



Introduction

Prelude to This Book

My relationship with cancer began when I was four years of age. I woke up like any other day to go to preschool. My parents weren't there; the lady that minded us was there instead and I remember asking her where my parents were, she did not say. 'They had to go' – she said. Yes, I know that much since they are not here, even at four I could certainly figure that out on my own.

I can't remember my day, probably nothing else seemed unusual about it to me. My mother came to pick me up from preschool and took my sister at the same time. That was weird; my sister and I usually went to my grandmother's house after school, in the school bus. Something was going on. (Routines are important for young children as we will discuss later in this book! And my routine was broken at this stage).

We were brought to my grandmother's house as usual in the afternoon. There were many people in the house. I won't lie and pretend like I remember everything, I don't. I was standing at the main door, facing the living room. I know I was standing on my own. My grandmother was laying on the couch and she screamed and cried in pain like if someone was hurting her. So many people were surrounding her, and it just looked very chaotic and unusual from my point of view. The room was dark, very dark, it was unusual and therefore scary for a four-year-old. I know my mother picked me in her arms and took me out of the situation as fast as she could. I was handed to somebody else and was told not to go into the living room again, as if I was the one who had done something wrong that I was never aware that I did.

My aunt Ana had died, I don't know at what stage I figured that out. I knew she was not in her room anymore; at some point I know I went down the stairs to look for her or just to make sure that she was not there. That was the first time I had 'consciously' heard of death ever before. I did not know what was happening. The distance between the word and the concept when you are four is hard to grasp.

I grew up always knowing that somebody was missing in my life, my aunt Ana. There was a yearly mass to celebrate her life. The first years many people would come, and my family would cook this extravagant amount of food to greet

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them. Over the years, less and less people showed up. I always knew that people had lovely things to say about her and that never changed so I decided to believe it was true. Cancer took away a wonderful person from me when I was four. I did not know what cancer was for a long time since then. As I grew up, the word cancer became part of language, science classes, other people and that yearly celebration. Cancer took something away from me, something good, and it owed me. All I knew about cancer is it does that, it takes away ... because it can.

I did not know anything about cancer for a long time in my life. My aunt got a 'fright' when I was a teenager, it was just that a 'fright'. The biopsy was negative, but the memories came back to life for all of us. Cancer did not take anything away this time although, genetically, apparently it could. And still can.

At 18 I decided to become a psychologist and then a health psychologist. Cancer was mentioned in the books, and I met a lovely lady that came to my clinic in remission, she had a history of cancer and from time to time the topic would emerge, making me think that cancer really doesn't enjoy just staying as 'history'. She had terrible side effects from the treatment that still impacted her daily life, but the therapy was not centred around that, however, it was ever present. When I got a scholarship for my PhD, I got sent a list of topics, one of which was cancer. I thought that if I was to follow the biggest dream of my life it might as well come with the oldest debt I had as well, cancer took something from me, and I was ready to look at it in the eye and claim back what it took.

Ever since I have been asking cancer so many questions, I do not think that it owes me anything anymore, but it took a long time to convince a four-year-old little girl of that. I do not want any other little four-year-old girl to grow up with that thought, and that has been my mission ever since. Less than a year ago I know the topic emerged in a conversation with my family and even though it has been proven by scientific research that it was the wrong thing to do, my family still thinks that keeping me 'out' of the situation was the best thing they could do. It is not, but I can understand that they had the best intentions, perhaps not enough information to make better and informed decisions and that is what was wrong. I am aware that when I was young, research and knowledge were not as advanced as they are today. So, this is the purpose of this book; this is where it comes from and hopefully what it will achieve. Children and young people should not be 'invisible' or left alone to deal with their own fears and misunderstandings, quite the opposite, children can provide meaning and strength to their parents during cancer, as a crucial part of the care team [1] In this book, cancer will be conceptualised as a family affair, where children and young people are protagonists with their ill parent.

Why This Book?

