The impact of parental cancer on adolescent and young adult offspring

Julia Nellie Morris

School of Psychology

The University of Adelaide

A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

September 2018

Contents

List of Tables

List of Figures

Abstract

A parent's cancer is linked to a variety of psychological, behavioural, and physical problems in their offspring. Despite what is already understood about parental cancer, there is a dearth of research specific to offspring aged in their adolescence and young adulthood at the time of their parent's illness. Understandings are also undermined by an absence of Australian data concerning the number of offspring whose parents have cancer. Furthermore, research in the area is limited by an overwhelming focus on offsprings' psychopathology, which overshadows the possibility of adaptive outcomes that may occur. This research therefore aims to improve understanding of how offspring in their adolescence and young adulthood at the time of parental cancer are impacted; enumerate and describe the cohort in Australia; and investigate adaption to parental cancer in terms of emotion, posttraumatic growth, and resilience. Three independent but related research papers are produced.

Study One is a systematic review of the psychological, social, and behavioural impact of parental cancer on offspring in their adolescence or young adulthood at the time of their parent's diagnosis. The majority of adolescents and young adults were significantly impacted by their parent's cancer. Daughters and offspring who experienced a greater number of problems at their parent's diagnosis were most impacted. Offspring refrained from communicating their disease-related concerns to their parents, but simultaneously expected open communication from their parents. Turning to oneself and peer-support were commonly-used coping strategies.

Study Two is a retrospective cohort study using linked whole-population data from the Western Australia Data Linkage System. From 1982 to 2015, 57,708 offspring were impacted by 34,600 parents' incident malignant diagnoses. The most common diagnosis was breast cancer (19%). Most families resided in regional areas (60%) and were of high or middle socioeconomic status (76%). Cox proportional hazard models indicated significant predictors of earlier parent death included low socioeconomic status and geographic remoteness.

Study Three is an online survey examining how coping predicts adaption to parental cancer in terms of resilience, emotion, and posttraumatic growth among (*n* = 244) adolescent and young adult offspring. Adaptive coping was associated with increased posttraumatic growth, resiliency, and positive affect; whereas maladaptive coping was associated with decreased resiliency and greater negative affect. Females and offspring who did not access support in relation to their parent's cancer reported higher adaptive coping. Offspring bereaved by parental cancer reported higher maladaptive coping, whilst those whose parents' cancer was of shorter duration and those who lived with their ill parent had lower adaptive and maladaptive coping.

Results of this research highlight the burden that parental cancer has on adolescent and young adult offspring, and has implications for supportive care. First, the proportion of maternal diagnoses demonstrate a possible need for practical support for offspring to alleviate caregiving burden. Second, socioeconomically disadvantaged and geographically isolated offspring may benefit from support that augments face-to-face delivery (i.e. internet-based), especially if they are bereaved. Third, adaption to parental cancer may be improved through interventions that aim to increase adaptive coping, as this was linked to positive emotion resilience, and posttraumatic growth.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968. I acknowledge that copyright of published works contained within this thesis resides with the copyright holder(s) of those works. I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time. I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Published work:

Morris J, Turnbull D, Preen D, Zajac I, Martini A. (2018). *The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10–24 at time of diagnosis: A systematic review.* Journal of Adolescence. 2018; 65:61-71. doi: 10.1016/j.adolescence.2018.03.001

Signed: Date: 13 September 2018

Acknowledgements

There are many people I would like to thank for helping me along this wild ride. First of all, my supervisory team, whose help was integral to my completion. To my principal supervisor, Professor Deborah Turnbull. You allowed me and my laugh to make camp in the Hughes 721 antechamber, and adopted me partway through PhD. Thank you for your ongoing support, wisdom, and guidance. Dr Angelita Martini, thank you for convincing me to give it a go, and for believing in my ability. I am grateful for your enthusiasm towards fostering my career, even when I tested your patience with my poor attention to detail. Dr Ian Zajac, thank you for your constructive ideas and feedback, and your candour. I appreciate how responsive and dependable you were, and for your efforts to communicate with me via memes. Professor David Preen, thank you for your consistency, thoroughness, and expertise. You gave me the opportunity to commence my PhD, and for that I am very thankful.

To the office, or what I will now call the Room of Ultimate Friendship and Support, I had a blast. Vic, Amber, Clare, Christianna, and Maddy, thank you for the very good time.

To my family, thank you for your unwavering love and support. Mum and Dad, I am so lucky to have you as my parents. Thank you for everything. I hope I make you proud.

To my friends, in particular Kate and Jemma, thank you for making me laugh, and for keeping up with my ceaseless rants.

And finally, to Dave. Thank you for your tireless support through the ups and downs of PhD, and for loving me even when I put my cold feet on you. You and our longboy Smog are everything a gal could want.

