71(1), 64-69.

Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. Successful qualitative research, 1-400.

Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic Analysis. Inmith JA. editor. Qualitative psychology: a practical guide to research methods.

Cloke, P., Cooke, P., Cursons, J., Milbourne, P., & Widdowfield, R. (2000). Ethics, reflexivity and research: Encounters with homeless people. *Ethics, Place & Environment*, *3*(2), 133-154.

Cohen, O., & Katz, M. (2015). Grief and growth of bereaved siblings as related to attachment style and flexibility. Death Studies, 39(3), 158-164.

Compas, B. E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D. C., & Malcarne, V. L. (1994). When mom or dad has cancer: markers of psychological distress in cancer patients, spouses, and children. Health Psychology, 13, 507-507.

Compas, B. E., Worsham, N. L., Ey, S., & Howell, D. C. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients. Health psychology, 15(3), 167.

Cordova, M. J., Cunningham, L. L., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: a controlled comparison study. Health psychology, 20(3), 176.

Coyle, A. (2007). Introduction to qualitative psychological research. Analysing qualitative data in psychology, 2, 9-30.

Coyne, J. C., Benazon, N. R., Gaba, C. G., Calzone, K., & Weber, B. L. (2000). Distress and psychiatric morbidity among women from high-risk breast and ovarian cancer families. Journal of Consulting and Clinical Psychology, 68(5), 864.

Cruess, D. G., Antoni, M. H., McGregor, B. A., Kilbourn, K. M., Boyers, A. E., Alferi, S. M., ... & Kumar, M. (2000). Cognitive-behavioral stress management reduces serum cortisol by enhancing benefit finding among women being treated for early stage breast cancer. Psychosomatic medicine, 62(3), 304-308.

De Boer, M. F., Ryckman, R. M., Pruyn, J. F. A., & Van den Borne, H. W. (1999). Psychosocial correlates of cancer relapse and survival: a literature review. Patient education and counseling, 37(3), 215-230.

Derogatis, L. R., & Spencer, P. M. (1982). The Brief Symptom Inventory (BSI): administration and procedures manual—I. Baltimore: Clinical Psychometric Research.

Dictionary, O. E. (1989). Oxford english dictionary. Simpson, JA & Weiner, ESC.

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. BMJ Quality & Safety, 13(3), 223-225.

Dodgson, J. E. (2019). Reflexivity in qualitative research. *Journal of human lactation*, *35*(2), 220-222.

Doll, R., & Peto, R. (1981). The causes of cancer: quantitative estimates of avoidable risks of cancer in the United States today. JNCI: Journal of the National Cancer Institute, 66(6), 1192-1308.

Drake, P. (2010). Grasping at methodological understanding: a cautionary tale from insider research. *International Journal of Research & Method in Education*, *33*(1), 85-99.

Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. (2006). Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. Journal of palliative medicine, 9(4), 912-921.

Dura, J. R., Stukenberg, K. W., & Kiecolt-Glaser, J. K. (1991). Anxiety and depressive disorders in adult children caring for demented parents. Psychology and aging, 6(3), 467.
Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. The Sage handbook of qualitative research in psychology, 193-209.

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International journal of qualitative methods*, *8*(1), 54-63.

Eatough, V., Smith, J. A., & Shaw, R. (2008). Women, anger, and aggression: An interpretative phenomenological analysis. Journal of interpersonal violence, 23(12), 1767-1799.

Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *13*(8), 562-576.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. British journal of clinical psychology, 38(3), 215-229.

Enright, R. B., & Friss, L. (1987). Employed caregivers of brain-impaired adults: An assessment of the dual role. Family Survival Project.

Erblich, J., Bovbjerg, D. H., & Valdimarsdottir, H. B. (2000). Psychological distress, health beliefs, and frequency of breast self-examination. Journal of behavioral medicine, 23(3), 277-292.

Ferlay, J. S. E. M., Soerjomataram, I., Ervik, M., Dikshit, R., Eser, S., Mathers, C., ... & Bray, F. (2012). Cancer incidence and mortality worldwide: IARC CancerBase. *Globocan*, *2013*(1), 11.

Ferrell, B. R., Ferrell, B. A., Rhiner, M., & Grant, M. (1990). Family factors influencing cancer pain management. Postgraduate medical journal, 67, S64-9.

Ferrell, B. R., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1998). Quality of life in breast cancer: Part II: Psychological and spiritual well-being. Cancer nursing, 21(1), 1-9.

Finlay, L. (2012). Five lenses for the reflexive interviewer. *The SAGE handbook of interview research: The complexity of the craft*, 317-333.

Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. *Qualitative health research*, *12*(4), 531-545.

Frederick, C. J. (1987). Psychic trauma in victims of crime and terrorism. In American Psychological Association Convention, Aug, 1986, Washington, DC, US; This chapter is based upon one of the 1986 Master Lectures that were presented at the aforementioned convention. (pp. 55-108). American Psychological Association.

Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. Journal of the American Geriatrics Society, 53(1), 59-65.

George, L. K., & Gwyther, L. P. (1986). Caregiver weil-being: a multidimensional examination of family caregivers of demented adults. The gerontologist, 26(3), 253-259.

Gilbar, O. (1997). Cancer caregiver support group: A model for intervention. Clinical Gerontologist, 18(1), 31-37.

Given, B. A., Given, C. W., & Kozachik, S. (2001). Family support in advanced cancer. CA: a cancer journal for clinicians, 51(4), 213-231.

Given, B., Wyatt, G., Given, C., Gift, A., Sherwood, P., DeVoss, D., & Rahbar, M. (2004, November). Burden and depression among caregivers of patients with cancer at the end-of-life. In Oncology nursing forum (Vol. 31, No. 6, p. 1105). NIH Public Access.

Glover, J., Dibble, S. L., Dodd, M. J., & Miaskowski, C. (1995). Mood states of oncology outpatients: does pain make a difference?. Journal of pain and symptom management, 10(2), 120-128.

Gorski, E. (2010). Stoic, stubborn, or sensitive: How masculinity affects men’s help-seeking and help-referring behaviors. *UW-L Journal of Undergraduate Research*, *13*, 1-6.

Grafanaki, S. (2010). ‘Counsellors in the making’: Research on counselling training and formative experiences of trainee counsellors.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., ... & Glossop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. Cmaj, 170(12), 1795-1801.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. Handbook of qualitative research, 2(163-194), 105.

Guendelman, S., Medeiros, S., & Rampes, H. (2017). Mindfulness and emotion regulation: Insights from neurobiological, psychological, and clinical studies. Frontiers in psychology, 220.

Hagedoorn, M., Sanderman, R., Buunk, B. P., & Wobbes, T. (2002). Failing in spousal caregiving: The 'identity-relevant stress' hypothesis to explain sex differences in caregiver distress. British Journal of Health Psychology, 7(4), 481-494.

Hailey Maier, E., & Lachman, M. E. (2000). Consequences of early parental loss and separation for health and well-being in midlife. International Journal of Behavioral Development, 24(2), 183-189.

Hamdan, A. K. (2010). Reflexivity of discomfort in insider-outsider educational research. McGill Journal of Education, 44(3), 377-404.

Hamnett, Michael P., Porter, Douglas J., Singh, Amarjit, and Kumar, Krishna (1984) Ethics, Politics and International Social Science Research: From Critique to Praxis. Honolulu: University of Hawaii Press

C. Harrington, C., Dean-Witt, C., & Z. Cacchione, P. (2023). Female caregivers' contextual complexities and familial power structures within Alzheimer's care. *Journal of Women & Aging*, *35*(5), 446-464.

Health & Care Professions Council. (2016). *Standards of conduct, performance and ethics.* Retrieved from https://www.hcpc-uk.org/globalassets/resources/standards/standards-of-conduct-performance-and-ethics.pdf

Heidegger, M. (1927). Sein und zeit.

Heidegger, M. (1962). Being and time, trans. J. Macquarrie and E. Robinson.

Hodges, L. J., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. Social science & medicine, 60(1), 1-12.

Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. Psychosomatic medicine, 41(3), 209-218.

Horowitz, A. (1985). Family caregiving to the frail elderly. Annual review of gerontology and geriatrics, 5(1), 194-246.

Hoyert, D. L., & Seltzer, M. M. (1992). Factors related to the well-being and life activities of family caregivers. Family relations, 74-81.

Hulbert-Williams, N. J., Storey, L., & Wilson, K. G. (2015). Psychological interventions for patients with cancer: psychological flexibility and the potential utility of Acceptance and Commitment Therapy. *European journal of cancer care*, *24*(1), 15-27.

Husserl, E. (1999). The essential Husserl: Basic writings in transcendental phenomenology. Indiana University Press.

IARC Working Group on the Evaluation of Carcinogenic Risks to Humans. (2008). IARC monographs on the evaluation of carcinogenic risks to humans. Volume 97. 1, 3-butadiene, ethylene oxide and vinyl halides (vinyl fluoride, vinyl chloride and vinyl bromide). IARC monographs on the evaluation of carcinogenic risks to humans, 97, 3.

Jaffray, L., Bridgman, H., Stephens, M., & Skinner, T. (2016). Evaluating the effects of mindfulness-based interventions for informal palliative caregivers: A systematic literature review. Palliative Medicine, 30(2), 117-131.

Janoff-Bulman, R. (1992). Shattered assumptions: Toward a new psychol- ogy of trauma. New York: Free Press.

Johnson, C. L. (1983). Dyadic family relations and social support. The Gerontologist, 23(4), 377-383.

Johnson, C. L., & Catalano, D. J. (1983). A longitudinal study of family supports to impaired elderly. The gerontologist, 23(6), 612-618.

Kabat-Zinn, J. (2013). Full catastrophe living, revised edition: how to cope with stress, pain and illness using mindfulness meditation. Hachette uK.

Kangas, M., Henry, J. L., & Bryant, R. A. (2002). Posttraumatic stress disorder following cancer: A conceptual and empirical review. Clinical psychology review, 22(4), 499-524.

Kang J., Shin D. W., Choi J. E., Sanjo M., Yoon S. J., Kim H. K., [horizontal ellipsis] Yoon W. H. (2013). Factors associated with positive consequences of serving as a family caregiver for a terminal cancer patient. Psycho-Oncology, 22, 564-571.

Kash, K. M., Holland, J. C., Halper, M. S., & Miller, D. G. (1992). Psychological distress and surveillance behaviors of women with a family history of breast cancer. JNCI: Journal of the National Cancer Institute, 84(1), 24-30.

Katz, R. C., Flasher, L., Cacciapaglia, H., & Nelson, S. (2001). The psychosocial impact of cancer and lupus: A cross validation study that extends the generality of “benefit-finding” in patients with chronic disease. Journal of behavioral medicine, 24, 561-571.

Kerr, M. E., & Bowen, M. (1988). Family evaluation. New York, NY: Norton and Company.

Khan, K. S., Kunz, R., Kleijnen, J., & Antes, G. (2003). Five steps to conducting a systematic review. *Journal of the royal society of medicine*, *96*(3), 118-121.

Kim, Y., Baker, F., Spillers, R. L., & Wellisch, D. K. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *15*(9), 795-804.

Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit finding in the cancer caregiving experience. Psychosomatic medicine, 69(3), 283-291.

Kim, Y., & Given, B. A. (2008). Quality of life of family caregivers of cancer survivors. Cancer, 112(S11), 2556-2568.

Kim, Y., Spillers, R. L., & Hall, D. L. (2012). Quality of life of family caregivers 5 years after a relative's cancer diagnosis: follow-up of the national quality of life survey for caregivers. Psycho-Oncology, 21(3), 273-281.

King, N., Brooks, J., & Horrocks, C. (2018). Interviews in qualitative research.

Kirk, R. (2012). Relativism and reality: a contemporary introduction. Routledge.
Lai, C., Luciani, M., Galli, F., Morelli, E., Cappelluti, R., Penco, I., ... & Lombardo, L. (2015). Attachment style dimensions can affect prolonged grief risk in caregivers of terminally ill patients with cancer. American Journal of Hospice and Palliative Medicine®, 32(8), 855-860.

Koerner, S. S., & Shirai, Y. (2012). The negative impact of global perceptions of and daily care-related family conflict on Hispanic caregivers: Familism as a potential moderator. *Aging & Mental Health*, *16*(4), 486-499.

Koerner, S. S., Shirai, Y., & Pedroza, R. (2013). Role of religious/spiritual beliefs and practices among Latino family caregivers of Mexican descent. *Journal of Latina/o Psychology*, *1*(2), 95.

Landridge, D. (2007). Phenomenological Psychology Theory. Research and Practice.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. Qualitative research in psychology, 3(2), 102-120.

Lau, D. T., Berman, R., Halpern, L., Pickard, A. S., Schrauf, R., & Witt, W. (2010). Exploring factors that influence informal caregiving in medication management for home hospice patients. Journal of palliative medicine, 13(9), 1085-1090.

Leedham, B., & Meyerowitz, B. E. (1999). Responses to parental cancer: A clinical perspective. Journal of Clinical Psychology in Medical Settings, 6(4), 441-461.

Lepore, S. J., Ragan, J. D., & Jones, S. (2000). Talking facilitates cognitive–emotional processes of adaptation to an acute stressor. Journal of personality and social psychology, 78(3), 499.

Lepore, S. J., Silver, R. C, Wortman, C. B., & Wayment, H. A. (1996). Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. Journal of Personality and Social Psychology, 70, 271-282.

Lerman, C., Daly, M., Sands, C., Balshem, A., Lustbader, E., Heggan, T., ... & Engstrom, P. (1993). Mammography adherence and psychological distress among women at risk for breast cancer. JNCI: Journal of the National Cancer Institute, 85(13), 1074-1080.

Levesque, J. V., &Maybery, D. (2012). Parental cancer: Catalyst for positive growth and change. Qualitative health research, 22(3), 397-408.

Lindberg, N. M., & Wellisch, D. K. (2004). Identification of traumatic stress reactions in women at increased risk for breast cancer. Psychosomatics, 45(1), 7-16.

Lopez–Anuarbe, M., & Kohli, P. (2019, May). Understanding male caregivers' emotional, financial, and physical burden in the United States. In *Healthcare* (Vol. 7, No. 2, p. 72). MDPI.

Lowenstein, A., & Gilbar, O. (2000). The perception of caregiving burden on the part of elderly cancer patients, spouses and adult children. Families, Systems, & Health, 18(3), 337.

Maccallum, F., & Bryant, R. A. (2018). Prolonged grief and attachment security: A latent class analysis. Psychiatry Research, 268, 297-302.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. British journal of psychology, 91(1), 1-20.

Madill, A., & Gough, B. (2008). Qualitative research and its place in psychological science. Psychological methods, 13(3), 254.

Mackinnon, C. J. (2009). Applying feminist, multicultural, and social justice theory to diverse women who function as caregivers in end-of-life and palliative home care. *Palliative & Supportive Care*, *7*(4), 501-512.

Maso, I. (2003). Necessary subjectivity: exploiting researchers' motives, passions and prejudices in pursuit of answering ‘true ‘questions. *Reflexivity: A practical guide for researchers in health and social sciences*, 49-51.

Maxwell, J. A., & Miller, B. A. (2013). Quantitative systematic statistics, research has a detailed and. *Handbook of emergent methods*, *461*.

Mazanec, S. R., Daly, B. J., Douglas, S. L., & Lipson, A. R. (2011). Work productivity and health of informal caregivers of persons with advanced cancer. Research in nursing & health, 34(6), 483-495.

Meyerowitz, B. E., & Hart, S. (1995). Women and cancer: Have assumptions about women limited our research agenda?.

Miao, H., Verkooijen, H. M., Chia, K. S., Bouchardy, C., Pukkala, E., Larønningen, S., ... & Hartman, M. (2011). Incidence and outcome of male breast cancer: an international population-based study. *J Clin Oncol*, *29*(33), 4381-4386.

McCubbin, H. I. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In families, health & illness: Perspectives on coping and intervention. Winstead & Fry, 21-63.

McGoldrick, M., Anderson, C. M., & Walsh, F. (Eds.). (1991). Women in families: A framework for family therapy. WW Norton & Company.

McDonald, F. E. J., Patterson, P., White, K. J., Butow, P. N., Costa, D. S. J., & Kerridge, I. (2016). Correlates of unmet needs and psychological distress in adolescent and young adults who have a parent diagnosed with cancer. Psycho-Oncology, 25(4), 447-454.

McPhail, C., Dwyer, J. J., Hanemaayer, R., & Preyde, M. (2017). The experience of parental cancer among emerging adult university students. *Journal of Psychosocial Oncology*, *35*(2), 202-219.

Miaskowski, C., Zimmer, E. F., Barrett, K. M., Dibble, S. L., & Wallhagen, M. (1997). Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. Pain, 72(1-2), 217-226.

Moran, D., & Mooney, T. (Eds.). (2002). The phenomenology reader. Psychology Press.

Mosher, C. E., & Danoff-Burg, S. (2005). Psychosocial impact of parental cancer in adulthood: A conceptual and empirical review. Clinical Psychology Review, 25(3), 365-382.

Mosher, C. E., Danoff-Burg, S., & Brunker, B. (2006, May). Post-traumatic growth and psychosocial adjustment of daughters of breast cancer survivors. In Oncology nursing forum (Vol. 33, No. 3).