Cancer is now classified as a chronic illness, due to the advancement in treatment. This means it is important to 'think family' throughout the cancer treatment and beyond [2]. Due to the substantial impact of parental cancer on

children and young people, there is a clear need for interventions and clinical practice guidelines to support healthcare services and healthcare professionals to identify vulnerable young people and provide appropriate supports, early and preventative supports [3].

Importantly, research has identified that parents may not be well supported by oncology professionals in how to manage and support their children at a very stressful and challenging time [4, 5]. During illness, particularly during a life-limiting illness like cancer, parents and children need to be supported by professionals involved in their care [6].

It is a fact that offspring of cancer patients may be overlooked by support services as they are not the patients themselves [7]. Young people expressed that they were rarely asked about how they were doing by adults in their lives [8]. Research with children themselves welcomed opportunities to discuss their parent's illness if given the opportunity to do so [6]. It is a fact that good communication between healthcare practitioners and patients can have a positive impact on the psychological adjustment to cancer [6]. Few adolescents, however, had direct access to a nurse or social worker and no adolescents had access to a physician [9]. This finding was supported by survivor research where adults expressed that support for children and grandchildren was not available and was particularly lacking for males [10].

The other purpose of this book is to support professionals, particularly those that are concerned about lacking the skills to support parents and children or may lack the possibility of being formally trained and access further education in this area.

Limitations of This Book

A word of caution about this book is that it is limited by the current knowledge and its own limitations. You will find that most of the knowledge that we currently have about the experience of children, young people and families is mostly portraying Western populations. There is a lack of research with minority cultural or linguistic groups also, including a lack of research on bereavement in non-Western groups and interventions to support offspring available in non-Western populations [3]. Most of the research carried out to date is focused on hospital-based populations, so findings may be limited to this population and not applicable to community-based studies, for example [3].

It has also been suggested (as we will discuss in future chapters) that the gender of the ill parent will have an impact on the cancer experience for patients as well as for their families, children and young people. Most research studies have been carried out with females. As much as 61% of participants are female, therefore less is known about father's experiences with cancer [3].

The research findings are also impacted by who the respondent is. For example, some studies focused on identifying the experiences of children and young people may have used parents as respondents. This may have influenced

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children's participation and presented the views of parents instead of those of children and young people [11]. This does not mean that all of them were inaccurate; however, to fully understand specific aspects, for example communication, research needs to expand on the respondents that are included, parent-child communication at the time of parental cancer could benefit from including the child and the ill parent's views but also the healthy co-parent [12]. So far, the different perspectives have usually not been included [12]. This would imply more time and more research resources, so there are practical reasons why including several sources of information is not a more common practice; however, the quality of the knowledge generated and made available might be more beneficial and provide a more comprehensive understanding. So, I would encourage it.

The term parental cancer will be used throughout this book to refer to findings of studies that included mothers exclusively, fathers exclusively or a mix of both in their samples. If information is available specifying the gender of the parent, this specification is mentioned and described in the chapters. Some studies report the sex of the ill parent, however, did not include an analysis of the results and findings by sex and this is the reason why the book cannot specify this in more detail.

This book is also attempting to provide a chronological understanding of cancer, which is a risk as cancer may have an unexpected course and sudden changes. It is, however, important to separate results by whether the parent had fully recovered, was still ill or passed away [11]. This is also why a full chapter of this book is also dedicated to approach bereavement separately (Chapter 7).

Another potential limitation of the knowledge included in this book is that research usually includes samples relying on retrospective data which can lead to recollection bias and miss important details of the experience of parental cancer on children and families [7]. Comparisons between studies are challenging as there are inconsistencies in the aspects of psychosocial functioning measured. It was found, for example that about 61 different outcomes and predictor variables have been measured in different studies [3]. Therefore, there is a need to explore the long-term efficacy of interventions and its impact on outcomes across interventions [3]. There is also a need to explore the impact of parental cancer over time and more systematic and targeted interventions that can be used internationally as well as locally to allow for comparisons if suitable [3].