Thank you.

Funding

My candidature was supported by an Australian Government Research Training Program Scholarship, and a University of Western Australia School of Population and Global Health Cancer Data Linkage Ad Hoc Scholarship. The linked data component of the research was supported by grant funding from the University of Western Australia's School of Population and Global Health and CanTeen Australia.

Overview

The thesis begins with a review of the literature regarding parental cancer, which provides the background through which this research evolved. Chapter 1 is concluded with an outline of the thesis aims. Following on from this, Chapter 2 provides rationale for decisions made in the thesis, in order to provide the reader with more context regarding definitions, terminology, and methodology used throughout the dissertation. Chapter 3 then describes the methodology of the three papers by detailing their designs, materials and analyses. Chapters 4 through 6 contain the three papers and respective statements regarding each author's contribution. In Chapter 7, the findings of the thesis are synthesised and discussed. This final chapter also acknowledges the strengths and limitations of the research, discusses its significance and implications, provides suggestions for future research, and presents a concluding statement.

References and appendices for all chapters are available at the end of the thesis. Throughout the thesis, tables and figures are numbered consecutively.

CHAPTER 1. INTRODUCTION AND LITERATURE REVIEW

1.1 Preamble

This thesis examines the impact that a parent’s cancer has on their adolescent and young adult offspring. The following chapter provides a review of the literature regarding the ways in which offspring of all ages are impacted by their parent’s cancer, and factors mediating this impact, such as disease factors. The following review considered any literature published up until August 2018. In this chapter, three major literature gaps are then outlined, which guide the studies undertaken in this thesis. These gaps include limited evidence specific to how adolescent and young adult offspring are impacted (12 – 24 years); the absence of data quantifying the number of offspring affected by a parent’s cancer in Australia; and limited understanding of positive outcomes occurring in response to parental cancer. To conclude, the aims of the thesis in terms of its three studies are outlined.

1.2 Literature Review

1.2.1 Parental cancer and its impact on offspring

Cancer is a leading cause of morbidity and mortality globally (World Health Organisation, 2015). Every year, it is estimated that 8 million people die from the disease (World Health Organisation, 2017), corresponding to 1 in 6 deaths due to cancer (World Health Organisation, 2017). In Australia, cancer is a major cause of illness and the leading cause of disease burden (Australian Institute of Health and Welfare, 2017). National estimates suggest that on average, 367 new diagnoses of cancer occur each day, with breast cancer being the most common, followed by colorectal, prostate, and melanoma (Australian Institute of Health and Welfare, 2017). Besides the public health challenges created by cancer, there are substantial consequences for the diagnosed individual and their families, who too are exposed to illness-related stressors (Armistead, Klein, & Forehand, 1995). When an individual diagnosed with cancer is a parent, the physical and mental health, and normative development of their offspring may be compromised (Pederson & Revenson, 2005).

A parent's cancer is a significant stressor for their offspring (Jeppesen, Bjelland, Fossa, Loge, & Dahl, 2016), and is linked to their experiencing a variety of psychological and physical health problems (Chen, Sjölander, et al., 2015; Huizinga, Van der Graaf, Visser, Dijkstra, & Hoekstra-Weebers, 2003; Krattenmacher et al., 2013; Niemelä et al., 2012; Phillips, 2014). As a result of parental cancer, offspring report both short- and long-term losses (Leedham & Meyerowitz, 1999). Various studies have demonstrated the impact of parental cancer on offspring, and have conceptualised this impact in terms of a range of emotional responses. First learning about a parent's cancer is experienced by offspring as a sense of loss (Finch & Gibson, 2009) and in many cases, a significant disruption to normality (Chalmers et al., 2000; Clemmens, 2009; Davey, Askew, & Godette, 2003; Davey, Gulish, Askew, Godette, & Childs, 2005; Finch & Gibson, 2009; Kristjanson, Chalmers, & Woodgate, 2004; Maynard, Patterson, McDonald, & Stevens, 2013; Phillips, 2015; Phillips & Lewis, 2015; Sheehan & Draucker, 2011; Spira & Kenemore, 2000).