Murray, B. L. (2003). Qualitative research interviews: therapeutic benefits for the participants. Journal of Psychiatric and Mental Health Nursing, 10(2), 233-236.

Nguyen, T. Q. T. (2015). Conducting semi-structured interviews with the Vietnamese. *Qualitative Research Journal*, *15*(1), 35-46.

Niemelä, M., Paananen, R., Hakko, H., Merikukka, M., Gissler, M., & Räsänen, S. (2012). The prevalence of children affected by parental cancer and their use of specialized psychiatric services: the 1987 Finnish Birth Cohort study. International Journal of Cancer, 131(9), 2117-2125.

Niemelä, M., Paananen, R., Hakko, H., Merikukka, M., Gissler, M., & Räsänen, S. (2016). Mental disorder diagnoses of offspring affected by parental cancer before early adulthood: the 1987 Finnish Birth Cohort study. Psycho-Oncology.

Northouse, L. L. (1994). Breast cancer in younger women: effects on interpersonal and family relations. Journal of the National Cancer Institute. Monographs, (16), 183.

Northouse, L., Williams, A. L., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. Journal of clinical oncology, 30(11), 1227-1234.

Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., & Mood, D. W. (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. CA: a cancer journal for clinicians, 60(5), 317-339.

Oktay, J. S. (2005). Breast cancer: Daughters tell their stories. New York: Haworth Press.

Packer, M. J., & Addison, R. B. (Eds.). (1989). Entering the circle: Hermeneutic investigation in psychology. Suny Press.

Padgett, D. K. (2016). *Qualitative methods in social work research* (Vol. 36). Sage publications.

Patterson, P., & Rangganadhan, A. (2010). Losing a parent to cancer: A preliminary investigation into the needs of adolescents and young adults. Palliative and Supportive Care, 8 (3), 255–265. doi:10.1017/S1478951510000052

Papastavrou, E., Tsangari, H., Kalokerinou, A., Papacostas, S. S., & Sourtzi, P. (2009). Gender issues in caring for demented relatives. *Health Science Journal*, *3*(1), 41-53.

Payne, S., Smith, P., & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. Palliative medicine, 13(1), 37-44.

Phillips, F., & Lewis, F. M. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. Palliative medicine, 0269216315578989.

Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii. *Czasopismo Psychologiczne*, *18*(2), 361-369.

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, *45*(1), 90-106.

Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. Nurse researcher, 18(3).

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. Journal of counseling psychology, 52(2), 126.
Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. Journal of counseling psychology, 52(2), 137.

Porter, L. S., Keefe, F. J., McBride, C. M., Pollak, K., Fish, L., & Garst, J. (2002). Perceptions of patients' self-efficacy for managing pain and lung cancer symptoms: correspondence between patients and family caregivers. Pain, 98(1-2), 169-178.

Potter, J., & Wetherell, M. (1987). Discourse and social psychology: Beyond attitudes and behaviour. Sage.
Powers, S. M., & Whitlatch, C. J. (2016). Measuring cultural justifications for caregiving in African American and White caregivers. *Dementia*, *15*(4), 629-645.

Puterman, J., & Cadell, S. (2008). Timing is everything: The experience of parental cancer for young adult daughters: A pilot study. Journal of Psychosocial Oncology, 26 (2), 103–121. doi:10.1300/J077v26n02_07

Radloff, L. S. (1997). Scale: A self-report depression scale for research in the general population. J Clin Exp Neuropsychol, 19, 340-356.

Rankin, E. D. (1990). Caregiver stress and the elderly: A familial perspective. Journal of Gerontological Social Work, 15(1-2), 57-73.

Rapley, M. (2004). The social construction of intellectual disability. Cambridge University Press.

Raveis, V. H., Karus, D. G., & Siegel, K. (1998). Correlates of depressive symptomatology among adult daughter caregivers of a parent with cancer. Cancer: Interdisciplinary International Journal of the American Cancer Society, 83(8), 1652-1663.

Raveis, V. H., Karus, D., & Pretter, S. (1999). Correlates of anxiety among adult daughter caregivers to a parent with cancer. Journal of Psychosocial Oncology, 17(3-4), 1-26.

Redinbaugh, E. M., Baum, A., DeMoss, C., Fello, M., & Arnold, R. (2002). Factors associated with the accuracy of family caregiver estimates of patient pain. Journal of Pain and Symptom Management, 23(1), 31-38.

Ricoeur, P. (1970, July). Hope and the structure of philosophical systems. In Proceedings of the American Catholic Philosophical Association (Vol. 44, pp. 55-69).

Roemer, L., Williston, S. K., & Rollins, L. G. (2015). Mindfulness and emotion regulation. Current Opinion in Psychology, 3, 52-57.

Rohleder, N., Marin, T. J., Ma, R., & Miller, G. E. (2009). Biologic cost of caring for a cancer patient: dysregulation of pro-and anti-inflammatory signaling pathways. J Clin Oncol, 27(18), 2909-2915.

Rolland, J. S. (1999). Parental illness and disability: a family systems framework. Journal of family therapy, 21(3), 242-266.

Rolland, J. S. (2005). Cancer and the family: An integrative model. Cancer: Interdisciplinary International Journal of the American Cancer Society, 104(S11), 2584-2595.

Rozmovits, L., & Ziebland, S. (2004). What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. Patient education and counseling, 53(1), 57-64.

Sattin, R. W., Rubin, G. L., Webster, L. A., Huezo, C. M., Wingo, P. A., Ory, H. W., & Layde, P. M. (1985). Family history and the risk of breast cancer. Jama, 253(13), 1908-1913.

Seale, C. (1999). Quality in qualitative research. Qualitative inquiry, 5(4), 465-478.

Sears, S. R., Stanton, A. L., & Danoff-Burg, S. (2003). The yellow brick road and the emerald city: benefit finding, positive reappraisal coping and posttraumatic growth in women with early-stage breast cancer. Health Psychology, 22(5), 487.

Seligman, M. E., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction (Vol. 55, No. 1, p. 5). American Psychological Association.

Schildkraut, J. M., & Thompson, W. D. (1988). Familial ovarian cancer: a population-based case-control study. American journal of epidemiology, 128(3), 456-466.

Schmidt, C. K., & Welsh, A. C. (2010). College adjustment and subjective well-being when coping with a family member’s illness. Journal of Counseling & Development, 88 (4), 397–406. doi:10.1002/j.1556-6678.2010.tb00039

Schnur, J. B., Valdimarsdottir, H. B., Montgomery, G. H., Nevid, J. S., & Bovbjerg, D. H. (2004). Social constraints and distress among women at familial risk for breast cancer. Annals of Behavioral Medicine, 28(2), 142-148.

Schrank, B., Ebert-Vogel, A., Amering, M., Masel, E. K., Neubauer, M., Watzke, H., ... & Schur, S. (2016). Gender differences in caregiver burden and its determinants in family members of terminally ill cancer patients. *Psycho-oncology*, *25*(7), 808-814.

Schwartz, M. D., Lerman, C., Miller, S. M., Daly, M., & Masny, A. (1995). Coping disposition, perceived risk, and psychological distress among women at increased risk for ovarian cancer. Health Psychology, 14(3), 232.

Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 14(2), 102-114.

Siegel, K., Raveis, V. H., Houts, P., & Mor, V. (1991). Caregiver burden and unmet patient needs. Cancer, 68(5), 1131-1140.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. Qualitative research in psychology, 1(1), 39-54.

Smith, J. A. (Ed.). (2015). Qualitative psychology: A practical guide to research methods. Sage.

Smith, J. A & Osborn, M. (2008) Interpretative Phenomenological Analysis. In J. A. Smith (ed.) Qualitative psychology. London: Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2009) Interpretative phenomenological analysis: Theory, method and research.

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. Psychology and health, 22(5), 517-534.

Soldo, B. J., & Myllyluoma, J. (1983). Caregivers who live with dependent elderly. The Gerontologist, 23(6), 605-611.

Speilberger, C. D., Gorsuch, R., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983). Manual for the state-trait anxiety inventory. Palo Alto, CA: Consulting Psychologists.

Stanton, A. L., Danoff-burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 11(2), 93-102.

Stone, R. I., & Kemper, P. (1989). Spouses and children of disabled elders: How large a constituency for long-term care reform?. The Milbank Quarterly, 485-506.

Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model: prospects and challenges for health psychology. Health psychology, 23(2), 119.

Tedeschi, R. G., & Calhoun, L. G. (2004). " Posttraumatic growth: conceptual foundations and empirical evidence". Psychological inquiry, 15(1), 1-18.

Teixeira, C. M., Vasconcelos-Raposo, J., Fernandes, H. M., & Brustad, R. J. (2013). Physical activity, depression and anxiety among the elderly. Social Indicators Research, 113(1), 307-318.

Teixeira, R. J., & Pereira, M. G. (2014). Psychological morbidity and autonomic reactivity to emotional stimulus in parental cancer: a study with adult children caregivers. European journal of cancer care, 23(1), 129-139.

Thastum, M., Munch-Hansen, A., Wiell, A., & Romer, G. (2006). Evaluation of a focused short-term preventive counselling project for families with a parent with cancer. *Clinical child psychology and psychiatry*, *11*(4), 529-542.

Thornton, A. A. (2002). Perceiving benefits in the cancer experience. Journal of Clinical Psychology in Medical Settings, 9(2), 153-165.

Thornton, A. A., & Perez, M. A. (2006). Posttraumatic growth in prostate cancer survivors and their partners. Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 15(4), 285-296.

Thune-Boyle, I. C., Stygall, J. A., Keshtgar, M. R., & Newman, S. P. (2006). Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Social science & medicine*, *63*(1), 151-164.

Valdimarsdottir, H. B., Bovbjerg, D. H., Kash, K. M., Holland, J. C., Osborne, M. P., & Miller, D. G. (1995). Psychological distress in women with a familial risk of breast cancer. Psycho-Oncology, 4(2), 133-141.

Van Manen, M. (1990). Beyond assumptions: Shifting the limits of action research. *Theory into practice*, *29*(3), 152-157.

Van Ryn, M., Sanders, S., Kahn, K., Van Houtven, C., Griffin, J. M., Martin, M., ... & Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue?. Psycho-oncology, 20(1), 44-52.

Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., ... & Holland, F. (2014). The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. The qualitative report, 19(24), 1-15.

Watson, W. H. (2012). Family systems.

Watson, W. H., & Enns, J. T. (2012). Encyclopedia of human behavior. Family systems, 184-193.
Wayment, H. A., & Vierthaler, J. (2002). Attachment style and bereavement reactions. Journal of Loss &Trauma, 7(2), 129-149.

Weiss, D. S., & Marmar, C. R. (1997). The Impact of Event Scale—Revised. In J. P. Wilson & T. M. Keane (Eds.), *Assessing psychological trauma and PTSD* (pp. 399–411). The Guilford Press.

Wellisch, D. K., Gritz, E. R., Schain, W., Wang, H. J., & Siau, J. (1992). Psychological functioning of daughters of breast cancer patients: Part II: Characterizing the distressed daughter of the breast cancer patient. Psychosomatics, 33(2), 171-179.

Wikgren, M. (2005). Critical realism as a philosophy and social theory in information science?. Journal of documentation, 61(1), 11-22.

Willig, C. (2001). Introducing qualitative research in psychology. Buckingham. Open University Press. Woolcock, M., & Narayan, D.(2000). Social capital: Implications for Development Theory, Research, and Policy. World Bank Research Observer, 152, 225-249.

Willig, C. (2008) Introducing qualitative research in psychology (2nd ed). Maidenhead: McGraw Hill Open University Press.

Willig, C. (2012). Perspectives on epistemological bases for qualitative research. In H. Cooper (Ed.), APA handbook of research methods in psychology: Vol 1. Foundations, planning, measures and psychometrics (pp. 5-21). American Psychological Association.

Willig, C. (2013). Introducing qualitative research in psychology. McGraw-Hill Education (UK).

Wilson, K. G., Scott, J. F., Graham, I. D., Kozak, J. F., Chater, S., Viola, R. A., ... & Curran, D. (2000). Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. Archives of Internal Medicine, 160(16), 2454-2460.

World Health Organization. (2016). *International statistical classification of diseases and related health problems* (10th ed.). https://icd.who.int/browse10/2016/en
World Health Organization. (2013). WHO report on the global tobacco epidemic, 2013: enforcing bans on tobacco advertising, promotion and sponsorship. World Health Organization.

Yardley, L. (2000). Dilemmas in qualitative health research. Psychology and health, 15(2), 215-228.

Zakowski, S. G., Valdimarsdottir, H. B., Bovbjerg, D. H., Borgen, P., Holland, J., Kash, K., ... & Van Zee, K. (1997). Predictors of intrusive thoughts and avoidance in women with family histories of breast cancer. Annals of behavioral medicine, 19(4), 362-369.

Zakowski, S. G., Valdimarsdottir, H. B., & Bovbjerg, D. H. (2001). Emotional expressivity and intrusive cognitions in women with family histories of breast cancer: Application of a cognitive processing model. British Journal of Health Psychology, 6(2), 151-165.

Appendices

Appendix 1 – Recruitment advert/poster

Department of Psychology
City University London

PARTICIPANTS NEEDED FOR RESEARCH EXPLORING THE EXPERIENCE OF INDIVIDUALS WHO HAVE A PARENT WITH CANCER

We are looking for volunteers to take part in a study that will aim to explore the experience having a parent with cancer.

The following is the criteria:

Has either of your parent been diagnosed with cancer in the last 5 years?

Are you aged between 23- 35?

Are you open/willing to share your experiences?

Interested individual must email and arrange a screening appointment with the researcher, to check eligibility

The study will require you to attend a semi-structured interview, at City University of London. The interview will take approximately 60 minutes.

Note that all participant data will be anonymised.

For more information about this study, or to take part,
please contact:
Aslihan Apat, or Dr.Trudi Edginton
Psychology Department
at
Email: *Aslihan.apat@city.ac.uk*

This study has been reviewed by, and received ethics clearance through the Research Ethics Committee, City University London. Ethics code:

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on 020 7040 3040 or via email: Anna.Ramberg.1@city.ac.uk

Appendix 2 – Information sheet

Title of study: The experience of adult individuals who have a parent with cancer

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this research is to gain information and an in-depth understanding of the subjective experiences of adult individuals who have a parent with cancer. This research is being conducted as part of a Doctorate project. The participants are asked to attend a single interview, which is expected to last approximately 60 minutes.

Who is recruited? / Why have I been invited?

Altogether 8 participants meeting the inclusion criteria will be recruited. The inclusion criteria is as follows: to have experienced parental cancer in the last 5 years, the parent to be alive and be aged 23-35. Individuals that have a psychiatric and neurological diagnosis, or is taking centrally acting medication and or is experiencing bereavement, will not be recruited to the study, as these factors may significantly affect their experiences.

Do I have to take part?

Participation in this research is entirely voluntary. You can withdraw at any time, and will not be penalised or put at any disadvantage for your decision in any way.

What will happen if I take part?

- The participants will need to attend a single interview for approximately 45 minutes
- The research will take place in private room at City University, London

What do I have to do?

Participants are expected to attend a semi-structured interview, which is expected to take about 60 minutes. The interview will be held in a private room at City University of London campuses.

What are the possible disadvantages and risks of taking part?

There are no foreseen dangers or disadvantages of taking part in this study. However, the research area under investigation could be a sensitive topic, and individuals may experience psychological arousal or discomfort. In such cases, the interview will be terminated if the participants do not wish to continue.

What are the possible benefits of taking part?
It is possible that the information/findings gained from this research will inform future research and lead to the development of tailored support systems for individuals experiencing parental cancer. The possible benefits of taking part in this study are subjective and may vary for different individuals. Individuals that participate may find that the interview process is soothing and therapeutic. It may give them an opportunity to process their inner experiences and enrich their understanding of it.

Will my taking part in the study be kept confidential?

- The data will be accessible to the researcher and supervisor, and after it is anonymised it may be published and therefore will be visible to the public
- The interviews will be audio recorded, to ensure no content is lost
- The data will be kept for 10+ years after publication
- During the interviews if any signs of abuse, harm to self or others are identified/noticed, this cannot be kept confidential. The supervisor and possibly GP's may be informed.
- The records will be locked in a cabinet at City, University of London
- If the project is abandoned before completion, the data will be destroyed

What will happen to the results of the research study?
The results and the study is part of a Doctoral thesis, and may be published in the future. Individuals can request to see their data/transcripts before it is published.

What will happen if I don't want to carry on with the study?
Participation is entirely voluntary, and participants could withdraw from the study when they wish to. The data could be withdrawn from the study until 6 weeks after it has been collected, as the analysis would have been started.

What if there is a problem?
Please contact one of the researchers
Aslihan Apat
No: 07593169708
Email: Aslihan.apat@city.ac.uk

Or
Dr Trudi Edginton
Email: Trudi.Edginton@city.ac.uk

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *The experience of having a parent with cancer: An Interpretative Phenomenological Analysis.*

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214

City University London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by City University London, Psychology Department, Research Ethics Committee,

Further information and contact details
[Trudi.Edginton@city.ac.uk]

Thank you for taking the time to read this information sheet.