Another possible limitation is the lack of clarity on ages and developmental stages of cancer in the research. Terms such as child and offspring are used interchangeably. Child is used for both under 12-year-olds and under 18-year-olds [3]. Findings for children and young people sometimes are reported together with no clarification of differences between them. Chapter 2 will present the impact of parental cancer by age group, even though the information is limited.

Lastly, in the interest of transparency, I am a psychologist with a background in clinical and health psychology. I have worked with cancer from this point of view but also as part of multidisciplinary teams where, over the years, I

have learnt about the medical terms and the medical language, but I am not an expert in the topic. This book is, therefore, focused mainly on a comprehensive understanding of cancer approaching the cultural, psychological, emotional, parenting and overall contexts and experiences of cancer for children, young people and families. This book is not suitable if you are looking for medical expertise. I do not personally have it and I would not attempt to write about it. I hope to share this comprehensive understanding with healthcare professionals and what I hope to achieve with that term is to be as comprehensive as possible. This means to include professionals who might work in the field of cancer, psychologists, social workers, medical doctors, nurses and therapists. I hope this book will be useful to all of you and the children, young people and families who experience cancer that you get to meet.

What Is Included in This Book?

This book includes eight chapters that provide knowledge and skills to healthcare practitioners (mainly) that are in contact or working directly with children, young people and families through an experience of parental cancer. Chapter 1 explores the impact of parental cancer, consciously exploring the knowledge by age group, and taking into consideration what we currently know about how cancer impacts children, young people and families according to their developmental stage. Research has suggested that cancer has different stages and, even though the course of the illness can change, it generally follows identifiable stages: diagnosis, treatment and survivorship. These stages have their own qualities and challenges for families. These will be described in Chapter 2. Chapters 3 and 4 are looking at the context of how culture, policy, socioeconomic backgrounds, parenting culture, parenting practices, religion and other external factors influence and shape the experiences of cancer and cancer care for families. After the impact of cancer and factors affecting that experience are thoroughly explored, Chapters 5 and 6 provide a description of the current available strategies to support children, young people and families, as well as formal interventions available and tested to determine their impact and efficacy. This will help practitioners to acquire more knowledge as well as skills on how to support different families. Chapter 7 is dedicated exclusively to bereavement as the experience of death is unique to some families, not all cancer diagnosis will lead to death, but some will. The needs of these families are unique and therefore healthcare practitioners may need equally specific skills to deal with these situations. It is an additional layer of complexity for a cancer experience, and therefore it is approached in a chapter on its own. The last chapter is focused on the well-being of healthcare practitioners offering some suggestions for self-care which is also a crucial part of being able to properly support children, young people and families who experience parental cancer.

These chapters attempt to be comprehensive and be applicable to as many families and possible experiences of parental cancer. What I would like you to

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obtain from this book is that every experience is unique, and each family and child will have unique experiences that healthcare practitioners need to empathetically listen to. Healthcare practitioners can have expert knowledge and this book is intended to contribute to that; families are experts in themselves and therefore two experts working together is key to supporting parenting through cancer.

How to Read This Book

Each chapter begins with an introduction of the content that is included in the chapter. Additionally, a summary of important topics in the chapter is included in the 'Chapter Highlights' section. All the chapters have suggested activities for children and families; they are included throughout the chapters, and they could be useful to work with families or to suggest it to families, children and young people to practice together. They may or may not be related to the content of the chapter. Finally, all chapters include a section specifically on the implications for practice that intends to motivate much needed changes to policy and practice that will facilitate and improve the work with children and families but also for you as a healthcare practitioner working in the field of cancer. Most of all, I hope you enjoy this book as much as I enjoyed writing it and learning so much in the process.

Chapter

Impact of Parental Cancer

1.1 Introduction

I begin this chapter by asking you as a reader to say the word **CANCER** out loud (or in your head) and write down everything that comes to your mind, thoughts, feelings, memories ... anything at all. It is important to understand what cancer means to you as a healthcare practitioner and remember why you decided to work in the area of cancer, what motivated you to even be reading this book.