In response to their parent's cancer diagnosis, offspring experience a variety of negative emotions, including worry (Davey et al., 2003; Davey et al., 2005; Finch & Gibson, 2009; Phillips & Lewis, 2015), sadness (Davey et al., 2005), and shock (Finch & Gibson, 2009), and report feeling worn down, unprepared, and nervous (Clemmens, 2009). Negative reactions to a parent's cancer diagnosis is related to greater dysfunction, both retrospectively and prospectively (Gazendam-Donofrio et al., 2011). Offspring whose parents have cancer demonstrate significantly higher levels of distress, anxiety, and depression compared to the general population (Phillips, 2014). They also exhibit problematic behaviour, including decreased competencies in school, sports, social relationships, and other activities that manifest as withdrawal, boisterousness, compulsivity (Huizinga et al., 2003), conduct problems, hyperactivity, inattention, or antisocial behaviour (Krattenmacher et al., 2013). The lasting detriment of parental cancer has been demonstrated in longitudinal studies, where offspring who experienced parental cancer in childhood or adolescence have lower educational and socioeconomic attainments in adulthood (Joergensen, Kjaer Urhoj, & Nybo Andersen, 2018). Furthermore, offspring affected by parental cancer access more specialized psychiatric services than the norm and do so at a younger age (Niemelä et al., 2012), and are at higher risk of all-cause mortality (Chen, Sjölander, et al., 2015).

1.2.1.1 Illness characteristics and their impact on offspring

Rather than conceptualising parental cancer as a single event, it is important to consider the different elements that may impact offspring across the trajectory of their parent's illness. Rolland's (1987) psychosocial typology of illness model defines illness in terms of different dimensions. In response to the illness dimension, one must perform relevant adaptive behaviours in response to varied psychosocial demands (Chen, 2017; Korneluk & Lee, 1998). These dimensions include illness onset (acute versus gradual); course (episodic/relapse, constant, or progressive); outcome (terminal or not); and degree of incapacitation (e.g. cognitive, sensation, movement, energy etc.) (Rolland, 1987).

Regarding disease onset, offspring may fare better if their parent's cancer progresses slowly, allowing offspring to adapt and adjust flexibly, and providing some level of preparedness (Pederson & Revenson, 2005). This has been demonstrated in the literature, where unpredictability around parental illness was associated with more difficulties in offspring (Ireland & Pakenham, 2010). Conversely, gradual onset has also been linked to offspring experiencing greater total difficulties, poorer physical health, and lower levels of prosocial behaviour (Ireland & Pakenham, 2010). Furthermore, results of a mixed-method cross-sectional study indicated that children bereaved by prolonged illness report higher maladaptive grief and posttraumatic stress symptoms than those bereaved by sudden death (Kaplow, Howell, & Layne, 2014). It is suggested that gradual onset may create more problems as offspring are exposed to a progressive decline in a parent’s physical and mental health (Ireland & Pakenham, 2010).

Relatedly, the outcome of a parent’s cancer will have significant implications for the ways in which offspring are impacted. A parent’s death is linked to long-term adverse psychological and physical consequences in their offspring (Marks, Jun, & Song, 2007; Patterson & Rangganadhan, 2010) who report a variety of negative feelings including grief, anger and depression (Patterson & Rangganadhan, 2010). As demonstrated in qualitative interviews, bereaved offspring have identified their parent’s death from cancer as the worst event to happen. However, these offspring also report relief for their parent and themselves following the death (Sveen, Kreicbergs, Melcher, & Alvariza, 2015). Reasonably, this may be somewhat due to offspring’s anticipatory grief regarding their impending loss (Werner-Lin & Biank, 2009) which may assist in preparing them for the event. It may also be because the deterioration of their parent due to cancer is more distressing than the death itself. Such deterioration may be worsened by aggressive cancer treatments that are favoured by patients with terminal cancer (Park et al., 2017), in order to maximise their time with their offspring (Arnholdt & Haier, 2017). The distress experienced by offspring may also be exacerbated by the increased emotional and practical responsibilities they must adopt to help their dying parent (Park et al., 2017). In this sense, offspring may experience the time preceding bereavement as more distressing than the death itself; which was demonstrated in a quantitative evaluation study where offspring’s anxiety and depression was elevated before their parent’s death, but comparable to the norm at 7 – 12 months post-death (Siegel, Karus, & Raveis, 1996).

Offspring may be differentially impacted by their parent’s cancer depending on the nature of the diagnosis. Offspring may be greater impacted if their parent’s cancer includes a significant degree of debilitation, which magnifies the sense of threat (Lewandowski, 1996; Pederson & Revenson, 2005) and poses a higher caregiving burden. Parental illness often necessitates altering normal roles (Pakenham & Cox, 2015), where other family members, including offspring, adopt the role of parent (Pederson & Revenson, 2005) or caregiver (Bartfai Jansson & Anderzen-Carlsson, 2017; Ireland & Pakenham, 2010, 2010). In this sense, offspring adopt a dual role in which they must support their parent, as well as themselves (Pederson & Revenson, 2005). Offspring may be relied upon to provide domestic support and care for their siblings, as well as provide direct care to the unwell parent, in terms of emotional and/or financial support and personal care (e.g. assistance showering) (Bartfai Jansson & Anderzen-Carlsson, 2017; Ireland & Pakenham, 2010, 2010; Pederson & Revenson, 2005; Torp, Thoresen, Grønningsæter, Grov, & Gustavsen, 2013). If the parent’s cancer is significantly debilitating, offspring may be burdened with more responsibilities. Alternatively, offspring may suffer greater impact if their parent’s cancer is one that is commonly stigmatised (Pederson & Revenson, 2005), such as lung cancer, because of the implied responsibility for being diagnosed with the disease (e.g. a history of tobacco use or other lifestyle behaviours (Cataldo & Brodsky, 2013)). Stigma related to the type of parental cancer may create psychological stress and subsequently affect health and wellbeing (Pederson & Revenson, 2005). Finally, offspring may be acutely distressed if their parent’s cancer has a strong hereditary component (Küçükoğlu & Çelebioğlu, 2013; Spira & Kenemore, 2000), because of the threat this poses for their own health.