Appendix 3 – Resource list of counselling services and help-lines

The Samaritans- Emotional support on the phone 24 hours/day and 365 days/year
08457 90 90 90
www.samaritans.org.uk

Saneline & Sanemail- Helpline offering on-going emotional and crisis support, information on local mental health services and treatments
0845 767 8000
http://www.sane.org.uk

CLASP (Counselling, Life Advice and Suicide Prevention) - Provides practical support via a national emergency helpline for those in despair or contemplating suicide.
020 3600 3601
http://www.claspcharity.com

SLAM NHS and Community Mental Health Team Provides extensive information on all NHS services available through their website Service Finder, including local community mental health teams
0800 731 2864
http://www.slam.nhs.uk/ourservices/

Cruse Bereavement Care is here to support you after the death of someone close
0844 477 9400
http://www.cruse.org.uk/

MIND Lambeth & Southwark - Provides extensive information on any local mental health services
020 7501 9203
http://lambethandsouthwarkmind.org.uk/

Waterloo Community Counselling - Low cost Individual and couple counselling in English and many other languages.
020 7928 3462
http://www.waterloocc.co.uk/

Macmillan Cancer Support
0800 808 0000
https://www.macmillan.org.uk/

Appendix 4 – Interview guide and questions

Semi-structured Interview Schedule

You have indicated that you are or have experienced having a parent with cancer within the last 5 years, and I will be asking you a series of questions. We will start this interview, when you feel ready. At any point in the interview, if you experience psychological arousal, and may need a break or wish to terminate the interview, please let me know.

When they learned about it

- Can you tell me about the first time you found out about that your parent's diagnosis?
    - What do you remember about that day?
    - How was that like for you, do you recall how you felt?
    - Can you recall your state of mind before the diagnosis?

Perception of Parents illness

- What is the situation now?
    - How does that feel for you?
    - Is it something you think about often?
    - Is it something that is spoken about in the family?

- How do you think your parent's cancer has changed the way you see them?
    - How does that feel for you?

Perception of self and life

- How do you think the experience is affecting you or has affected you psychologically?
    - Has it impacted the way you see yourself
    - Has it impacted the way you live or experience your life

- How do you think it affects your own daily life?
    - At work?
    - At University?
    - At home?
    - Family/friends?
    - Have you had to make any changes?

Coping

- How do you feel you are coping?
    - What is helping you deal with this experience?

- How do you feel your parent is coping?
    - What do you think is helping them cope with this experience?

Relationships

- What sort of impact do you think this experience has had on the family?
    - Has it changed the family communication?

  - Has it impacted the way you see your family?

- How has your relationship with both of your parent changed, if it did?
  - How is this different from before?
  - How is that for you that the relationship is like that?

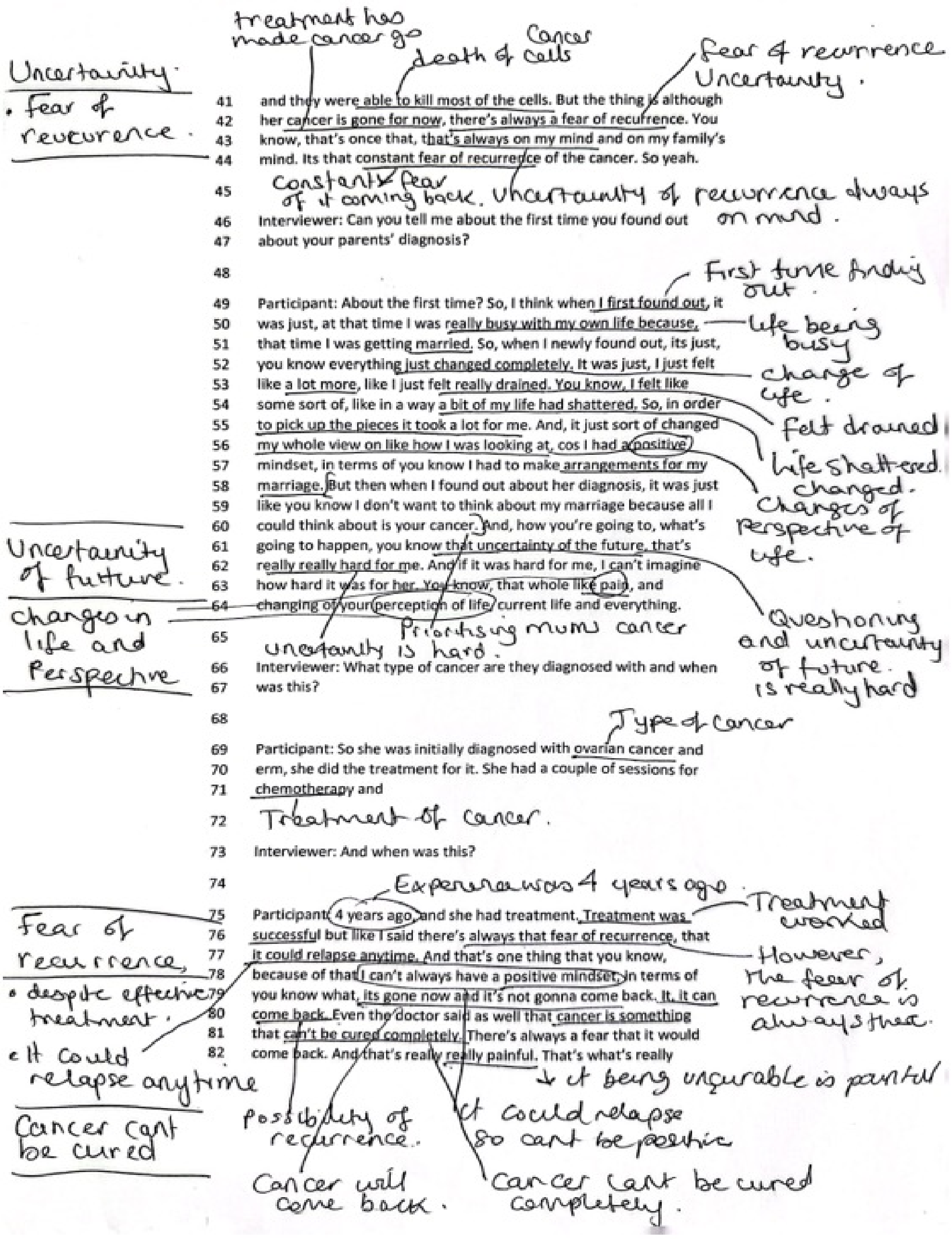
- How has your relationship with others (friends, family) changed?
  - How is this different from before?
  - How is that for you that the relationships are like that?

- Is there anything you would like to add?

If the interviewees do not share the type of cancer their parent has or has had in the last 5 years with during the interview, they will be asked at the end of the interview with the following question:

- Tell me about the type of cancer your parent has or had in the last 5 years.

Appendix 5 – Transcript example of the analytical process



Uncertainity.
- Fear of reucurence.

treatment has made cancer go

death of cancer cells

fear of recurrence Uncertainty.

and they were able to kill most of the cells. But the thing is although her cancer is gone for now, there's always a fear of recurrence. You know, that's once that, that's always on my mind and on my family's mind. Its that constant fear of recurrence of the cancer. So yeah.

constant fear of it coming back. Uncertainty of recurrence always on mind.

Interviewer: Can you tell me about the first time you found out about your parents' diagnosis?

First time finding out.

Participant: About the first time? So, I think when I first found out, it was just, at that time I was really busy with my own life because, that time I was getting married. So, when I newly found out, its just, you know everything just changed completely. It was just, I just felt like a lot more, like I just felt really drained. You know, I felt like some sort of, like in a way a bit of my life had shattered. So, in order to pick up the pieces it took a lot for me. And, it just sort of changed my whole view on like how I was looking at, cos I had a positive mindset, in terms of you know I had to make arrangements for my marriage. But then when I found out about her diagnosis, it was just like you know I don't want to think about my marriage because all I could think about is your cancer. And, how you're going to, what's going to happen, you know that uncertainty of the future, that's really really hard for me. And if it was hard for me, I can't imagine how hard it was for her. You know, that whole like pain, and changing of your perception of life, current life and everything.

life being busy

change of life.

Felt drained

life shattered.

changed.

Changes of perspective of life.

Uncertainity of future.

changes in life and perspective

Priortising mums cancer

uncertainty is hard.

Questioning and uncertainty of future. is really hard

Interviewer: What type of cancer are they diagnosed with and when was this?

Type of cancer

Participant: So she was initially diagnosed with ovarian cancer and erm, she did the treatment for it. She had a couple of sessions for chemotherapy and

Treatment of cancer.

Interviewer: And when was this?

Experience was 4 years ago.

Participant: 4 years ago, and she had treatment. Treatment was successful but like I said there's always that fear of recurrence, that it could relapse anytime. And that's one thing that you know, because of that I can't always have a positive mindset, in terms of you know what, its gone now and it's not gonna come back. It, it can come back. Even the doctor said as well that cancer is something that can't be cured completely. There's always a fear that it would come back. And that's really really painful. That's what's really

Treatment worked

However, the fear of recurrence is always there.

Fear of recurrence,
- despite effective treatment.
- It could relapse anytime

Cancer cant be cured

+ it being uncurable is painful

possibility of recurrence.

it could relapse so cant be positive

Cancer will come back.

Cancer cant be cured completely.

Appendix 6 - Ethics application

Psychology Department Standard Ethics Application Form: Undergraduate, Taught Masters and Professional Doctorate Students

This form should be completed in full. Please ensure you include the accompanying documentation listed in question 19.

Does your research involve any of the following? ***For each item, please place a 'x' in the appropriate column***	**Yes**	**No**
Persons under the age of 18 *(If yes, please refer to the Working with Children guidelines and include a copy of your DBS)*		x
Vulnerable adults (e.g. with psychological difficulties) *(If yes, please include a copy of your DBS where applicable)*		x
Use of deception *(If yes, please refer to the Use of Deception guidelines)*		X
Questions about topics that are potentially very sensitive *(Such as participants' sexual behaviour, their legal or political behaviour; their experience of violence)*		X
Potential for 'labelling' by the researcher or participant (e.g. 'I am stupid')		X
Potential for psychological stress, anxiety, humiliation or pain	X	
Questions about illegal activities		X
Invasive interventions that would not normally be encountered in everyday life (e.g. vigorous exercise, administration of drugs)		X
Potential for adverse impact on employment or social standing		X
The collection of human tissue, blood or other biological samples		X
Access to potentially sensitive data via a third party (e.g. employee data)		X
Access to personal records or confidential information		X
Anything else that means it has more than a minimal risk of physical or psychological harm, discomfort or stress to participants.		X

If you answered 'no' to all the above questions your application may be eligible for light touch review. You should send your application to your supervisor who will approve it and send it to a second reviewer. Once the second reviewer has approved your application they will submit it to psychology.ethics@city.ac.uk and you will be issued with an ethics approval code. You cannot start your research until you have received this code.

If you answered 'yes' to any of the questions, your application is NOT eligible for light touch review and will need to be reviewed at the next Psychology Department Research Ethics Committee meeting**.** You should send your application to your supervisor who will approve it and send it to psychology.ethics@city.ac.uk. The committee meetings take place on the first Wednesday of every month (with the exception of January and August). Your application should be submitted at least 2 weeks in advance of the meeting you would like it considered at. We aim to send you a response within 7 days. Note that you may be asked to revise and resubmit your application so should ensure you allow for sufficient time when scheduling your research. Once your application has been approved you will be issued with an ethics approval code. You cannot start your research until you have received this code.

Which of the following describes the main applicant? ***Please place a 'x' in the appropriate space***	
Undergraduate student	
Taught postgraduate student	
Professional doctorate student	x
Research student	
Staff (applying for own research)	
Staff (applying for research conducted as part of a lab class)	

1. Name of applicant(s). (All supervisors should also be named as applicants.)
Aslihan Apat (Researcher) Dr.Trudi Edginton (Supervisor)
2. Email(s).
Aslihan.apat@city.ac.uk Trudi.Edginton@city.ac.uk
3. Project title.
The experience of adult individuals who have a parent with cancer: An Interpretive Phenomenological Analysis
4. Provide a lay summary of the background and aims of the research. (No more than 400 words.)
There are more than 200 types of cancer and every two minutes someone in the UK is diagnosed with Cancer. The most common types of cancer in the UK are breast cancer (15%), prostate cancer (13%), lung cancer (13%) and bowel cancer (11%) (Cancer Research UK, 2014). Cancer is a disease that not only effects the individual on a physical and psychological level, it also has the potential to impact psychological wellbeing in family members (Kim &Given, 2008).To date, studies have mainly explored the impact of having a parent with cancer on young children and adolescent, whilst research exploring the

experience of who have a parent with cancer is minimal (Mosher & Danoff-Burg, 2005). The literature reveals that having a parent with cancer may have a significant psychological impact, causing serious emotional distress (Compas et al, 1994), as many adult children become their parent's primary caregiver, providing social, emotional and practical support (Ferrell, Ferrell, Rhiner& Grant, 1990). In addition, these adults may also have their own families, a factor that would contribute to greater responsibilities, and higher levels of psychological distress (Brody, 1981). It is clear that having a parent with cancer is a highly complex and individual experience that will be influenced by many factors including the type of cancer, treatment options, prognosis, coping styles, care needs and family relationships (Texeira, 2013).

An extensive review of the literature published since 1990, demonstrated that a "sizeable minority" of adult children of cancer patients experience psychological distress, including anxiety, depression and PTSD (Mosher &Danoff-Burg, 2005). However, it is also acknowledged that some individuals could report positive experiences such as improved family relationships and personal growth (Thornton, 2002). The majority of the findings in this area rely on quantitative approaches and tools such as questionnaires, which cannot capture the richness of individual experience that is known to be impacted by many different factors. As such, a qualitative approach that can explore the subjective experience of adults with a parent who has cancer in more depth will add to our understanding of individual experiences.

The aim of this research study is to explore and gain a more nuanced understanding of the unique and widely varying experience of adult individuals who have a parent with cancer. The analysis of the subjective data will inform support programmes, tailored interventions and future research to address the needs of this group.

5. Provide a summary of the design and methodology.

The following research will employ Interpretive Phenomenological Analysis (IPA) which is a qualitative method that aims to study how people perceive an experience, and particularly how they make sense of their lived experiences (Langdridge, 2007). The theoretical frameworks underpinning the epistemological stance and research methodology of IPA are 'phenomenology', 'hermeneutics' and 'idiography' (Shinebourne, 2011). The researcher's own worldviews and or experiences play a significant role when interpreting the participant's experiences, which Smith & Osborn (2003) refer to as double hermeneutic. In other words, interpretation (hermeneutics) is a necessary part of phenomenology (Shinebourne, 2011) and IPA (Willig, 2013). Furthermore, IPA is an idiographic approach, which aims to elicit detailed information about the subjective experience of a particular group experiencing a specific phenomenon (Smith et al, 2009). It is clear that IPA is an appropriate and workable methodology to explore the subjective experience of having a parent with cancer (specific phenomenon) amongst adult children (specific group). In addition, the aim of this analysis is to establish an in-depth examination of each case, cautiously exploring differences and similarities, to produce detailed accounts of patterns of meaning for participants reflecting on a shared experience. Therefore, given the time consuming nature of IPA analysis, Eight participants will be ideal to capture the experience of adult children who have a parent with cancer effectively.

6. Provide details of all the methods of data collection you will employ (e.g., questionnaires, reaction times, skin conductance, audio-recorded interviews).

The data will be gathered via semi-structured interviews, which allows each individual to share their experiences through verbal and conscious descriptions. Semi-structured interviews will help the interviewer maintain consistency throughout the interviews while, also offering flexibility (Landridge, 2007). The interview will consist of open-ended questions and the researcher will avoid using leading questions (Smith, 2009), which will allow participants to express their subjective experience with minimal researcher impact. The interviews are expected to be around 60 minutes and will be recorded by a digital audio recorder. The interviews will be held in a private room, at City University campuses, depending on availability and proximity to the participants. The interview questions will be designed to explore participant's experience of having a parent with cancer, and how they make sense of the experience. The initial questions will be designed to gain information about the feelings experienced during the initial diagnosis process and the present time. In addition, questions specifically exploring experiences relating to the participants perception of their self, parent, family and relationships will be included (See appendix 1). The researcher will conduct the interviews in a professional, warm and empathetic manner, providing a safe and supportive environment.

7. Is there any possibility of a participant disclosing any issues of concern during the course of the research? (e.g. emotional, psychological, health or educational.) Is there any possibility of the researcher identifying such issues? If so, please describe the procedures that are in place for the appropriate referral of the participant.

Although the aim is to recruit participants that do not appear to have mental health difficulties or disorders that may make them vulnerable to significant psychological arousal. It is possible that participants will discuss issues that are emotional and individuals may experience an understandable and expected degree of psychological distress regarding their experience of having a parent with cancer. The researcher is a trainee Counselling Psychologist who has experience of working with clients who report emotional distress and recognising early signs of emotional distress. Any participants who experience distress will be asked if they are happy to continue with the interview schedule and all participants will be signposted to available support services and provided with resources outlining local charities and organisations that offer psychological support (see appendix 2). Participants will be made aware that they have the right to terminate the interview at any time. Participants will be offered a time to speak to the interviewer before they leave. If the interview is terminated, the supervisor will be informed immediately to ensure that appropriate help and referrals are made.