The impact of parental cancer on children and young people is associated with the word cancer and what it evokes in them. Family members' initial expectations of the threat of cancer and their anticipatory loss are crucial for their experience [13]. According to research, cancer evokes a variety of emotional and cognitive reactions. Cancer has been associated with death, fear and uncertainty, none of which is a positive concept or emotion. Research specifically on young people identified that death was described as the 'first thought' that entered the minds of young people when they found out about a parental diagnosis [8]. Overall, Visser et al. [14] specified that children's perception of how serious the illness is affected emotional problems more than objective illness characteristics such as type, stage and time since diagnosis. There is still little evidence to suggest that the illness stages of cancer and/or parental treatment determine how children and adolescents function [15]. Chin and Lin [16], for example, found that children in their study were informed about the diagnosis soon after; however, few understood why it happened, which meant that some children thought they were the cause of cancer. Over time, for example at school, children learnt about the causes of cancer including genetics, nutrition and lifestyle.

O'Neill et al. [17] found discrepancies in how the word cancer is perceived by parents, compared with children. Some parents were amazed at how their children adapted to the illness terminology, openly used the word 'cancer' and were able to understand treatments and side effects. When children themselves were asked about the word, they expressed hatred towards the word, feeling scared, shocked, annoyed as well as silly, mean and ridiculous [17]. These discrepancies, overall, support what research has suggested that factual knowledge about cancer is lacking in society and is poorly portrayed in the media [8].

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This chapter is focused on exploring the impact of parental cancer on families, children and young people, based on the knowledge currently available, as well as critically exploring the current limitations and areas where more research is required for a more comprehensive understanding of cancer on the family, children and young people. The chapter also shows the variety of effects that parental cancer can have in general, but it is important to consider the individual, their personality, their coping abilities and the context they were living in at the time of parental cancer. This means their experience is unique and should be understood fully as unique, as their own. Young people share some similarities or could share some outcomes in common, but it is important to understand the individuality and provide support to the specific needs and struggles of a particular child or young person.

Chapter Highlights

- Cancer experiences are shaped by children, young people and families' understanding of the illness.
- The impact of parental cancer is varied; the literature has reported mixed findings.
- Cancer research methodologies are different and therefore comparisons between studies and contexts are limited.
- Children and young people are entitled to experience positive outcomes even at a critical time of parental cancer.
- Different factors can also explain differences in outcomes including illness stage, age, sex, coping skills, previous knowledge and relationships with professionals.

1.2 Understanding the Impact of Parental Cancer

Children and young people around the world can be significantly impacted by a diagnosis of parental cancer; however, a major challenge that currently exists is accurately quantifying how many children and young people are affected by parental cancer. Different studies, within the same country and in different ones, include reports of the percentage of patients that have dependent children, which range anywhere between 5% and 30% [18]. Several reasons can explain this difference. One of the reasons is a lack of a systematic approach to quantifying patients accurately and a failure to include information about their family, particularly those who have young children or adolescents. Leedham and Meyerowitz [19] described the children of cancer patients as 'second order patients' due to the impact that parental cancer can have on them, as parental cancer is described as a 'unique stressor' that can lead to a deterioration in their quality of life.

One of the current limitations to comprehensively understanding the impact of parental cancer in children and young people is that research usually presents the effects of parental cancer as two very definite and separate categories. Effects

are either positive or negative, but to date the author has not identified a study that is purposefully aimed to understand the effects as a continuum, where children and young people may experience negative, positive and mixed effects of parental cancer in different areas of their lives. This chapter, following the way the evidence is presented currently, includes a separate section for positive and negative outcomes, but proposes that the impact of parental cancer on children and young people should be understood as a continuum that may affect some areas of a child's life differently and this continuum may also be dynamic and change over time.