1.2.1.2 The family structure and relationship dynamics

Besides illness characteristics, the family structure may have implications for the ways in which offspring are impacted by their parent’s cancer. In two-parent households, offspring may be protected against the brunt of their parent’s cancer by having another healthy parent who they perceive as emotionally and physically available (Houck, Rodrigue, & Lobato, 2007) and thus can rely on for support. Alternatively, in single-parent households, offspring may have less support and more practical and emotional responsibilities, as their parent’s incapacitation is more distinct (Park et al., 2017). Among offspring affected by parental cancer, single parenting status is related to higher posttraumatic stress disorder symptoms (Kobayashi, Heiney, Osawa, Ozawa, & Matsushima, 2017). Moreover, offspring’s psychological symptoms are more strongly correlated with the quality of communication with their healthy parent than with their ill parent (Houck et al., 2007), highlighting the degree to which offspring rely on the healthy parent. Reliance on the healthy parent may be particularly relevant among bereaved offspring in terms of their psychological wellbeing (Cohen, Wellisch, Ormseth, & Yarema, 2017). Also, where parents with terminal cancer report concerns about how their widowed partner will manage alone with children (Park et al., 2017), such concern would be extremely challenging for single-parents with terminal cancer.

Although there are clear benefits to offspring belonging to a two-parent family, there are also problems unique to this structure. Facing a partner’s cancer whilst rearing children can impact the healthy parent’s psychological functioning and quality of life, and in turn affect their parenting abilities (Senneseth, Hauken, Matthiesen, Gjestad, & Laberg, 2017). If offspring detect a lack of emotional availability in their healthy parent, they may be acutely distressed. Such distress may occur as conflict with a healthy parent can prompt feelings of vulnerability and isolation if the child concurrently perceives their sick parent as fragile and thus unreliable for support (Houck et al., 2007). Additionally, tension between parents can occur if the healthy parent’s needs are overshadowed by the ill parent’s cancer (Corney, Puthussery, & Swinglehurst, 2016). If offspring notice such tension between their parents, it may further exacerbate their distress related to their ill parent’s cancer.

In addition to the parenting structure, other family members and the family dynamic may change the ways in which offspring experience and are impacted by their parent’s cancer. Arguably, offspring may benefit from a larger nuclear and extended family, from who they could receive emotional and practical support in regards to their parent’s cancer. However, a larger family may mean more complicated family dynamics, which may also be a factor that moderates how offspring are impacted. Family roles are commonly restructured as a result of parental cancer (Pakenham & Cox, 2015), and functioning can be affected if new roles are perceived to be unfairly assigned (Pederson & Revenson, 2005). Presumably, the likelihood of this occurring may be higher in families with more members, as more people must be satisfied.

If role restructuring is perceived to be unfair, it may be problematic for offspring, as chaotic family functioning at the time of parental cancer is found to be a predictor of later posttraumatic stress disorder symptoms (Teixeira & Pereira, 2016). Dysfunction and stress among family members may occur if offspring’s illness appraisals or coping strategies are incongruent with those with other family members (Pederson & Revenson, 2005). Also, research has demonstrated that offspring report disappointment in other family members including siblings and their healthy parent if they are perceived as being unhelpful to the parent with cancer (Bartfai Jansson & Anderzen-Carlsson, 2017). Given that variation in illness appraisals, coping strategies and perceived helpfulness will likely increase if there are more family members encountering the illness, there is greater potential for conflicting perspectives within larger families. Overall, it appears that in the wake of parental cancer, family dynamics and discordance between family members may influence how offspring are impacted by their parent’s illness.