8. Details of participants (e.g. age, gender, exclusion/inclusion criteria). Please justify any exclusion criteria.

For the purposes of this study, Eight participants will be recruited, which is the commonly accepted sample size in IPA studies, given the complexity of analysing human phenomena (Smith, 2009; Landridge, 2007).

Individuals that are interested will be recruited to the study subject to meeting the inclusion criteria. The participants need to have experienced having a parent with cancer in the last 5 years, to avoid recall being affected by memory decay, as the possibility of forgetting is known to increase after 4 to 5 years of the experience (Cansino, 2009). In addition, as the study is aiming to gain an insight in to having a parent with cancer and not the process of bereavement, the ill parent must be alive. Furthermore, in an aim to achieve a homogenous sample, individuals between the ages of 23 to 35 will be recruited, as the experience of having an ill parent may vary significantly in different stages of life. For instance, adults who have a parent with cancer may be more likely to be involved in their parent's care (Ferrel, Ferrel, Rhiner, Grant, 1990), which may be an element that children and adolescence are less likely to experience. In addition, facing the possibility of losing a parent in different stages of life could also be a distinctive experience in itself. An individual who faces the possibility of losing a parent at a young phase of their life may have a different experience to an individual who is older and has an elderly parent that is ill. This research is interested in gaining the subjective experiences of young adults who experience having a parent with cancer at earlier stages of adult life.

Participants are welcomed from any ethnic, cultural, religious and social background or sexual orientation. All participants are required to be able to communicate in English clearly, to ensure information is conveyed correctly. There will be no constraints regarding type and stage of diagnosis of the parent's cancer, as the research is interested in exploring the subjective perception of each individual, rather than the wider population.

On the other hand, exclusion criteria has been carefully considered and the following decisions were made to make sure a homogenous sample and a safe environment is achieved. The exclusion criteria is that individuals who has a psychiatric and or neurological diagnosis, and or is taking centrally acting medication (Prescribed and or drugs) will not be recruited to the study. In addition, individuals who have recently experienced bereavement will also not be recruited to the study. However, if a participant loses a parent between recruitment and interviews, they will not be excluded from the study, unless they requested to be excluded. Firstly, these factors could interfere and influence the experience of an individual, and a homogenous sample may not be achieved. For instance, the study is not aiming to explore the experience of loosing a parent, it is rather interested in gaining insight in to the experience of having a parent who is alive and has cancer. Secondly, although psychological distress is not anticipated, individuals that experience the highlighted exclusion criteria may be at a higher risk of experiencing significant distress.

Indivdiuals excluded from the study will be signposted to sources of mental health, and will be provided a document that contains all the sources they could access (See appendix). They will also be given an opportunity to discuss their feelings with the researcher.

9. How will participants be selected and recruited? Who will select and recruit participants?

Recruitment method

All participants will be recruited via purposive criterion sampling (Polkinghorne, 2005), since the research employs an idiographic approach and aims to explore a specific phenomenon experienced by a specific population (Smith, 2009). To recruit participants, advertisement posters will be put around City University campuses (See appendix 3).

Screening & Briefing

The advertisement poster will highlight the requirement for a screening and briefing before any individual is recruited to the study. The researchers email will be provided on the poster and individuals interested in the study, will be instructed to arrange a face-to-face meeting or a phone meeting with the researcher. This is essential to ensure that participants meeting the inclusion criteria is selected carefully.

During this screening the following questions will be directed:
- Are you between the ages of 23-35?
- Has your parent been diagnosed with cancer over the last 5 years?
- Do you have any neurological or psychiatric diagnosis?
- Are you under the care of a psychiatrist?
- Are you currently on any centrally acting medication (prescriptions or drugs)?

Participants that meet with the inclusion and exclusion criteria will be recruited to the study by the researcher. Participants will be briefed and given the opportunity to ask any questions they may have relating to the research and its process. Following this, they will be given or sent an information sheet. Once they were happy to participate in the study, a date for the interview will be set.

10. Will participants receive any incentives for taking part? (Please provide details of these and justify their type and amount.)

Participants will not receive any incentives or pressure to take part in the study. Participation is voluntary.

11. Will informed consent be obtained from all participants? If not, please provide a justification. (Note that a copy of your consent form should be included with your application, see question 19.)

An informed consent will be obtained from all participants (see appendix 4).

12. How will you brief and debrief participants? (Note that copies of your information sheet and debrief should be included with your application, see question 19.)

Participants will be briefed and debriefed verbally. All participants will be given an information sheet (see appendix 5) and debrief sheet (see appendix 6) to read and take away with them. The participants will be given time to read the information and ask any questions.

13. Location of data collection. (Please describe exactly where data collection will take place.)

Data will be collected at private rooms booked at City University campuses.

13a. Is any part of your research taking place outside England/Wales?

No	X	
Yes		If 'yes', please describe how you have identified and complied with all local requirements concerning ethical approval and research governance.

13b. Is any part of your research taking place <u>outside</u> the University buildings?

No	X	
Yes		If 'yes', please submit a risk assessment with your application or explain how you have addressed risks.

13c. Is any part of your research taking place <u>within</u> the University buildings?

No		
Yes	X	If ‘yes’, please ensure you have familiarised yourself with relevant risk assessments available on Moodle.

14. What potential risks to the participants do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.

Participants will be selected carefully, and those that appear high risk or vulnerable will not be recruited to the study. However, the topic under investigation could be sensitive for some individuals and cause emotional distress. If the level of emotional experience is too distressing the study will be terminated and the supervisor will be informed immediately, to gain appropriate guidance/support.

Also, all participants will be provided with a handout of resources, consisting of details of charities and community services that offer psychological support (see appendix 2).

Participant data will be anonymised. However, due to the nature of qualitative research, complete confidentiality regarding the transcripts cannot be guaranteed. Participants will be informed and invited to see their data, before it is published, on their request.

15. What potential risks to the researchers do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.

The interviews will take place in a private room at City University campuses to ensure safety both to the researcher and participants. Additionally, the researcher will work closely with the supervisor at all times to make sure they are working ethically and safely. There are no risks to the researcher that are foreseen.

16. What methods will you use to ensure participants’ confidentiality and anonymity? (Please note that consent forms should always be kept in a separate folder to data and should NOT include participant numbers.)

Please place an ‘X’ in all appropriate spaces

Complete anonymity of participants (i.e. researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification.)	
Anonymised sample or data (i.e. an *irreversible* process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.)	

De-identified samples or data (i.e. a *reversible* process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location.)	x
Participants being referred to by pseudonym in any publication arising from the research	x
Any other method of protecting the privacy of participants (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only.) ***Please provide further details below.***	x
Before data/quotations are published, the participants may see them on their request.	

17. Which of the following methods of data storage will you employ?	
Please place an 'X' in all appropriate spaces	
Data will be kept in a locked filing cabinet	x
Data and identifiers will be kept in separate, locked filing cabinets	x
Access to computer files will be available by password only	x
Hard data storage at City University London	x
Hard data storage at another site. *Please provide further details below.*	

18. Who will have access to the data?	
Please place an 'X' in the appropriate space	
Only researchers named in this application form	x
People other than those named in this application form. *Please provide further details below of who will have access and for what purpose.*	
The full data will be accessible to the researchers named on this application. However, post publication, quotations from the data will be accessible to the public.	

19. Attachments checklist. *Please ensure you have referred to the Psychology Department templates when producing these items. These can be found in the Research Ethics page on Moodle.		
Please place an 'X' in all appropriate spaces		
	Attached	**Not applicable**
***Text for study advertisement**	x	
***Participant information sheet**	x	
***Participant consent form**	x	
Questionnaires to be employed	x	
Debrief	x	

Copy of DBS		
Risk assessment	x	
Others (interview guide and questions)	x	

20. Information for insurance purposes. **(a) Please provide a <u>brief</u> abstract describing the project**		
This research aims to explore the subjective experience of adult individuals who has a parent diagnosed with cancer. A qualitative approach will be employed, and the data will be analysed via Interpretive Phenomenological Analysis, which aims to explore the subjective experience of individuals and how they make sense of their experience (Landridge, 2007). The data will be gathered via individual semi-structured interviews. The interview questions will focus primarily on the participant's perception about their parent's cancer, and the experience of their relationships, responsibilities and mental health functioning since the diagnosis. Six participants will be recruited via purposive sampling, as the research aims to explore a specific phenomenon experienced by a specific individual.		
Please place an 'X' in all appropriate spaces		
(b) Does the research involve any of the following:	**Yes**	**No**
Children under the age of 5 years?		x
Clinical trials / intervention testing?		x
Over 500 participants?		x
(c) Are you specifically recruiting pregnant women?		x
(d) <u>Excluding</u> information collected via questionnaires (either paper based or online), is any part of the research taking place outside the UK?		x

If you have answered ‘no’ to all the above questions, please go to section 21.

If you have answered ‘yes’ to any of the above questions you will need to check that the university’s insurance will cover your research. You should do this by submitting this application toinsurance@city.ac.uk, before applying for ethics approval. Please initial below to confirm that you have done this.

I have received confirmation that this research will be covered by the university’s insurance.

Name …………………………………………… Date……………………………

21. Information for reporting purposes.		
Please place an ‘X’ in all appropriate spaces		
(a) Does the research involve any of the following:	**Yes**	**No**
Persons under the age of 18 years?		x
Vulnerable adults?		x
Participant recruitment outside England and Wales?		x
(b) Has the research received external funding?		x

22. Final checks. Before submitting your application, please confirm the following, noting that **your application may be returned to you without review** if the committee feels these requirements have not been met.	
Please confirm each of the statements below by placing an ‘X’ in the appropriate space	
There are no discrepancies in the information contained in the different sections of the application form and in the materials for participants.	x
There is sufficient information regarding study procedures and materials to enable proper ethical review.	x
The application form and materials for participants have been checked for grammatical errors and clarity of expression.	x
The materials for participants have been checked for typos.	x

23. Declarations by applicant(s)	
Please confirm each of the statements below by placing an 'X' in the appropriate space	
I certify that to the best of my knowledge the information given above, together with accompanying information, is complete and correct.	x
I accept the responsibility for the conduct of the procedures set out in the attached application.	x
I have attempted to identify all risks related to the research that may arise in conducting the project.	x
I understand that **no** research work involving human participants or data can commence until ethical approval has been given.	x

	Signature (Please type name)	**Date**
Student(s)	ASLIHAN APAT	11/07/2017
Supervisor	TRUDI EDGINTON	21/11/2017

Appendix 7: Ethics approval letter

Psychology Research Ethics Committee
School of Arts and Social Sciences
City University London
London EC1R 0JD

28 June 2018

Dear Aslihan and Trudi

Reference: PSYETH (P/F) 17/18 174

Project title: ***The experience of adult individuals who have a parent with cancer: An Interpretive Phenomenological Analysis***

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval
Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments
You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

(a) Recruit a new category of participants
(b) Change, or add to, the research method employed
(c) Collect additional types of data
(d) Change the researchers involved in the project

Adverse events
You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee (anna.ramberg.1@city.ac.uk), in the event of any of the following:

(a) Adverse events
(b) Breaches of confidentiality
(c) Safeguarding issues relating to children and vulnerable adults
(d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Jay Leighton

Ethics committee Secretary
Email: psycology.ethics@city.ac.uk

Sophie Lind

Chair
Email:Sophie.Lind.2@city.ac.uk

Appendix 8 – Informed consent

Title of Study: *The experience of adult individuals who has a parent with cancer*
Ethics approval code:

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher • allowing the interview to be audiotaped	
2.	This information will be held and processed for the following purpose(s): *'to explore the subjective experience of experiencing parental cancer'* I understand that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. The identifiable data will be shared with Supervisors at City University. This organisation has made a written agreement with the University to abide by the Data Protection Principles. I understand that the data will be kept locked up in a cabinet at City University. All identifying information will be anonymised by the use of codes, which will be done to protect my identity from being made public. I understand that I will be given a transcript of data concerning me, if I make such a request before it is included in the write-up of the research. I consent to the use of sections of the audiotapes in publications.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

______________________ ______________________________ ______________
Name of Participant Signature Date

______________________ ______________________________ ______________

Name of Researcher Signature Date

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix 9 – Debrief sheet

Adult individuals experience of having a parent with cancer

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it has finished we would like to tell you a bit more about it.

This research aims to explore the subjective, unique and complex experiences of adult individuals who have a parent diagnosed with cancer. Therefore, semi-structured interviews were conducted, and you were asked specific questions about your experience of having a parent with cancer.

If you feel psychologically aroused or distressed at any point, please refer to the 'support services resource' handout we have given you. The handout will provide contact details of possible services to access for help.

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Aslihan Apat
Email: Aslihan.apat@city.ac.uk

Trudi Edginton
Email: Trudi.Edginton@city.ac.uk

Ethics approval code:

End of part A – Research study

PART B: Journal Article

Young adults experience of caregiving for their parent with cancer: “A process of role transformation”

Intended journal of publication: European Journal of Oncology Nursing

Author: Aslihan Apat
School of Arts and Social sciences, Department of Psychology, City University of London,
London, UK

Abstract

Purpose: Majority of individuals diagnosed in the UK are 75 years old or over (Cancer research UK, 2018) and are therefore more likely to have children who are adults. These children also go on to play vital caregiving roles for their ill parent (De boer et al, 1999) However, little is known about their lived experiences, as qualitative research has fallen short. Therefore, the aim of this study is to explore young adults' experiences of having a parent with cancer.

Design/methodology/approach: This study employed a qualitative research design. Six participants who have experienced having a parent with cancer in the last 5 years were interviewed using semi-structured interviews. The data was analysed using Interpretative Phenomenological Analysis (IPA).

Findings: Using IPA, four superordinate themes and eleven subordinate themes emerged altogether. For the purposes of this paper the second superordinate theme "A process of role transformation" will be presented and discussed. This theme reflects the cycle of changes that occurred between the ill parent and their adult offspring.

Conclusion/Value: This study adds to our understanding of the process of parental cancer and what it is like for the young adults. It provides an insight into the changes the family faces, the difficulties and needs experienced as a caregiver and offspring. Therefore, this study provides guidance for future research and the development of interventions that could support this population in the best way possible.

Keywords: Young adults, adult-offspring caregivers, parental Cancer, caregiving.

Introduction

Research has shown that a life-threatening illness such as cancer can have significant impact on the ill individual, as well as their families (Finley, 2018). Cancer is a disease that affects the entire family, and that family members are "second-order patients" with unique needs (Arnaert, Gabos, Ballenas, & Rutledge, 2010). Family members are also crucial figures in the support and caregiving of cancer patients (Gilliss et al, 2019), impacting disease morbidity and mortality (De Boer et al, 1999). Unfortunately, despite the growing awareness of the interplay between the biological, social, and psychological processes in adaptation to psychical illnesses, the social context of illnesses, such as the experiences of cancer patient's family members, caregivers, and their young adults, continues to be understudied (Suls & Rothman, 2004).

Palliative care for cancer patients requires the dedicated help of caregivers alongside the support of care teams (Aranda & Hayman-White, 2001). They play a primary role in the cancer patient's symptom management, monitoring of treatment and disease progression, methods of transportation, and maintenance of medical equipment such as an IV (Given, Given & Kozachik, 2001). In addition, they play an important supportive role by aiding in personal care and providing emotional, financial, and spiritual support (Given et al., 2001). The caregiver may become responsible for certain former responsibilities that the cancer patient can no longer maintain due to his/her illness, and it is common for caregivers to suffer from anxiety and/or depression during the caregiving experience (Given et al., 2001). Caregivers are expected to provide complex care in the home with little preparation or support (Van Ryn et al, (2011). When the demands placed on caregivers exceed their resources, caregivers feel overwhelmed and report significant distress (Siegel, Ravies, Mor & Houts, 1991). It was reported that most of these caregivers are family members, primarily a spouse or an adult child (Stone & Kemper, 1989; Horowitz, 1985). However, young adults impacted by parental cancer has not been the focus of literature, as it was assumed that the impact was minimal (Northouse, 1994). This is a concern, as more than half of the individuals diagnosed with cancer are aged 75 and over (Cancer research UK, 2018). Therefore, those that are parents are more likely to have affected children that are adults. According to research, cancer will influence both the person with cancer and their family equally with significant burden from depression, physical health changes, declines in social functioning and reduction in quality of life (QoL) (Ferrell and Wittenberg, 2017; Dieperink et al., 2018). Caregivers of cancer patients (children or spouses) experienced negative effects to their day-to-day lives. For instance, during the caregiving period, participants had an average decrease in work productivity of 22.9% (Mazanec et al, 2011). The consequences of caregiving may include physical problems such as fatigue, sleep disturbances, loss of weight and appetite, headaches, and psychological distress including anxiety and depression (Romito et al., 2013; Rha et al., 2014, 2015). The various challenges caregivers face can impact their health and psychological wellbeing. Caregivers who have high distress also have changes in their immune system that can lead to flare-ups in auto-immune diseases, worsened glucose control in the body, and increased vulnerability to cardiovascular diseases (Rohleder, Marin, Ma, *et al, 2009*) These changes increase the likelihood that the caregiver's own health will suffer and, subsequently, hinder their capacity to provide care. In addition, distressed caregivers have more difficulty providing optimal patient care (Van Ryn et al, (2011) and administering medications to patients (Lau, Berman, Halpern, *et al, 2010).* Caregiving can impact all aspects of a caregiver's life and the cumulative impact of these stresses can diminish their ability or motivation to continue as a caregiver overtime (Seigel et al, 1991).