1.3 Mixed Findings

This section is focused on identifying the impact of parental cancer. From the start it is important to be transparent and the answer is *it depends*. The findings are mixed and there are also several reasons why this is the case. Some studies have even reported mixed findings within the same study. There are also very different outcomes reported across studies, contexts and countries, so comparison can be complex. Another reason for mixed findings is the fact that little evidence exists from a longitudinal perspective. Studies are usually cross-sectional and therefore more clarity on and understanding of the impact over time are needed to be able to better support children and young people.

Walczak et al. [3] reported, for example, that parental cancer may have both a positive and a negative impact on children and young people. Most children who experience parental cancer will show resilience and capacity to cope; however, some will experience separation anxiety, anger, sleep disturbance and low self-esteem [20]. For example, other studies reported only negative outcomes. Altun et al. [21] carried out a study in Turkey to explore the impact of maternal breast cancer on children. It was found that, in comparison with the control group with healthy parents, these children had more behavioural problems, higher levels of attention deficit, hyperactivity and total difficulty scores. Girls in this study also had higher levels of emotional and peer relationship issues than boys and more fear of getting ill themselves [21].

Visible and external cancer symptoms also impact on the way adolescents perceive parental cancer. Lindqvist et al. [22] found that better physical health in the ill parent was associated with more psychological distress in adolescents. There are two explanations of this finding. First, the lack of visible physical symptoms may make adolescents feel insecure about what to expect from the illness. The second explanation provided was that the lack of physical symptoms might mean that families do not acknowledge cancer due to the lack of tangible evidence and, because of this, adolescents are not provided with opportunities to express themselves and deal with their emotions [22]. This is something healthcare practitioners need to be aware of, ensuring opportunities are provided for children and young people to express their emotions and concerns particularly when parents do not have visible or obvious indications of the cancer (scars, hair loss, etc.).

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Several reasons have been provided by the literature to help understand these mixed findings:

1. **The informant.** Studies have found differences in the level of distress reported depending on who it is reporting on the child or young person's symptoms, specifically if it is the parents or the children themselves [14, 23]. According to the literature, parents struggle to perceive and report on children's distress regarding both internalising (anxiety/depression) and externalising behaviour (e.g. aggression) as well as emotional and behavioural problems [23]. Watson et al. [24] found that fathers identified lower rates of problems than mothers, suggesting that fathers may be less aware of their children's needs than mothers. However, this study is 15 years old and gender roles in the family may have evolved since then.
2. **Timing.** Differences in the impact and symptoms reported have to do with the timing of when the reports were made (close to diagnosis, months or years after diagnosis) [23]. Longitudinal studies have also been able to identify that those outcomes tend to change over time, for example some studies reported a decrease in adolescents' anxiety and depression over time. This shows that reporting outcomes, in effect, vary depending on when the outcome is measured alongside the development of the illness [23]. Other studies, for example, found that relapse placed additional strain on the family and therefore was also linked to higher levels of unmet needs that may not have been identified at other stages [25].
3. **Age.** Regarding age, findings are mixed. Some studies have described that children's level of experienced emotional distress varies according to their age [23]. Older children have an increased capacity to foresee the potential consequences of cancer and therefore older adolescents seem to experience more externalising problems due to this increased awareness [15, 25]. Other studies, however, have found no evidence to suggest age as a predictive factor of children's adjustment to parental cancer [26]. Some studies also include a very wide age range and use 'children' as an umbrella term. For example, Graungaard et al. [27] evaluated somatic symptoms in children who had a parent with cancer and included 0- to 20-year-olds. This may eliminate the possibility of having a developmental understanding of parental cancer, ignoring the emotional, physical and overall developmental differences that human beings experience at every stage of their life which can impact on how parental cancer may or may not affect them.
4. **Gender of the ill parent.** Differences were identified according to the ill parent's gender. For example, some studies found that girls with ill mothers experienced more anxiety and depression than girls with ill fathers and having an ill father was associated with more unmet needs in young people [23, 25].