1.2.1.3 Parent-child communication

It has been consistently demonstrated that communication about the parent’s cancer is important to supporting offspring (Finch & Gibson, 2009; Lindqvist, Schmitt, Santalahti, Romer, & Piha, 2007; Morris, Martini, & Preen, 2016; Thastum, Johansen, Gubba, Olesen, & Romer, 2008; Turner, 2017). Where transparent and honest (i.e. open) communication has demonstrated benefits, withdrawn or avoidant (i.e. closed) communication has done the opposite. Open communication is linked to promoting trust between the ill parent and their child (Landry-Dattee et al., 2016), and fostering family resilience (Chen et al., 2017). Among offspring bereaved by parental cancer, communication with the surviving parent is essential to their coping and their ability to grieve (Sveen et al., 2015). Further, daughters bereaved by maternal cancer face a higher psychiatric risk if their families were characterised by closed communication about their mother’s cancer and death (Cohen et al., 2017). For parents with cancer, closed communication with their offspring is linked to increased anxiety and depression (Meriggi et al., 2017), whereas open communication is linked to better relational and physical health (Fisher, Wolf, Fowler, & Canzona, 2017). Understandably, a parent’s cancer may compromise their ability to support their offspring (Berggren & Hanson, 2016; Laccetti & Vessey, 2007), and many parents may fail to recognise and may even minimise their offspring’s needs because they are overwhelmed by their illness (Lewandowski, 1996). Meanwhile, their offspring will often hide their feelings (Bartfai Jansson & Anderzen-Carlsson, 2017; Clemmens, 2009; Finch & Gibson, 2009; Fisher et al., 2017) about their parent’s cancer, in order not to further burden their ill parent. This presents a problematic dynamic in which there is a lack of parent-child communication about the parent's cancer and its impact on the offspring.

Despite the benefits of communication, parents find it difficult to discuss their cancer (Landry-Dattee et al., 2016) as doing so is emotionally distressing (Park et al., 2016). Parents report concerns about openly communicating with their offspring, and identify barriers that hinder them from doing so, which include difficulty accepting their prognosis, uncertainty about their disease, offspring avoiding communication (Yopp, Mayer, & Park, 2016), and a lack of professional guidance and resources to assist their communication (Park et al., 2016; Yopp et al., 2016). Whilst these concerns and barriers exist, failing to communicate with offspring about the parent's cancer is suggested to be more damaging (Landry-Dattee et al., 2016). On the contrary, it is suggested that open communication can increase offspring's agency and thus wellbeing in response to their parent's cancer (Turner, 2017).

1.2.1.4 Unmet needs and support

Research has demonstrated that offspring affected by parental cancer have reported unmet needs in accessing support in professional, emotional and social domains (Patterson, McDonald, White, Walczak, & Butow, 2017; Patterson, Pearce, & Slawitschka, 2011). Moreover, their level of unmet needs are positively correlated with adverse mental health scores (Patterson et al., 2011) and greater distress (Patterson et al., 2017). Where some unmet needs are specific to bereaved offspring (e.g. having time to grieve) (Patterson & Rangganadhan, 2010), others are reported by both bereaved and non-bereaved offspring (e.g. time out or help to address their feelings) (Patterson et al., 2017; Patterson & Rangganadhan, 2010). Among a sample of parents who had survived cancer, 50% reported that their children were not emotionally supported throughout their cancer experience (Bell, Reed, Blackmon, Kim, & Joseph, 2016). Further, results of cross-sectional research has demonstrated that offspring report that they encounter a lack of support in dealing with their parent’s cancer (Giesbers, Verdonck-de Leeuw, van Zuuren F. J., Kleverlaan N., & H., 2010).

Although there is a lack of support provided to these families, the existing support programs and interventions have demonstrated favourable outcomes. Examples of such support includes group and individual therapy for children, family-based psychosocial support, and parenting programs. Cross-sectional studies have reported improved parent-child communication (Landry-Dattee et al., 2016; Phillips & Prezio, 2017; Vestergaard & Dieperink, 2017), improved school performance (Phillips & Prezio, 2017) and reduced anxiety (Phillips & Prezio, 2017). Pre- and post-intervention evaluations have demonstrated reduced stress among offspring (Kobayashi et al., 2017), better quality of life among parents (Kobayashi et al., 2017), and greater psychological wellbeing among family members (Lovely et al., 2016). Also, randomised control trials have demonstrated improved family functioning (Hauken, Pereira, & Senneseth, 2017), and social support (Senneseth et al., 2016). Despite the mounting evidence that interventions are helpful to families affected by parental cancer (Olsson, Lundberg, Furst, Ohlen, & Forinder, 2017; Shah, Armaly, & Swieter, 2017), there are also reported problems with what support is available, and concerns regarding the degree to which these are backed by empirical evidence regarding their effectiveness (Phillips & Prezio, 2017). Offspring report that family based interventions are too parent-focused (Phillips & Prezio, 2017), whilst parents report interventions are offered too late (Stinesen Kollberg, Wilderäng, Möller, & Steineck, 2014) and that support is not applicable to their illness needs (Turner et al., 2007).