Caregiving is a very broad area, and everyone may be impacted differently, and various factors could influence this impact. Research suggests that a caregiver's individual characteristics such as their age, own health, and relationship to the patient are factors that could influence the impact of the caregiving experience (Given et al, 2004; Fried et al, 2005). Also, a sense of personal accomplishment is a factor that may positively impact the psychological distress related to caregiving (Hagedoorn, Sanderman & Buunk, 2002; Dumont et al, 2000). In addition, the patient's characteristics could also inform the psychological distress experienced by caregivers. For instance, the type of cancer and severity of symptoms were found to impact the level of stress experienced by caregivers (Given et al, 2004; Hodges, Humphris and Macfarlane, 2005). The demands of the caregiving, such as monitoring the patient's symptoms around the clock, administering medications, and coping with treatment side effects, were factors that contributed to physical and emotional exhaustion for caregivers (Blanchard et al., 1997, Porter et al., 2002). Other factors such as the availability of homecare (Sharpe et al, 2005), social support (Sharpe et al, 2005; Payne, Smith & Dean, 1999) and financial burden (Grunfeld et al, 2004) were found to impact caregiver experiences too. Parental illness has a significant impact on young adult’s lives and this impact may be subject to various factors. In addition, young adults also play vital roles in their ill parent’s life, from caregiving for them to adapting their parent roles. Therefore, it is vital for research to explore the experience of young adults impacted by parental cancer, to support them and their ill parents through this life-threatening journey of cancer.

Considering the research, caregivers and patients should be conceptualized as a unit rather than caregivers as individuals that are separate from patients (Bell and Wright, 2015; Coyne et al., 2017). In addition, considering interpersonal relationships and complexity of family networks when conducting research, developing interventions and supporting persons with cancer may be more useful and holistic (Illingworth et al., 2009).

In this paper, young adult’s experiences of parental cancer were explored. In gaining a deeper understanding of this experience, our aim was to

1. Further our understanding about this populations experience as explained by them

2. To identify the gaps in the literature and direct future research in ways that could increase our knowledge

3. And in turn, to help develop support for this population in the best ways possible, by developing interventions and treatment approaches or moderating psychological services.

Methodology

This study employed Interpretative Phenomenological Analysis (IPA) to explore and analyse how young adults experienced having a parent with cancer.

Data collection

The data was collected via six semi-structured interviews. Semi-structured interviews allow the participants to explore their experiences while at the same time honouring their status as having the experiential expertise for the phenomenon explored (Smith et al, 2009).

Procedure

Participants were recruited via purposive criterion sampling (Polkinghorne, 2005), since the research employed an idiographic approach and the aim was to explore a specific phenomenon experienced by a specific population (Smith et al, 2009). To recruit the participants, advertisement posters were put up around a London University (See appendix 3). Altogether six participants aged between 23-35 were recruited, who were selected based on meeting the inclusion criteria. The participants were required to have had experienced having a parent with cancer in the last 5 years. We chose to include those that experienced having a parent with cancer in the last 5 years, to avoid recall being affected by memory decay, as the possibility of forgetting is known to increase after 4 to 5 years of the experience (Cansino, 2009).

Table 1. Characteristics of participants.

PARTICIPANT	AGE RANGE	ETHNICITY	TYPE OF CANCER	THE PARENT WITH CANCER
Shirley (F)	**18 - 24**	**Black British**	**Ovarian cancer**	**Mother**
Maria (F)	**25 - 34**	**Asian**	**Ovarian cancer**	**Mother**
Dalia (F)	**25 - 34**	**Asian**	**Breast cancer**	**Mother**
Nyla (F)	**25 - 34**	**White**	**Skin cancer**	**Father**
Harry (M)	**25 - 34**	**White other**	**Urethral cancer**	**Mother**
Grace (F)	**25 - 34**	**Asian**	**Stomach cancer**	**Father**

Data analysis

The data analysis followed IPA guidelines as set by Smith, Flowers & Larkin (2009). Firstly, the interviews were transcribed. Secondly, all interviews were thoroughly read, while also listening to the audio recordings, paying attention to the tone of voice and how everything was expressed. Then, initial notes examining the language and content, were made (Smith et al, 2009). Afterwards, emergent themes were labelled and when a rich number of themes were identified, the connections between these themes were sought. These were clustered and the final superordinate and subthemes emerged.

Findings/Synthesis

Four superordinate themes and eleven subordinate themes emerged from the analysis (See. Table 1 for full list of themes). For the purposes of this article, the second superordinate theme "A process of role transformation" will be presented and analysed in greater detail. In exploring this theme, the aim is to understand the process from the onset of a parent's cancer, and how the changes in roles within the family evolve. It is valuable to understand this process to understand the changes that occurs for the ill parent and the family systems.

Table 1. Summary of Superordinate themes and sub-themes.

Superordinate Theme	Subthemes
1. Having to face cancer	1.1 Psychological Pain 1.2 Anxiety of uncertainty 1.2.3 Fear losing parent 1.2.4 Fear of own illness risk
2. A process of role transformation	2.1 Observing parents' deterioration 2.2 Adapting a parent mode 2.3 Putting self on hold
3. Coping through cancer	3.1 Invulnerable self 3.2 Estranged from others 3.3 A source of support
4. The positive growth	4.1 Stronger family bond 4.2 Desiring a healthier lifestyle 4.3 A better person

Theme: “A process of role transformation”

The theme “A process of role transformation” aims to capture the experience amongst the participants about the process of change that occurred after their parents’ diagnosis of cancer. It describes and reflects how the ill parent, the roles, responsibilities, and dynamics in the family have changed. Furthermore, this theme explores the changes and feelings the participants have experienced in their role as a child of a cancer patient, with particular focus on them becoming the caregiver and the consequent changes they have made in their lives, decisions, and responsibilities.

Having a parent with cancer brought together a lot of changes to the family, as well as the ill-parent. Often, the ill parent became needy due to their illness, and the adult child became involved fully or partially in their care. It also emerged that along with these changes and due to the caregiving responsibilities, young adults reported sacrificing from their own life and duties. They felt the need to make changes to their own priorities and day to day lives. This cycle was common amongst the participants and there was a domino effect. The parent’s change was leading to changes in the roles and responsibilities in the family and consequently the young adult became the caregiver. To reflect on this cycle experienced, the following three subthemes emerged: ‘observing parent’s deterioration’, ‘Adapting a parent mode, and ‘putting self on hold’.

Subtheme one: ‘Observing parent’s deterioration’

Changes in parents after the cancer diagnosis was a common topic that was expressed during the interviews. While some participants reflected seeing physical changes occurring due to cancer and the treatment process involved, other participants reflected on the changes in their own perception about their parents. Participants expressed that their parents after cancer became more vulnerable, needy, and weak. Observing these changes was highly distressing for the young adults. The subtheme: “Observing parents’ deterioration” aims to reflect this experience.

When describing the changes in her father, Grace uses the term “deteriorating”.

> **Grace:** It's basically you can see that person like deteriorating, in to like a little person. Like, a strong man, he was very like tall and built, he just turned in to like a little, like shrunk (Continues to cry while she speaks). (Page 9, 336 – 339.

Grace’s emphasis on her father’s changes shows that the changes that occurred in her father is visible and therefore, watching the impact cancer has on her parent is unavoidable. Cancer has taken away these traits from her father and has made him weak, causing her great upset.

Likewise, Shirley described the traits her mother held before cancer and described her mother as a “strong lady”.

> **Shirley:** Its, it’s very ermm, I, my mum she’s a very strong lady. She’s very strong and seeing her, melting. It’s very heart-breaking. Its, it’s very scary, it’s horrible……(Shirley - page 4, 117-122).

She used the term ‘melting’ to describe her mother’s change after cancer. This expression may reflect her experience of observing her mother gradually loose against cancer. She described her feelings of this experience as horrible and heart-breaking. As the changes in a parent with cancer can be physical, it may make the process feel unavoidable to think about. The physical changes in a parent that occurs after cancer means it keeps the experience at the forefront of the eye and therefore the mind. They are faced with having to watch cancer diminish their parent.

From a differing perspective, Harry also reflects up on the changes that his mother had in her attitudes and behaviour.

> **Harry:** … Secondly her actions are different, she’s always either sleeping or. I mean even when she’s with us, she doesn’t have the same energy no more. She doesn’t go out as much as before. I mean, she just spends a lot of time with her family, doesn’t do that. At the same time err, I think she craves more attention and love and caring. So, she’s always expecting for people to err, think about her and look after her. And she does get upset quiet easily than before. (Page 6, 221-229)

Harry highlights that his mother's actions have also changed after her cancer diagnosis. She has lost energy and is spending more time resting. He also reflects on the changes of her expectations and desire for attention and care. Cancer may be tiring her out and making her more needy. Being needy and having expectations from others may resemble a weaker or more vulnerable person for Harry. Therefore, cancer not only changes parents physically but the impact it has on their stance/ability as a parent also changes. Consequently, a parent becoming more needy, may take away the strong parent model that their children perceive of them.

However, Harry feels the need to express that he still thinks of his mother as a strong woman with a special character. There is clearly a dilemma in his expressions with regards to whether he sees his mother as weaker or not.

> **Harry:** I mean my mum has never changed in my eyes. She's always the same lady, because my mum is actually a very strong woman. And, she is still really strong and there. She still has the same place for me, like, as before. And this, this, this weakness, this illness has taken you know err, her strength away. But even though my mum is, really really. She has got a really strong and special character. (Page 6, 235-241)

It appears that Harry struggles to complete sentences when describing his mother and appears to have a desire to describe his mother as someone that is very strong. It comes across to me that Harry feels guilty when describing his mother as needy or weak. Each time he thinks of her in this way, he aims to reverse it by emphasising that she has not changed in his perception and refers to her as the same strong lady. It may be that he struggles to face the changes in his mother and tries to keep a perception of her that it less painful for him. Or Harry may feel that he is shaming his mother if he describes her as someone weak. Perhaps, describing her as 'stronger' makes him believe she is stronger and is a way of honouring her battle against cancer.

Subtheme two: ‘Adapting a Parent mode’

Most participants reported the multiple roles and added responsibilities they have had to take on since their parent’s diagnosis. The subtheme ‘Adapting a parent mode’ aims to reflect what the experience of caregiving for a parent with cancer was like. Furthermore, this theme explores how the added parent-like duties and responsibilities were experienced by the young adults.

An interesting similarity between some participants was that they used very similar sentences to reflect their experience. Shirley & Maria reflected feeling like they became the new parent, like the new mum of their ill parent.

> **Shirley:** At home, ermm, well, ermm. I’m the one who’s caring for my mum. So erm, whenever she needs to, I am the one who erm cleans her, I’m the one who, dresses her, I am the one who cooks, I’m the one who cleans. So, erm it’s like, it feels like I am the new mum. So, I, it ooh (tired voice). Its erm, I am the caregiver basically, I am the one who makes sure that the families all supported, all, they feel ok. I make sure that, their all ok. It’s hard for me as well, cos having everything on your shoulders is very difficult, it’s very tiering, it’s very stressful. (Shirley - page 8, 286-294)

The added responsibility and caregiving duties that Shirley has had to take on since her mother’s cancer diagnosis has made her feel like she is the “new mum”. She lists the duties she has had to take on and reflects that this is putting her under stress. Her mother’s cancer has taken away her mother’s role as a parent, and Shirley is feeling the need to replace that figure in the house, to maintain the family home. It comes across that replacing her mother is somewhat providing herself and the family with comfort, achieving normality and making them feel supported through the process.

Maria also emphasises that she is being her mother’s parent and explains the changes she has had to make to cater for this parent like role.

> **Maria:** So, in order to encourage her further, I have changed my diet as well. So, just so that it could erm, so I could support her with it as well. Yeah so, I guess because I was there for her as a supportive figure, its made me more responsible. So, my responsibilities in that sense have increased. I feel like although she’s my parent, in a way, I have to be her parent. So yeah, caregiving in term of me being her parent. I do play that caregiver role isn’t it. (Maria - page 12, 483- 495)

Maria feels the need to make changes to her life such as changing her diet, in an aim to change her mother’s diet too. She says that the added responsibilities that came with having to be the supportive figure for her mum, has made her feel like she must be the parent. The experience of having a parent with cancer changed the roles, adding more caregiving responsibilities to Maria. This change felt unavoidable for Maria, as she say’s “*I feel like although she’s my parent, in a way, I have to be her parent.*”. It is almost like Maria’s new role is set out for her and she must cater for it.

Dalia’s expressions reveal burden because of the caregiving too.

> **Dalia:** like I said I have responsibilities for myself and I cant even take care of myself cos of her. I have to be always there for her, care for her, speak for her, cook for her, clean for her. It's just really difficult for me at times. But then again, I cant do anything about it. I have to just accept the way she is. (Page 7, 284-288).

Dalia is frustrated and expresses not being able to take care for herself. The role demands and the duties she must cater for appears to have taken over all of Dalia’s time. She feels helpless and feels that her new role is unavoidable. She says, *“I have to just accept the way she is”.* Her use of tone and language suggests a possible degree of blame and frustration towards her mother for being needy and relying on Dalia. Her mother’s neediness is taking over Dalia’s life and impairing her ability to function as she normally would. Even though Dalia is an adult, she is not the parent, and may not be equipped to handle the psychological burden that this role brings.

Subtheme three: ‘Putting self on hold’

Other than taking on responsibilities, it appears that the experience of having a parent with cancer has led the participants to prioritise their ill parent and put themselves on hold. In other words, to cater for their new caregiving role, participants may have had to neglect their own needs. Some participants explained that they have put certain events or parts of their life on hold/pause due to their parent’s illness. They prioritised their ill parent and avoided doing chores or progress for themselves. For some engaging in activities for themselves felt wrong and made them feel guilty. It just felt right and safer to devote their time and energy to their ill parent. And for some the caregiving duties took over all their time and capacity. The subtheme ‘Putting self on hold’ aims to reflect this experience and explains experiences of the participants in detail.

For instance, Maria expresses having to put her marriage planning on hold:

> ***Maria:*** *And I had to put all my plans on hold as well because I just couldn’t go through with it, like planning my marriage and stuff at the time. (Maria - Page 3, 105-113)*

“I couldn’t go through with it” is the words Maria chose to use to reflect her feelings about getting married while her mother was experiencing cancer. Her use of language and tone of voice reflected feelings of upset, burden and guilt. It appeared that engaging in positive events such as marriage while her mother was suffering with cancer, made Maria feel like it was not feasible to go ahead with the marriage planning. In addition, it may have been an additional burden for Maria at a time that she was also not enjoying herself. Therefore, putting her own plans on hold may have been an easier decision to take both to avoid additional stress and feelings of guilt.

Furthermore, Shirley reflects sacrificing from her own plans and relationships in an aim to support her mother.

> **Shirley:** It has, I’ve, I’ve ermm, basically I’ve put that at the centre of my life, I don’t know if that makes sense. Its I’ve isolated myself from my friends. If I want to go shopping, I just first make sure that my mum is ok. Or I just ignore doing what I have to do. Ermm, at work sometimes I call in sick, to make sure my mum is ok, or I go to

> my mums appointments. Ermm, I've, I, though of applying for my masters, I've at the moment, I've decided not to, I've just put that. I wanted to ermm, I had so much stuff that I wanted to do. But now I, I don't, I, my mum is what's more important, so I want to make sure she is Ok, ermm. And then, yeah. (Shirley - page 7, 235-244)

Shirley has isolated herself from social relationships, has taken time off work, and decided not to pursue her education, as she prioritised her mother and the caregiving duties. Shirley says "*I had so much stuff that I wanted to do. But now I, I don't, I, my mum is what's more important, so I want to make sure she is Ok".* These expressions confirm that the experience of having a parent with cancer is very demanding and may change one's responsibilities, forcing them to priorities their parent and causing them to give up on some areas of their own life. They may lose their own desires and focus solely on their parent's wellbeing.

Similarly, Dalia also expresses that she had to sacrifice a lot from her life to give more to her mum.

> **Dalia:** So at home, it's her. Like, I am living her life. It's not me again. At home, at work, when Im with family and friends I am always thinking of her. I feel like that is not my life, like I am living the life of my mum. I feel responsible for her. I feel like maybe it's, it's not maybe, I always think that what if she's not going to be there tomorrow. What if something happens to her and I am not there for her. I feel like I have to be there for her all the time. Yeah, so I had to sacrifice a lot from my life to be able to give more to my mum. (Page 11, 442-450).

From Dalia's tone of voice and pace it came across that she felt anger when describing the process of having a parent with cancer. She explains feeling that her life was taken over by her mother's life. She also adds that the worry of not being around when something may happen to her mum, prevents her from going out. This fear makes her devote her life to her mother.

Harry reports finding a balance in socialising. This is different from how most other participants explained the changes that occurred in their lives.

> **Harry:** Yeah, I spend. I try to spend more time with my parents, my mum. So, I do spend less time socialising with friends and going out and etc. But, I do believe I have found the right balance. There is no point of me always being next to her, cos I got such a big family. I do try to spend as much time as I can with her, but at the same time yeah, I do go out and stuff as well. With my friends and like university and work and stuff. I do remember though, during my university times, at one point I did miss out on 2 to 3 weeks because my mum was in hospital for a long period of time. And it may have affected my exams… (page 12, 432 - 446)

It is interesting that Harry refers to a balance that he aims to achieve between spending time with his family and socialising. His need to find this balance is rooted in the experience of having a parent with cancer. He is making conscious decisions and considers trying to achieve a balance between his family and social life, which may have not been a priority if his mother did not have cancer. In addition, Harry did not refer to any caregiving duties. Nonetheless, Harry does report the impact of his mother's illness on his coursework and exams. However, he later adds that he has never applied to get extra time or re sit any components of his course.

> **Harry:** I never erm, I never used any of that. Because I just didn't wana feel guilty. I didn't want to seem like using her situation in my favour like. Err, that's, she's in a bad situation and I'm taking that and trying to make something else easier for myself. I never wanted to do that. (page 12, 454-462)

Although Harry believes that his performance at university may have been affected by his mother's condition, he made the conscious choice not to get support. Obtaining some sort of benefit made him feel guilty. Although he probably would have been eligible to re sit another time, he did not want to obtain any advantage from it. Therefore, having a parent with cancer has also caused harry to deprioritise his exams and success at university. This also shows that when a parent is ill, they become the centre and like the main character, that everything else forms around.

Discussion

In this chapter, my aim is to address the findings identified during the data analysis in relation to the wider theoretical and empirical context. The aim of this paper and the comparison with existing literature is to gain a greater understanding about young adult's experience of parental cancer, specifically focussing on the "A process of role transformation", in which they become their ill parents' primary caregiver.

A Process of role Transformation

In Superordinate theme "A process of role transformation" we have explored the changes that has occurred within the family, particularly for the adult child after a parent is diagnosed with cancer. I chose to refer to this theme as a process of role transformation, as the experiences that occurred were related to the changes that occurred in the shift of the roles and responsibilities between the ill parent and adult child. The findings revealed that the process started with the changes that occurred in the ill parent. These changes were both physical, emotional, and behavioural. The ill parent became weak, vulnerable, and needy. They required help with their day-to-day lives and someone to replace them within the home. Consequently, the adult offspring found themselves having to step in to cater for these needs and replace their parents' space. It appears that these changes occurred automatically and unavoidably. The adult offspring found themselves trying to provide care for their ill parent both physically and emotionally, as well as stepping in to keep the family and home going. However, in picking up these responsibilities and catering for the role of their parents, the adult offspring often neglected their own lives. They had to deprioritise their day-to-day tasks and or commitments, to cater for their parents one's. This sometimes made them feel like they were living someone else's life and resulted in feelings of burden and frustration.

Cancer can affect the ill person physically and psychologically. All participants reflected on the changes that they observed in their parents' post-cancer. Cancer took away their strong parent, and terms such as 'deteriorating' and 'melting' were used to express this change. Moreover, in the study by Almarza (2008), adult children also described how their parents deteriorated and changed. As treatment unfolded, an altered reality emerges when a strong father figure lies down fragile, despondent, and weak on a hospital bed. Their findings were based on experience of paternal cancer, and so the experiences that emerged amongst their participants' may not be the same for adults whose mother has cancer. In other words, the parent's gender may be a significant factor that impacts the experience of parental cancer for adults. In our study, the experiences of parental cancer related mainly to maternal cancer, and similar accounts were shared to those in Almarza (2008). Together these findings provide a more in-depth understanding of what it is like for adults experiencing parental cancer. It highlights novel understanding around how the phases of cancer can be a crucial factor in how difficult the experience could be. It also highlights that adult children will experience a perceptual change of their parent because of the treatment process. It appears that there is no research that has explored gender and gender roles of a parent with cancer, and how this may impact their adult child. Evidently, studies exploring maternal and paternal cancer can provide novel understanding that could be helpful to understand the difficulties and needs of this population.

In addition, observing changes in a parent with cancer was inevitable because the treatment side effects and physical changes was physically visible (Kangas et al, 2002). Therefore, it was a highly distressing and upsetting experience. In an earlier study by Texeira, (2013) findings suggested that children who perceived their parents as highly dependent showed more distress, higher PTSD, greater caregiving burden and less satisfaction with social support. Other studies have confirmed this finding, by reporting that depression and burden levels increase as patient's functional status declines (Grunfeld et al, 2004). It occurs that the higher levels of distress reported in some participants may be associated to their parents' level of functioning. Findings in this study have reflected that as cancer took away their parent's strength and ability, the young adults found themselves stepping in to cater for the roles of their parent. In other words, there level of responsibility and related difficulties increased as their parents' health declined.

Moreover, observing changes in their parents was extremely upsetting for patients and inconsistent with the perspective they held of their parent. The changes that occurred in the parent caused participants to experience a battle against their own perceptions. They experienced contrasting views about their mother/father. For instance, their parent was both the ill and weak women, and the strong and brave lady. Participants did not to want to change their perception of their parent. It was often difficult to accept that their parent had lost their strength and physically became weak because of cancer. It may be that accepting that cancer has changed their mother, was like accepting that their parent was dying, causing emotional disturbance. In addition, according to the attachment theory (Bowlby, 1982) seeing a parent become weak and needy is a threat to the attachment bond and the perceived secure base. The participants had a desire to continue describing their ill parent as strong, which may be a desperate attempt to avoid facing the loss of this secure base.

The contrasting views of the mother may be difficult to contain for their daughters as it may be contributing to their own self-representation. The theoretical perspective by Wellisch et al. (1992) suggests that the image of a sick and potentially dying mother might be integrated by the daughter into her own sense of self, along with the pre-existing image of an intact and well mother. These contrasting views of the mother, when fused with a daughter's nascent self-concept, may form the basis for the daughter's ultimate self-representation. In other words, individuals impacted by parental cancer may struggle to differentiate between themselves and their ill-parent. Therefore, the way they perceive their parent may also form the basis of how they perceive themselves. The findings from the present study contributes to this theoretical perspective. A participant reported feeling like she was living the life of her mother. She found it difficult to differentiate between her life and her mothers. The fusion of an ill parents and her healthy daughter's life implies that a daughter's self-image or self-concept may be impacted by her experience of her parent's cancer. This is a concern as it may lead young adults to develop a self-concept that is ill, vulnerable, or weak. This theoretical perspective may have great clinical implications and can be useful when working with individuals who report similar feelings to that of the cohort in this study. Working with individuals by helping them differentiate between themselves and their parents may be a useful way to foster some level of independence and remove the ill and vulnerable self-concept.

Moreover, the changes that occurred in the ill parents led all female participants to become involved significantly in the care of the ill parent. They reported having to provide care physically, emotionally and became the source of support. They perceived this to be unavoidable and a duty that was essential for the wellbeing of their parents. They reported feeling the urge to become their parents' caregiver, and support them in all ways possible, to improve their health and moral. Sociological explanations have emphasised expectations of traditional roles, in which women are expected to adopt the role of a caregiver. This is ingrained in females through their social and cultural experiences starting from childhood and leads to a different approach to caregiving compared to men (Papastavrou et al, 2009). In this study there was only 1 male participant and making significant comparisons is challenging.

However, the experience of parental cancer may vary significantly for males and females and is an area for future research to explore further. Indeed, in a recent study by Bagautdinova et al., (2023) caregivers and some of their siblings associated the caregiving role with being a woman or a daughter in the family system. Adult daughters may be more likely to become their parents' caregiver and in turn may experience a greater burden from becoming the caregiver.

Another common experience between the participants was their tendency to give up on their lives and priorities their ill parent. Participants gave up on their marriage planning, university plans and working life to cater for the needs of their new caregiving role. Some of the feelings associated with these choices was the feeling of guilt about continuing with their own lives while their parent was suffering. This was also a pattern reported in previous literature. Employed caregiving daughters that face these demands do not reduce their caregiving, they eliminate their leisure time (Horowitz, 1985; Johnson, 1983), reduce their work hours or leave their jobs (Enright & Friss, 1987). If unemployed, they have chosen to defer entering employment (Soldo & Myllyluoma, 1983). Dura et al, (1991) point out that various long-term care situations have documented the increased incidence of depressive symptomatology and psychiatric morbidity among familial caregivers. Together these findings show that parental cancer is a very demanding experience and may alter an adult child's life and priorities completely, causing psychological burden. Some individuals may be equipped and ready for this change, while for some this may be extremely difficult. They may need support through their adjustments and to cope with the long-term consequences.

On the other hand, a different experience emerged from Harry. He reported finding a balance in socialising. This is different from how most other participants explained the changes that occurred in their lives. Harry does admit that he spends more time with his family, but he also says that he feels he found the right balance and continues to socialise with others too. It is interesting that Harry refers to a balance that he aims to achieve between spending time with his family and socialising. His need to find this balance is rooted in the experience of having a parent with cancer. He is making conscious decisions and considers trying to achieve a balance between his family and social life, which may have not been a priority if his mother did not have cancer. However, Harry does not refer to any caregiving duties or commitments he feels. He was the only male participant, and at this moment it makes me feel that his experience of changes in family roles and responsibilities may have differentiated from the other participants due to gender. Unfortunately, research exploring the experience of male participants impacted by parental cancer is non-existent, as adult daughters usually become the primary caregivers for ill parents (Wellisch et al, 1992). However, Harry does report on the impact his parents' cancer had on his university life, coursework, and exams. It is important to stress that Harry was the only male participant, and it is worth engaging with research incorporating the experiences of more men impacted by parental cancer to shed light on the possible variations in their experiences.

In discussing the findings and the previous literature it becomes clear that on facing a parent's diagnosis of cancer, various changes occur within the family. The family finds themselves in a process in which they are forced to make shifts in their roles and adapt to their new lives. This process can be understood by the family systems model, which was developed by Rolland (2005) with the aim to evaluate how families deal with chronic illnesses. The family systems model highlights that During the acute phase of the disease, shortly after diagnosis and while the patient is undergoing treatment, the family is challenged with reorganizing in the short term and becoming flexible so that they can deal with treatment and the psychosocial demands of the illness (Rolland, 2005). Later, during the chronic phase, a key task is to try to maintain a normal life. In families coping with a terminal illness, family members are faced with the process of letting go and, eventually, family reorganization. Therefore, the effect that the cancer has on the family may be affected by the phase the family is currently in. This provides an explanation to why the experience of parental cancer may differentiate based on the stage of cancer a parent is experiencing.

Clinical implications

When a parent is ill, majority of young adults become a crucial figure, providing psychological and practical care, which in turn could impact their parent's mortality (De Boer et al, 1999). Appropriate emotional and informational support to assist this group through this difficult period is essential. In addition, the role of counselling psychologists is to improve the quality of life for their clients, which should be welcomed and possible for this client group too. Therefore, the first and most important clinical implication of this study is the importance of providing support for this group.

To provide appropriate support, it is very important for practitioners to develop an insight into the difficulties that young adults who have a parent with cancer may face. When developing an individual case formulation, it is important to consider the unique aspects of the experience and help clients understand the factors mediating their psychological distress. The findings from this study can help practitioners develop an insight into what participants may be experiencing, as findings revealed commonly occurring themes amongst this group. For instance, some participants experienced a difficulty in accepting their parents' illness and tried to avoid the associated feelings. Individuals could be offered a space to be heard, and process the feelings associated to their parents' illness through therapeutic acceptance interventions. Although research has not explored the impact of acceptance therapy on adults experiencing parental cancer, research has found that cancer-patients have benefitted from Acceptance and Commitment therapy (Hulbert-Williams, Storey, & Wilson, 2015).

As well as thinking about possible forms of effective interventions when working with young adults who have a parent with cancer, it is important to acknowledge the possible obstacles that could impact their adjustment to their parents' cancer. For example, a potential obstacle that would be helpful for practitioners and therapists to be mindful of is the way young adults guarded their own vulnerable emotions to appear 'strong' and 'adapt a parent role'. As participants in this study were so familiar with suppressing their emotions from their parents and society, it's possible that they may reproduce this within the therapeutic relationship to protect their self- identity and maintain their inner strength. As a result, healthcare professionals may fail to recognise their needs and therefore it will be important for practitioners to foster a warm, empathic, safe, and supportive therapeutic environment to enable these young adults to be expressive and open about their feelings. This may serve to help these adults fulfil their caregiving roles and will help normalise the idea that seeking support and being expressive is acceptable rather than interpreted as undermining the strong self.

The findings and clinical implications addressed are not only relevant for families impacted by cancer but can also be used in an aim to make sense of individuals who may be impacted by the illness of other family members (i.e., spouse). Or it can be useful to help understand individuals who may have parents that are experiencing other life-threatening conditions/illnesses (i.e., kidney failure, heart disease). The findings above have shown that family members can become second-order patients when a family member is ill. Therefore, it is crucial to take consider the ill individual and their families as unit, when tailoring support for them.

Limitations and directions for future research

A common limitation of IPA research studies is the small sample sizes (Pringle, Drummond, McLafferty & Hendry, 2011). Although, the possibility of generalisation is not dismissed in the approach, and a concept that can be employed to explain how this fits with IPA is that of ‘theoretical transferability’ rather than ‘empirical generalisability’ (Smith et al., 2009). ‘Theoretical transferability’ means that if the researcher provides a “rich, transparent and contextualised analysis of the participants’ accounts this in turn can allow the reader to evaluate its transferability to persons in contexts which are more, or less similar” (Smith et al., 2009).

IPA studies usually advise obtaining a homogenous sample (Smith et al., 2009). In terms of sample homogeneity in the present study, this was not without limitations. The characteristics of the participants of this study are homogenous in terms of the fact that they all experienced having a parent with cancer in the last 5 years. However, there was no control over the stage, type of cancer or the treatments the parents were impacted by. It is known that different kinds of cancer may have different physical impact and may differ significantly in terms of the treatment process and chances of heredity.

In addition, despite efforts to recruit a roughly equal balance of males and females to the study, the present research also only incorporated a single male participant. It’s possible that the females were more willing to take part in the research and share their experiences. Meyerowitz & Hart (1995) suggest that the experience of men impacted by parental cancer is often ignored by literature, possibly based on the assumption that “women feel, and men act”. However, more effort is needed to explore men’s experience of parental cancer and unravel their unique, subjective experiences. Men are not traditionally expected to become caregivers, which leads to a dissimilar approach towards caregiving among them. Due to their role-socialization, men may also be less adept at expressing their difficulties or emotions. This could result in a response-bias, in which men may be less likely to report difficulties in providing care than women (Akpinar et al, 2011). Clearly, the experiences of men may show significant differentiation, and their support needs may therefore differ significantly as well.

In addition, most studies exploring the experience of parental cancer have incorporated homogenous samples with regards to gender, race/ethnicity, and socioeconomic status and type of parental cancer. More specifically, middle, and upper class, white women experiencing maternal breast cancer has generally been the focus of research. Therefore, research exploring the experience of different population with regards to gender, race, ethnic group, the parent that is ill, and the type of cancer the parent has are all areas for future research to consider.

References

Akpınar, B., Küçükgüçlü, Ö. and Yener, G., 2011. Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of nursing scholarship*, *43*(3), pp.248-254.

Almarza, C. C. 2008. When a parent has cancer: An examination of the lived experience of adult children living at home.

Aranda, S. K., & Hayman-White, K. 2001. Home caregivers of the person with advanced cancer: an Australian perspective. Cancer nursing, 24(4), 300-307.

Arnaert, A., Gabos, T., Ballenas, V., & Rutledge, R. D. 2010. Contributions of a retreat weekend to the healing and coping of cancer patients' relatives. Qualitative health research, 20(2), 197-208.

Bagautdinova, D., Bylund, C. L., Kastrinos, A., Hampton, C. N., Vasquez, T. S., Weiss, E. S., ... & Fisher, C. L. 2023. Adult sibling-related experiences while caring for a parent diagnosed with a blood cancer. *Families, Systems, & Health*, *41*(2), 140.

Bell, J.M. and Wright, L.M., 2015. The Illness Beliefs Model: Advancing practice knowledge about illness beliefs, family healing, and family interventions. *Journal of Family Nursing*, *21*(2), pp.179-185.

Blanchard, C. G., Albrecht, T. L., & Ruckdeschel, J. C. 1997. The crisis of cancer: psychological impact on family caregivers. Oncology (Williston Park, NY), 11(2), 189-94.

Bowlby, J. 1982. Attachment and loss: retrospect and prospect. American journal of Orthopsychiatry, 52(4), 664.

Cancer Research UK., 2018. Cancer statistics for the UK: Cancer incidence. Retrieved from http://www.cancerresearchuk.org/health-professional/cancer-statistics

Cansino, S. 2009. Episodic memory decay along the adult lifespan: a review of behavioral and neurophysiological evidence. International Journal of Psychophysiology, 71(1), 64-69.