1.2.1.5 Summary

In sum, a parent’s cancer is linked to psychological (Niemelä et al., 2012; Phillips, 2014), behavioural (Huizinga et al., 2003; Krattenmacher et al., 2013), physical (Chen, Sjölander, et al., 2015) and social (Krattenmacher et al., 2013) consequences in offspring. Such consequences are moderated by various domains including illness characteristics, family structure and interfamilial relationships, communication, and offspring's unmet needs and support. If offspring are challenged by circumstances in the aforementioned domains, they may suffer greater impact from their parent's cancer. For example, offspring who have unmet needs relating to communication with their parent may suffer acute impact. This impact may be compounded if offspring also have a limited family network or strained familial relationships from which they receive little emotional support.

Whilst there is understanding as to what impact a parent's cancer has on their offspring, there is a dearth of evidence specific to the experiences of offspring in their adolescence and young adulthood (12 – 24 years) at the time of parental cancer. In addition, there are limitations in the current literature relating to the number of offspring affected and their sociodemographic characteristics, as well as the overwhelming focus on psychopathology. These limitations are discussed in the following section.

1.2.2 Adolescent and young adult offspring

Research focused on the impact of parental cancer has largely overlooked the experiences of offspring in their adolescence and young adulthood (12 – 24 years) at the time of parental cancer. Considering these young people is warranted, as experiencing parental cancer during these formative years may have significant development consequences. To summarise the extent to which adolescent and young adults are overlooked, a list of peer-reviewed studies regarding parental cancer and the age of offspring at the time of the disease is available in Table A1 (see page 161). Evidently, research has commonly focused on the impact of parental cancer on dependent children (0 – 18 years; *n* = 88 studies), with other studies focusing on adult offspring (*n* = 6 studies), or offspring of all ages (*n* = 5 studies).

Many studies also overlooked offspring age at the time of their parent’s cancer by not defining their age (*n* = 53 studies). Furthermore, of the studies that did not specify offspring age, most (*n* = 35) specified in their title that the study focused on adolescents, teenagers, or young adults. This means that potentially distinct or shared experiences and reactions to parental cancer have not been disentangled between age groups. Of the research that has claimed to focus on adolescent and young adult offspring, much of it is methodologically flawed in that its samples consist of offspring in their adolescence or young adulthood at the time of the study, rather than at the time of parental cancer. This has implications for understanding the impact of parental cancer on adolescent or young adult offspring, as current understanding is arguably based on non-representative samples. Maintaining focus on adolescent and young adult offspring (12 – 24 years) impacted by parental cancer can only be realised if the sample consists of adolescents and young adults. This can be achieved by focusing on offspring in their adolescence or young adulthood at the time of their parent’s cancer diagnosis.

1.2.2.1 Offspring age

It is posited that offspring’s age at the time of their parent’s cancer mediates the ways in which offspring respond to the illness (Armistead et al., 1995). Literature reviews have indicated there are age-related differences in offspring’s coping and support needs (Ellis, Wakefield, Antill, Burns, & Patterson, 2016), perceived stress (Lazarus, 1974), and comfort (Mosher & Danoff-Burg, 2005). Results of cross sectional research has demonstrated age differences in variability in functioning (Visser, Huizinga, Hoekstra-Weebers, van der Graaf, & Hoekstra, 2004), distress (Compas et al., 1994), anxiety (Hauken, Senneseth, Dyregrov, & Dyregrov, 2017), as well as differences in offspring’s communication and relationship with their sick parent (Schrag, Morley, Quinn, & Jahanshahi, 2004). Moreover, results of a population-based survey found a link between age and variations in psychosocial maladjustment symptomology (Barkmann, Romer, Watson, & Schulte-Markwort, 2007).

Evidently, there is a need to consider age-related differences by defining offspring age at the time of their parent’s cancer; especially in relation to adolescent and young adult offspring, who have been underrepresented in the research. Besides their underrepresentation, research suggests that older children are at greater risk than younger children in response to parental illness (Pederson & Revenson, 2005), and are therefore worthy of investigation. Where younger children report more stress response symptoms in response to a parent’s cancer, adolescent and young adult offspring report higher levels of anxiety and depression (Compas et al., 1994). Adolescents and young adults whose family member is diagnosed with cancer report levels of distress symptoms comparable to that of young people seeking treatment for mental health issues (Patterson et al., 2017). Additionally, adolescents and young adults report more distress, higher mean levels of distress, and higher levels of unmet needs if they have a parent with cancer, compared to those with a sibling with cancer (Patterson et al., 2017). Older children of chronically ill parents have greater role responsibilities than younger children, including household and caregiving responsibilities; and face more activity restrictions, isolation, daily hassles, stress (Sieh, Visser-Meily, & Meijer, 2013). Also, older children often assume responsibility to protect younger siblings from parental illness (Bartfai Jansson & Anderzen-Carlsson, 2017), as well as manage additional external responsibilities, including school (Sieh et al., 2013).