Coyne, E., Dieperink, K.B., Østergaard, B. and Creedy, D.K., 2017. Strengths and resources used by Australian and Danish adult patients and their family caregivers during treatment for cancer. *European Journal of Oncology Nursing*, *29*, pp.53-59.

De Boer, M. F., Ryckman, R. M., Pruyn, J. F. A., & Van den Borne, H. W. 1999. Psychosocial correlates of cancer relapse and survival: a literature review. Patient education and counseling, 37(3), 215-230.

Dieperink, K.B., Coyne, E., Creedy, D.K. and Østergaard, B., 2018. Family functioning and perceived support from nurses during cancer treatment among Danish and Australian patients and their families. *Journal of Clinical Nursing*, *27*(1-2), pp.e154-e161.

Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. 2006. Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. Journal of palliative medicine, 9(4), 912-921.

Dura, J. R., Stukenberg, K. W., & Kiecolt-Glaser, J. K. 1991. Anxiety and depressive disorders in adult children caring for demented parents. Psychology and aging, 6(3), 467.

Enright, R. B., & Friss, L. 1987. Employed caregivers of brain-impaired adults: An assessment of the dual role. Family Survival Project.

Ferrell, B. and Wittenberg, E., 2017. A review of family caregiving intervention trials in oncology. *CA: a cancer journal for clinicians*, *67*(4), pp.318-325.

Finley, J.P., 2018. Caregiver café: Providing education and support to family caregivers of patients with cancer. *Number 1/February 2018*, *22*(1), pp.91-96.

Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. 2005. Unmet desire for caregiver-patient communication and increased caregiver burden. Journal of the American Geriatrics Society, 53(1), 59-65.

Gilliss, C. L., Pan, W., & Davis, L. L. 2019. Family involvement in adult chronic disease care: reviewing the systematic reviews. *Journal of Family Nursing*, *25*(1), 3-27.

Given, B. A., Given, C. W., & Kozachik, S. 2001. Family support in advanced cancer. CA: a cancer journal for clinicians, 51(4), 213-231.

Given, B., Wyatt, G., Given, C., Gift, A., Sherwood, P., DeVoss, D., & Rahbar, M. 2004. Burden and depression among caregivers of patients with cancer at the end-of-life. In Oncology nursing forum (Vol. 31, No. 6, p. 1105). NIH Public Access.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., ... & Glossop, R. 2004. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. Cmaj, 170(12), 1795-1801.

Hagedoorn, M., Sanderman, R., Buunk, B. P., & Wobbes, T. 2002. Failing in spousal caregiving: The 'identity-relevant stress' hypothesis to explain sex differences in caregiver distress. British Journal of Health Psychology, 7(4), 481-494.

Hodges, L. J., Humphris, G. M., & Macfarlane, G. 2005. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. Social science & medicine, 60(1), 1-12.

Horowitz, A. 1985. Family caregiving to the frail elderly. Annual review of gerontology and geriatrics, 5(1), 194-246.

Hulbert-Williams, N. J., Storey, L., & Wilson, K. G. 2015. Psychological interventions for patients with cancer: psychological flexibility and the potential utility of Acceptance and Commitment Therapy. *European journal of cancer care*, *24*(1), 15-27.

Illingworth, N., Forbat, L., Hubbard, G. and Kearney, N., 2010. The importance of relationships in the experience of cancer: a re-working of the policy ideal of the whole-systems approach. *European Journal of Oncology Nursing*, *14*(1), pp.23-28.

Johnson, C. L. 1983. Dyadic family relations and social support. The Gerontologist, 23(4), 377-383.

Kangas, M., Henry, J. L., & Bryant, R. A. 2002. Posttraumatic stress disorder following cancer: A conceptual and empirical review. Clinical psychology review, 22(4), 499-524.

Lau, D. T., Berman, R., Halpern, L., Pickard, A. S., Schrauf, R., & Witt, W. 2010. Exploring factors that influence informal caregiving in medication management for home hospice patients. Journal of palliative medicine, 13(9), 1085-1090.

Mazanec, S. R., Daly, B. J., Douglas, S. L., & Lipson, A. R. 2011. Work productivity and health of informal caregivers of persons with advanced cancer. Research in nursing & health, 34(6), 483-495.

Meyerowitz, B. E., & Hart, S. 1995. Women and cancer: Have assumptions about women limited our research agenda?.

Northouse, L. L. 1994. Breast cancer in younger women: effects on interpersonal and family relations. Journal of the National Cancer Institute. Monographs, (16), 183.

Papastavrou, E., Tsangari, H., Kalokerinou, A., Papacostas, S. S., & Sourtzi, P. 2009. Gender issues in caring for demented relatives. *Health Science Journal*, *3*(1), 41-53.

Payne, S., Smith, P., & Dean, S. 1999. Identifying the concerns of informal carers in palliative care. Palliative medicine, 13(1), 37-44.

Polkinghorne, D. E. 2005. Language and meaning: Data collection in qualitative research. Journal of counseling psychology, 52(2), 137.

Porter, L. S., Keefe, F. J., McBride, C. M., Pollak, K., Fish, L., & Garst, J. 2002. Perceptions of patients' self-efficacy for managing pain and lung cancer symptoms: correspondence between patients and family caregivers. Pain, 98(1-2), 169-178.

Rha, S.Y., Park, Y., Song, S.K., Lee, C.E. and Lee, J., 2015. Caregiving burden and health-promoting behaviors among the family caregivers of cancer patients. *European Journal of Oncology Nursing*, *19*(2), pp.174-181.

Rohleder, N., Marin, T. J., Ma, R., & Miller, G. E. 2009. Biologic cost of caring for a cancer patient: dysregulation of pro-and anti-inflammatory signaling pathways. J Clin Oncol, 27(18), 2909-2915.

Rolland, J. S. 2005. Cancer and the family: An integrative model. Cancer: Interdisciplinary International Journal of the American Cancer Society, 104(S11), 2584-2595.

Romito, Francesca, Gil Goldzweig, Claudia Cormio, Mariët Hagedoorn, and Barbara L. Andersen. "Informal caregiving for cancer patients." *Cancer* 119 (2013): 2160-2169.

Siegel, K., Raveis, V. H., Houts, P., & Mor, V. 1991. Caregiver burden and unmet patient needs. Cancer, 68(5), 1131-1140.

Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. 2005. The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 14(2), 102-114.

Stone, R. I., & Kemper, P. 1989. Spouses and children of disabled elders: How large a constituency for long-term care reform?. The Milbank Quarterly, 485-506.

Smith, J. A., Flowers, P., & Larkin, M. 2009 Interpretative phenomenological analysis: Theory, method and research.

Soldo, B. J., & Myllyluoma, J. 1983. Caregivers who live with dependent elderly. The Gerontologist, 23(6), 605-611.

Suls, J., & Rothman, A. 2004. Evolution of the biopsychosocial model: prospects and challenges for health psychology. Health psychology, 23(2), 119.

Teixeira, C. M., Vasconcelos-Raposo, J., Fernandes, H. M., & Brustad, R. J. 2013. Physical activity, depression and anxiety among the elderly. Social Indicators Research, 113(1), 307-318.

Wellisch, D. K., Gritz, E. R., Schain, W., Wang, H. J., & Siau, J. 1992. Psychological functioning of daughters of breast cancer patients: Part II: Characterizing the distressed daughter of the breast cancer patient. Psychosomatics, 33(2), 171-179.

Van Ryn, M., Sanders, S., Kahn, K., Van Houtven, C., Griffin, J. M., Martin, M., ... & Rowland, J. 2011. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue?. Psycho-oncology, 20(1), 44-52.

Acknowledgements

I would also like to thank the participants as without them offering to share their experiences in depth, this project could not have been completed.

Declarations of interest

None

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Author guidelines

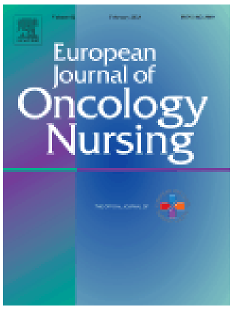
EUROPEAN JOURNAL OF ONCOLOGY NURSING

TABLE OF CONTENTS

DESCRIPTION

AUTHOR INFORMATION PACK

ISSN: 1462-3889



European Journal of Oncology Nursing

The *European Journal of Oncology Nursing* is an international journal which publishes research of direct relevance to **patient care**, **nurse education**, **management** and **policy development**. *EJON* is proud to be the official journal of the European Oncology Nursing Society.

The journal publishes the following types of papers: • Original research articles
• Review articles

Benefits to authors

We also provide many author benefits, such as free PDFs, a liberal copyright policy, special discounts on Elsevier publications and much more. Please click here for more information on our author services.

Please see our Guide for Authors for information on article submission. If you require any further information or help, please visit our Support Center

IMPACT FACTOR

2021: 2.588 © Clarivate Analytics Journal Citation Reports 2022

ABSTRACTING AND INDEXING

Scopus
PubMed/Medline
CINAHL
Referativnyi Zhurnal VINTI-RAN (Russian Academy of Sciences) BDLIC
Embase
British Nursing Index

EDITORIAL BOARD

Editor-in-Chief

Alex Molasiotis, University of Derby College of Arts, Humanities and Education, Derby, United Kingdom AUTHOR INFORMATION PACK 22 Mar 2023 www.elsevier.com/locate/ejon

Associate Editors

A. Charalambous, Cyprus University of Technology, Lemesos, Cyprus
E. Coyne, Griffith University School of Nursing and Midwifery - Logan Campus, Meadowbrook, Australia
L. Maree, University of the Witwatersrand Johannesburg, Department of Nursing Education, Johannesburg, South Africa
A. McCarthy, University of Queensland, School of Nursing, Midwifery and Social Work, Saint Lucia, Queensland, Australia
Pergert, Karolinska Institute, Stockholm, Sweden
J. Yorke, The University of Manchester Division of Nursing Midwifery and Social Work, Manchester, United Kingdom

Founding Editor

A. Richardson, University of Southampton, Southampton, United Kingdom ***Past Senior Associate Editor***

F. Gibson, Great Ormond Street Hospital for Children NHS Foundation Trust, London, United Kingdom

EONS Representatives

Wendy Oldenmenger

Rotterdam, The Netherlands
Theresa Wiseman, London, United Kingdom Nursing

Ex-Officio Member

Daniel Kelly, Cardiff, United Kingdom ***Editorial Board Members***

C. Baggott, Stanford University, Stanford, California, United States of America **R. Chan**, Queensland Health, Brisbane, Australia
K. Cheng, The University of Tokyo, Bunkyo-Ku, Japan
P. Di Giuglio, University of Turin, Torino, Italy

J. L. Ferreira Antunes, University of Sao Paulo, SAO PAULO, Brazil
M. Fitch, Canadian Partnership Against Cancer, Toronto, Ontario, Canada
B. Given, Michigan State University, East Lansing, Michigan, United States of America
S. Kav, Baskent University, Department of Nursing, Ankara, Turkey
Patterson Kelly, The George Washington University School of Medicine and Health Sciences, Washington, District of Columbia, United States of America
A. Kjaergaard Danielsen, Herlev Hospital, Herlev, Denmark
G. Kotronoulas, University of Glasgow School of Medicine Dentistry and Nursing, Glasgow, United Kingdom **R. Krcmar**
M. Krishnasamy, The University of Melbourne, Department of Nursing, Carlton, Australia
Y.-H. Lai, National Taiwan University College of Medicine, Taipei, Taiwan
A. Lannie, University of Dundee School of Nursing and Health Sciences, Dundee, United Kingdom
C. Miaskowski, University of California San Francisco, San Francisco, California, United States of America
L. Monterosso, The University of Notre Dame Australia, Fremantle, Australia
S. Pearce, University of Plymouth, Plymouth, United Kingdom
B.F. Piper, National University, La Jolla, California, United States of America
J. Y Tan, Charles Darwin University, Casuarina, Australia
R. Taylor, University College London Hospitals NHS Foundation Trust, London, United Kingdom
M. Wells, Imperial College London, London, United Kingdom
K. White, The University of Sydney, Faculty of Nursing Library, Camperdown, New South Wales, Australia
P. Yates, Queensland University of Technology, Brisbane, Queensland, Australia
Z.J. Ye, Guangzhou University of Chinese Medicine, Guangzhou, China

Editorial Office

European Journal of Oncology Nursing Editorial Office, Global Journals Production, Elsevier Ltd., Stover Court, Bampfylde Street, Exeter, Devon, EX1 2AH, , UK

GUIDE FOR AUTHORS

INTRODUCTION

The *European Journal of Oncology Nursing* is an international journal which publishes research of direct relevance to patient care, nurse education, management and policy development. EJON is proud to be the official journal of the European Oncology Nursing Society.

The European Journal of Oncology Nursing publishes material in the form of editorials, original research reports, papers and reviews. The Journal Editor, Alexander Molasiotis, welcomes the submission of manuscripts on all aspects of cancer nursing whether in the field of practice, education or research. Manuscripts should usually be between 2500 and 5000 words, although longer manuscripts of up to 7000 words will also be considered in some cases.

All papers are subject to single blind peer review and will be judged on their suitability and quality for the readership of the journal. The review process can take an average of eight weeks and reviewers' comments will be shared with the author(s) whether the manuscript is accepted or rejected. The Editor retains the right to edit material accepted for publication.

EJON will consider manuscripts prepared according to the guidelines adopted by the International Committee of Medical Journal Editors ("Uniform requirements for manuscripts submitted to biomedical journals", available as a PDF from http://www.icmje.org). Authors are advised to read these guidelines.

Submission of an article implies that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis), that it is not under consideration for publication elsewhere, that its publication is approved by all Authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or any other language, without the written consent of the Publisher.

If excerpts from other copyrighted works are included, the Author(s) must obtain written permission from the copyright owners and credit the source(s) in the article. Elsevier has preprinted forms for use by Authors in these cases: contact Elsevier's Rights Department, Philadelphia, PA, USA: phone (+1) 215 239 3804, fax (+1) 215 239 3805, email healthpermissions@elsevier.com. Requests may also be completed online via the Elsevier homepage (https://www.elsevier.com/permissions).

For any submission questions, please contact the Editorial Office at ejon@elsevier.com.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details: • E-mail address
- Full postal address

All necessary files have been uploaded:
Manuscript:
- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided • Indicate clearly if color should be used for any figures in print *Graphical Abstracts / Highlights files* (where applicable)

Supplemental files (where applicable)

Further considerations
- Manuscript has been 'spell checked' and 'grammar checked'
- All references mentioned in the Reference List are cited in the text, and vice versa

- Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- A competing interests statement is provided, even if the authors have no competing interests to declare

- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

For further information, visit our Support Center.

Reporting guidelines

The editors require that manuscripts adhere to recognized reporting guidelines relevant to the research design used and require authors to submit a checklist verifying that essential elements have been reported for all primary research and systematic reviews.

Reporting guidelines endorsed by the journal are listed below: *Observational cohort, case*
control and cross sectional studies - STROBE - Strengthening the Reporting of Observational
Studies in Epidemiology, http://www.equator-network.org/reporting-guidelines/strobe/ *Qualitative*
studies - COREQ - Consolidated criteria for reporting qualitative research, http://www.equator-network.org/reporting-guidelines/coreq *Quasi-experimental/non-randomised evaluations* - TREND - Transparent Reporting of Evaluations with Non-randomized Designs, http://www.cdc.gov/trendstatement/ *Randomised (and quasi-randomised) controlled trial* - CONSORT - Consolidated Standards of Reporting Trials, http://www.equator-network.org/reporting-guidelines/consort/ *Study of Diagnostic accuracy/ assessment scale* - STARD - Standards for the Reporting of Diagnostic Accuracy Studies, http://www.equator-network.org/reporting-guidelines/stard/ *Systematic Review*
of Controlled Trials - PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses, http://www.equator-network.org/reporting-guidelines/prisma/ *SRQR*
checklist is for qualitative studies http://www.equator-network.org/reporting-guidelines/srqr/
AGREE checklist is for clinical guidelines type of articles http://www.equator-network.org/reporting-guidelines/the-agree-reporting-checklist-a-tool-to-improve-report

You are required to adhere to these guidelines (or a suitable recognized alternative) and to submit a completed checklist from the reporting guideline to assist the editors and reviewers of your paper. You can search for the correct guideline for your study using the tools provided by the EQUATOR network: http://www.equator-network.org/ The guideline used must be indicated in the **Author Checklist** and the completed Standards of Reporting Checklist must also be included in your submission.

BEFORE YOU BEGIN

Ethics in publishing

Please see our information on Ethics in publishing.

Studies in humans and animals

If the work involves the use of human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The manuscript should be in line with the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals and aim for the inclusion of representative human populations (sex, age and ethnicity) as per those recommendations. The terms sex and gender should be used correctly.

Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.

All animal experiments should comply with the ARRIVE guidelines and should be carried out in accordance with the U.K. Animals (Scientific Procedures) Act, 1986 and associated guidelines, EU Directive 2010/63/EU for animal experiments, or the National Research Council's Guide for the Care and Use of Laboratory Animals and the authors should clearly indicate in the manuscript that such guidelines have been followed. The sex of animals must be indicated, and where appropriate, the influence (or association) of sex on the results of the study.