The aforementioned findings dispute the notion that reactions to parental cancer are much the same for offspring regardless of their age (Giesbers et al., 2010), thereby highlighting the need to consider age-related differences. The impact that a parent’s cancer has on their adolescent and young adult offspring is largely unclear because research that has aimed to provide such understanding has been based on non-representative samples.

Specifically, by not defining the age of their sample, or by not including offspring in their adolescence or young adulthood at the time of their parent's cancer. This gap in the evidence has created the need to better understand the impact of parental cancer on their adolescent and young adult offspring, by focusing directly on offspring of this age (12 – 24 years) at the time of their parent's cancer.

1.2.2.2 Developmental considerations

Offspring's developmental stage at which they experience parental illness is a significant moderator of their wellbeing (Pederson & Revenson, 2005). For adolescent and young adult offspring, a parent's cancer may be experienced with heightened acuity because they are concurrently contending with a major developmental transition (Shulman & Ben-Artzi, 2003). Specifically, adolescence represents a formative period (Spear, 2000; World Health Organisation, 2016) that is underpinned by heightened vulnerability (Steinberg, 2005) and characterized by significant physical, emotional and cognitive change (Institute of Medicine & National Research Council, 2015; Sieh, Meijer, Oort, Visser-Meily, & Van der Leij, 2010).

During adolescence, neurodevelopmental changes lead to an intensification of motivational and emotional experiences, which creates challenges in terms of emotional regulation and self-control (Crone & Dahl, 2012) Adolescents are largely driven by social and affective influences, motivating them to explore and take risks (Crone & Dahl, 2012). As a result, this period is underpinned by suboptimal decision making and impulsivity (Crosnoe & Johnson, 2011; Institute of Medicine & National Research Council, 2015): behaviour which is perpetuated when endorsed by their peers (Crone & Dahl, 2012). Although these behaviours lead towards social and emotional learning that is necessary for development, it also indicates that adolescence is a period of intense volatility. As an adolescent transitions into young adulthood, they must make various social, emotional and cognitive advances (Institute of Medicine & National Research Council, 2015; Siegler, 2011) that facilitate developmental milestones such as the capacity to self-regulate one's behaviour and emotions (Gee et al., 2013; Institute of Medicine & National Research Council, 2015; Ryan, 2009). Alongside achieving these developmental goals, the individual must assume greater psychological and practical responsibilities (Shulman & Ben-Artzi, 2003) that are formative for their adulthood and within that, their transition to employment, financial independence, and life partnerships (Patton et al., 2016).

Although developmental change that occurs during young adulthood is less obvious than that during adolescence or childhood, it is no less important (Institute of Medicine & National Research Council, 2015). As the brain is still maturing, a young adult's strengths and vulnerabilities continue to emerge (Institute of Medicine & National Research Council, 2015), and compared to later adulthood, many processes are still in their infancy, such as their socioemotional processing (Institute of Medicine & National Research Council, 2015). Young adulthood is also a time of instability brought on by a need to utilise cognitive control skills that are useful in modifying attention, emotion, and behaviour necessary for later adulthood (Crone & Dahl, 2012).

Compared to preadolescent children, adolescents' advanced cognitive and empathetic capacities result in greater awareness of potential loss and their parent's physical and emotional pain (Christ, Siegel, & Sperber, 1994). Where younger children may be shielded by a lack of understanding, older children (i.e. adolescents and young adults) are able to conceptualise and appraise the event (Lewandowski, 1996) and its consequences. As a result of their increased understanding, older offspring may be more prone to heightened distress and intrusive thoughts (Houck et al., 2007; Pederson & Revenson, 2005) and thus, experience their parent's cancer with greater acuity than younger offspring.

During adolescence and young adulthood (12 – 24 years), success in navigating one’s developmental trajectory is imperative as failure to do so may have profound consequences for psychological and emotional wellbeing. A parent’s cancer diagnosis during these years may be detrimental to offspring by impairing a young person’s ability to meet their normative milestones, thereby disrupting their developmental trajectory. Compared to younger offspring, older offspring have more responsibilities in the wake of parental illness (Sieh et al., 2013) that include caregiving responsibilities (Ireland & Pakenham, 2010). Caregiving has been linked to prosocial behaviours, such as increased maturity and confidence (Ireland & Pakenham, 2010). Conversely, caregiving has also been found to foster adverse outcomes (Ireland & Pakenham, 2010) and interfere with development by interrupting individuation and autonomous identify formation (Barkmann et al., 2007; Pakenham & Cox, 2015).