Informed consent and patient details

Studies on patients or volunteers require ethics committee approval and informed consent, which should be documented in the paper. Appropriate consents, permissions and releases must be obtained where an author wishes to include case details or other personal information or images of patients and any other individuals in an Elsevier publication. Written consents must be retained by the author but copies should not be provided to the journal. Only if specifically requested by the journal in exceptional circumstances (for example if a legal issue arises) the author must provide copies of the consents or evidence that such consents have been obtained. For more information, please review the Elsevier Policy on the Use of Images or Personal Information of Patients or other Individuals. Unless you have written permission from the patient (or, where applicable, the next of kin), the personal details of any patient included in any part of the article and in any supplementary materials (including all illustrations and videos) must be removed before submission.

Declaration of interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential competing interests include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. Authors must disclose any interests in two places: 1. A summary declaration of interest statement in the title page file (if double anonymized) or the manuscript file (if single anonymized). If there are no interests to declare then please state this: 'Declarations of interest: none'. 2. Detailed disclosures as part of a separate Declaration of Interest form, which forms part of the journal's official records. It is important for potential interests to be declared in both places and that the information matches. More information.

Declaration of generative AI in scientific writing

The below guidance only refers to the writing process, and not to the use of AI tools to analyse and draw insights from data as part of the research process.

Where authors use generative artificial intelligence (AI) and AI-assisted technologies in the writing process, authors should only use these technologies to improve readability and language. Applying the technology should be done with human oversight and control, and authors should carefully review and edit the result, as AI can generate authoritative-sounding output that can be incorrect, incomplete or biased. AI and AI-assisted technologies should not be listed as an author or co-author, or be cited as an author. Authorship implies responsibilities and tasks that can only be attributed to and performed by humans, as outlined in Elsevier's AI policy for authors.

Authors should disclose in their manuscript the use of AI and AI-assisted technologies in the writing process by following the instructions below. A statement will appear in the published work. Please note that authors are ultimately responsible and accountable for the contents of the work.

Disclosure instructions

Authors must disclose the use of generative AI and AI-assisted technologies in the writing process by adding a statement at the end of their manuscript in the core manuscript file, before the References list. The statement should be placed in a new section entitled 'Declaration of Generative AI and AI- assisted technologies in the writing process'.

Statement: During the preparation of this work the author(s) used [NAME TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

This declaration does not apply to the use of basic tools for checking grammar, spelling, references etc. If there is nothing to disclose, there is no need to add a statement.

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract, a published lecture or academic thesis, see 'Multiple, redundant or concurrent publication' for more information), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify compliance, your article may be checked by Crossref Similarity Check and other originality or duplicate checking software.

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Reporting sex- and gender-based analyses

Reporting guidance

For research involving or pertaining to humans, animals or eukaryotic cells, investigators should integrate sex and gender-based analyses (SGBA) into their research design according to funder/ sponsor requirements and best practices within a field. Authors should address the sex and/or gender dimensions of their research in their article. In cases where they cannot, they should discuss this as a limitation to their research's generalizability. Importantly, authors should explicitly state what definitions of sex and/or gender they are applying to enhance the precision, rigor and reproducibility of their research and to avoid ambiguity or conflation of terms and the constructs to which they refer (see Definitions section below). Authors can refer to the Sex and Gender Equity in Research (SAGER) guidelines and the SAGER guidelines checklist. These offer systematic approaches to the use and editorial review of sex and gender information in study design, data analysis, outcome reporting and research interpretation - however, please note there is no single, universally agreed-upon set of guidelines for defining sex and gender.

Definitions

Sex generally refers to a set of biological attributes that are associated with physical and physiological features (e.g., chromosomal genotype, hormonal levels, internal and external anatomy). A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth"), most often based solely on the visible external anatomy of a newborn. Gender generally refers to socially constructed roles, behaviors, and identities of women, men and gender-diverse people that occur in a historical and cultural context and may vary across societies and over time. Gender influences how people view themselves and each other, how they behave and interact and how power is distributed in society. Sex and gender are often incorrectly portrayed as binary (female/male or woman/man) and unchanging whereas these constructs actually exist along a spectrum and include additional sex categorizations and gender identities such as people who are intersex/have differences of sex development (DSD) or identify as non-binary. Moreover, the terms "sex" and "gender" can be ambiguous—thus it is important for authors to define the manner in which they are used. In addition to this definition guidance and the SAGER guidelines, the resources on this page offer further insight around sex and gender in research studies.

Author contributions

For transparency, we encourage authors to submit an author statement file outlining their individual contributions to the paper using the relevant CRediT roles: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Roles/Writing - original draft; Writing - review & editing. Authorship statements should be formatted with the names of authors first and CRediT role(s) following. More details and an example.

Authorship

All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

Changes to authorship

Authors are expected to consider carefully the list and order of authors **before** submitting their manuscript and provide the definitive list of authors at the time of the original submission. Any addition, deletion or rearrangement of author names in the authorship list should be made only **before** the manuscript has been accepted and only if approved by the journal Editor. To request such a change, the Editor must receive the following from the **corresponding author**: (a) the reason for the change in author list and (b) written confirmation (e-mail, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed.

Only in exceptional circumstances will the Editor consider the addition, deletion or rearrangement of authors **after** the manuscript has been accepted. While the Editor considers the request, publication of the manuscript will be suspended. If the manuscript has already been published in an online issue, any requests approved by the Editor will result in a corrigendum.

Reporting clinical trials

Randomized controlled trials should be presented according to the CONSORT guidelines. At manuscript submission, authors must provide the CONSORT checklist accompanied by a flow diagram that illustrates the progress of patients through the trial, including recruitment, enrollment, randomization, withdrawal and completion, and a detailed description of the randomization procedure. The CONSORT checklist and template flow diagram are available online.

Registration of clinical trials

Registration in a public trials registry is a condition for publication of clinical trials in this journal in accordance with International Committee of Medical Journal Editors recommendations. Trials must register at or before the onset of patient enrolment. The clinical trial registration number should be included at the end of the abstract of the article. A clinical trial is defined as any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects of health outcomes. Health-related interventions include any intervention used to modify a biomedical or health-related outcome (for example drugs, surgical procedures, devices, behavioural treatments, dietary interventions, and process-of-care changes). Health outcomes include any biomedical or health-related measures obtained in patients or participants, including pharmacokinetic measures and adverse events. Purely observational studies (those in which the assignment of the medical intervention is not at the discretion of the investigator) will not require registration.

Article transfer service

This journal uses the Elsevier Article Transfer Service to find the best home for your manuscript. This means that if an editor feels your manuscript is more suitable for an alternative journal, you might be asked to consider transferring the manuscript to such a journal. The recommendation might be provided by a Journal Editor, a dedicated Scientific Managing Editor, a tool assisted recommendation, or a combination. If you agree, your manuscript will be transferred, though you will have the opportunity to make changes to the manuscript before the submission is complete. Please note that your manuscript will be independently reviewed by the new journal. More information.

Copyright

Upon acceptance of an article, authors will be asked to complete a 'Journal Publishing Agreement' (see more information on this). An e-mail will be sent to the corresponding author confirming receipt of the manuscript together with a 'Journal Publishing Agreement' form or a link to the online version of this agreement.

Subscribers may reproduce tables of contents or prepare lists of articles including abstracts for internal circulation within their institutions. Permission of the Publisher is required for resale or distribution outside the institution and for all other derivative works, including compilations and translations. If excerpts from other copyrighted works are included, the author(s) must obtain written permission from the copyright owners and credit the source(s) in the article. Elsevier has preprinted forms for use by authors in these cases.

For gold open access articles: Upon acceptance of an article, authors will be asked to complete a 'License Agreement' (more information). Permitted third party reuse of gold open access articles is determined by the author's choice of user license.

Author rights

As an author you (or your employer or institution) have certain rights to reuse your work. More information.

Elsevier supports responsible sharing

Find out how you can share your research published in Elsevier journals.

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement, it is recommended to state this.

Open access

Please visit our Open Access page for more information.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's Author Services.

Submission

Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

Submit your article

Please submit your article via https://www.editorialmanager.com/yejon/default.aspx.
Suggesting reviewers

Please submit the names and institutional e-mail addresses of several potential reviewers.

You should not suggest reviewers who are colleagues, or who have co-authored or collaborated with you during the last three years. Editors do not invite reviewers who have potential competing interests with the authors. Further, in order to provide a broad and balanced assessment of the work, and ensure scientific rigor, please suggest diverse candidate reviewers who are located in different countries/ regions from the author group. Also consider other diversity attributes e.g. gender, race and ethnicity, career stage, etc. Finally, you should not include existing members of the journal's editorial team, of whom the journal are already aware.

Note: the editor decides whether or not to invite your suggested reviewers.

PREPARATION

Queries

For questions about the editorial process (including the status of manuscripts under review) or for technical support on submissions, please visit our Support Center.

Peer Review

This journal operates a single blind review process. There is no requirement for the blinding of author information in a submitted paper. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. More information on types of peer review.

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Subdivision - unnumbered sections

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross- referencing text: refer to the subsection by heading as opposed to simply 'the text'.

Essential information

- ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- ***Author names.*** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled.

- ***Professional and academic qualifications.*** Please include each author's highest professional and/ or educational qualification, for example:
Alex Molassiotis, RN, Phd *or* Alex Molassiotis, FRCP, Phd.
- ***Affiliations.*** Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

- ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**
- ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Highlights

Highlights are optional yet highly encouraged for this journal, as they increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Immediately after the abstract, provide a maximum of ten keywords, avoiding general and plural terms and multiple concepts (avoid, for example, "and", "of"). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Units

Follow internationally accepted rules and conventions: use the international system of units (SI). If other units are mentioned, please give their equivalent in SI.

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Artwork

Electronic artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman,

Symbol, or use fonts that look similar.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.
- Ensure that color images are accessible to all, including those with impaired color vision.

A detailed guide on electronic artwork is available.
You are urged to visit this site; some excerpts from the detailed information are given here. *Formats*
If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.
Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):
EPS (or PDF): Vector drawings, embed all used fonts.
TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.
TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi. TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.
Please do not:
- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;

- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

Color artwork

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. **For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article**. Please indicate your preference for color: in print or online only. Further information on the preparation of electronic artwork.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Reference links

Increased discoverability of research and high quality peer review are ensured by online links to the sources cited. In order to allow us to create links to abstracting and indexing services, such as Scopus, Crossref and PubMed, please ensure that data provided in the references are correct. Please note that incorrect surnames, journal/book titles, publication year and pagination may prevent link creation. When copying references, please be careful as they may already contain errors. Use of the DOI is highly encouraged.

A DOI is guaranteed never to change, so you can use it as a permanent link to any electronic article. An example of a citation using DOI for an article not yet in an issue is: VanDecar J.C., Russo R.M., James D.E., Ambeh W.B., Franke M. (2003). Aseismic continuation of the Lesser Antilles slab beneath northeastern Venezuela. Journal of Geophysical Research, https://doi.org/10.1029/2001JB000884. Please note the format of such citations should be in the same style as all other references in the paper.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

Preprint references

Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software

Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley. Using citation plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide. If you use reference management software, please ensure that you remove all field codes before submitting the electronic manuscript. More information on how to remove field codes from different reference management software.

Reference style
The *European Journal of Oncology Nursing* uses the Harvard referencing style.
Text: All citations in the text should refer to:
1. *Single author:* the author's name (without initials, unless there is ambiguity) and the year of publication;
2. *Two authors:* both authors' names and the year of publication;
3. *Three or more authors:* first author's name followed by 'et al.' and the year of publication. Citations may be made directly (or parenthetically). Groups of references can be listed either first alphabetically, then chronologically, or vice versa.
Examples: 'as demonstrated (Allan, 2000a, 2000b, 1999; Allan and Jones, 1999).... Or, as demonstrated (Jones, 1999; Allan, 2000)... Kramer et al. (2010) have recently shown ...'
List: References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.
Examples:
Reference to a journal publication:
Van der Geer, J., Hanraads, J.A.J., Lupton, R.A., 2010. The art of writing a scientific article. J. Sci. Commun. 163, 51–59. https://doi.org/10.1016/j.Sc.2010.00372.
Reference to a journal publication with an article number:
Van der Geer, J., Hanraads, J.A.J., Lupton, R.A., 2018. The art of writing a scientific article. Heliyon. 19, e00205. https://doi.org/10.1016/j.heliyon.2018.e00205.
Reference to a book:
Strunk Jr., W., White, E.B., 2000. The Elements of Style, fourth ed. Longman, New York.
Reference to a chapter in an edited book:
Mettam, G.R., Adams, L.B., 2009. How to prepare an electronic version of your article, in: Jones, B.S., Smith , R.Z. (Eds.), Introduction to the Electronic Age. E-Publishing Inc., New York, pp. 281–304. Reference to a website:
Cancer Research UK, 1975. Cancer statistics reports for the UK. http://www.cancerresearchuk.org/ aboutcancer/statistics/cancerstatsreport/ (accessed 13 March 2003).
Reference to a dataset:
[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T., 2015. Mortality data for

Japanese oak wilt disease and surrounding forest compositions. Mendeley Data, v1. https://doi.org/10.17632/ xwj98nb39r.1.

Video

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the file in one of our recommended file formats with a preferred maximum size of 150 MB per file, 1 GB in total. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect. Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction pages. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

Data visualization

Include interactive data visualizations in your publication and let your readers interact and engage more closely with your research. Follow the instructions here to find out about available data visualization options and how to include them with your article.

Supplementary material

Supplementary material such as applications, images and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file. Do not annotate any corrections on a previous version. Please switch off the 'Track Changes' option in Microsoft Office files as these will appear in the published version.

Research data

This journal encourages and enables you to share data that supports your research publication where appropriate, and enables you to interlink the data with your published articles. Research data refers to the results of observations or experimentation that validate research findings. To facilitate reproducibility and data reuse, this journal also encourages you to share your software, code, models, algorithms, protocols, methods and other useful materials related to the project.

Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

Data linking

If you have made your research data available in a data repository, you can link your article directly to the dataset. Elsevier collaborates with a number of repositories to link articles on ScienceDirect with relevant repositories, giving readers access to underlying data that gives them a better understanding of the research described.

There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page.

For supported data repositories a repository banner will automatically appear next to your published article on ScienceDirect.

In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

Mendeley Data

This journal supports Mendeley Data, enabling you to deposit any research data (including raw and processed data, video, code, software, algorithms, protocols, and methods) associated with your manuscript in a free-to-use, open access repository. Before submitting your article, you can deposit the relevant datasets to *Mendeley Data*. Please include the DOI of the deposited dataset(s) in your main manuscript file. The datasets will be listed and directly accessible to readers next to your published article online.

For more information, visit the Mendeley Data for journals page.

Research Elements

This journal enables you to publish research objects related to your original research – such as data, methods, protocols, software and hardware – as an additional paper in a Research Elements journal.

Research Elements is a suite of peer-reviewed, open access journals which make your research objects findable, accessible and reusable. Articles place research objects into context by providing detailed descriptions of objects and their application, and linking to the associated original research articles. Research Elements articles can be prepared by you, or by one of your collaborators.

During submission, you will be alerted to the opportunity to prepare and submit a manuscript to one of the Research Elements journals.

More information can be found on the Research Elements page.

Data statement

To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

AFTER ACCEPTANCE

Online proof correction

To ensure a fast publication process of the article, we kindly ask authors to provide us with their proof corrections within two days. Corresponding authors will receive an e-mail with a link to our online proofing system, allowing annotation and correction of proofs online. The environment is similar to MS Word: in addition to editing text, you can also comment on figures/tables and answer questions from the Copy Editor. Web-based proofing provides a faster and less error-prone process by allowing you to directly type your corrections, eliminating the potential introduction of errors.

If preferred, you can still choose to annotate and upload your edits on the PDF version. All instructions for proofing will be given in the e-mail we send to authors, including alternative methods to the online version and PDF.
We will do everything possible to get your article published quickly and accurately. Please use this proof only for checking the typesetting, editing, completeness and correctness of the text, tables and figures. Significant changes to the article as accepted for publication will only be considered at this stage with permission from the Editor. It is important to ensure that all corrections are sent back to us in one communication. Please check carefully before replying, as inclusion of any subsequent corrections cannot be guaranteed. Proofreading is solely your responsibility.

Offprints

The corresponding author will, at no cost, receive a customized Share Link providing 50 days free access to the final published version of the article on ScienceDirect. The Share Link can be used for sharing the article via any communication channel, including email and social media. For an extra charge, paper offprints can be ordered via the offprint order form which is sent once the article is accepted for publication. Corresponding authors who have published their article gold open access do not receive a Share Link as their final published version of the article is available open access on ScienceDirect and can be shared through the article DOI link.

AUTHOR INQUIRIES

Visit the Elsevier Support Center to find the answers you need. Here you will find everything from Frequently Asked Questions to ways to get in touch.
You can also check the status of your submitted article or find out when your accepted article will be published.

© Copyright 2018 Elsevier | https://www.elsevier.com

End of part B – Journal article