Besides caregiving responsibilities, older offspring are allocated more household responsibilities. Such responsibilities have developmental ramifications, as they impede on offspring’s leisure time, prohibit them from engaging with their peers (Pederson & Revenson, 2005; Sieh et al., 2013), and reduce their autonomy by tethering them to the family unit (Schmidt & Welsh, 2010). Alongside caregiving and household responsibilities, a mixed-method observational study found that older offspring took financial responsibility following their parent’s cancer by gaining employment (Torp et al., 2013). On the one hand, employment may be beneficial to development by building human capital useful for future job prospects; alternatively, it may also detract from academic pursuits (Crosnoe & Johnson, 2011) which is significant to healthy development (Patton et al., 2016). Similarly, practical responsibilities tasked to older offspring may undermine their capacity to engage beyond their family unit, which is essential for social and emotional development (Patton et al., 2016). Further, a high level of responsibilities may mean that offspring who experience parental cancer in their adolescence or young adulthood will suffer significant ramifications as a result of their parent’s illness, because they are already developmentally vulnerable or instable (Arnett, 2000; Steinberg, 2005).

Overall, research regarding the impact of a parent’s cancer on offspring has largely overlooked the experiences of offspring in their adolescence or young adulthood (12 – 24 years) at the time of their parent’s cancer. Besides the dearth of evidence specific to this cohort, greater focus on adolescent and young adult offspring is warranted because of factors pertaining to age-related differences. The increased cognitive capacity combined with the emotional volatility specific to this age (12 – 24 years) may exacerbate their distress associated with their parent’s cancer. In addition to this, adolescents and young adults must meet a variety of developmental challenges. The practical responsibilities that are commonly tasked to older offspring in the aftermath of parental illness may detract from these developmental milestones and have long term ramifications. Therefore, further research regarding the psychological, behavioural and social impact of a parent’s cancer on their adolescent and young adult offspring (12 – 24 years) is warranted.

1.2.3 An absence of data that quantifies parental cancer

Alongside the dearth of research that specifically examines the impact of a parent’s cancer on their adolescent and young adult offspring, there is also a lack of population-based data that enumerates and describes this cohort in Australia. Outside of Australia, parental cancer has been quantified in an effort to understand the extent of the problem.

In Sweden, a population-based cohort study found that 4% of 2,871,242 children (0 – 18 years) followed between 1991 and 2009 had a parent diagnosed with cancer (Chen, Sjölander, et al., 2015). Among these offspring, there was an increased rate of death by cancer and non-cancer deaths, and this association was greater among adolescents (Chen, Sjölander, et al., 2015).

A separate population-based cohort study found that in Finland, 6.6% of children (0 – 21 years) born in 1987 in Finland had a parent diagnosed with cancer by the age of 22 (Niemelä et al., 2012). This study demonstrated that offspring whose parents had cancer were more likely to access specialised psychiatric care compared to the norm, especially if female (Niemelä et al., 2012).

In Norway, population-based cohort research found that 0.3% of families with children (≤ 18 years) faced a parent's cancer diagnosis each year (Syse, Aas, & Loge, 2012). By 2008, it was estimated that 3.1% of children (0 – 17 years) and 8.4% of young adults (19 – 24 years) had experienced parental cancer, corresponding to a population prevalence of 1.4% (Syse et al., 2012). Of these offspring, 1.9% of children and 2.5% of young adults experienced parental death from cancer in 2007, and most common was a father's death from cancer (Syse et al., 2012).

A Japanese study that utilised hospital data to calculate the population of parents with cancer at a national level concluded that 87,017 children (0 – 18 years) and 56,143 parents experienced parental cancer between 2009 and 2013 (Inoue et al., 2015). Projections from the study indicated that the proportion of children in Japan who had a parent newly diagnosed with cancer was 0.38% in 2010 (Inoue et al., 2015).

Finally, United States estimates derived from national survey data proposed that in 2007, 562,000 dependent children (≤ 18 years) lived with a parent in the early phases of cancer (Weaver, Rowland, Alfano, & McNeel, 2010).

It is proposed that each year in Australia, 10,000 parents are diagnosed with cancer (Camp Quality, 2014), affecting 21,000 adolescents and young adult offspring (12 – 24 years) (Patterson et al., 2017; Walczak, McDonald, Patterson, Dobinson, & Allison, 2017). Problematically, these estimates have been stated without any explanation as to how they were calculated, and there is seemingly no other evidence that quantifies this cohort in

Australia that is based on robust population-based data. Obtaining such data is critical to understanding the extent of the problem in Australia.

International research has demonstrated that large service gaps in the provision of support exist for these families (Semple & McCaughan, 2013; Su & Ryan-Wenger, 2007), with offspring commonly overlooked by supportive care services (Rauch & Moore, 2010) as they themselves are not the patient. By identifying the number and characteristics of Australian families affected by parental cancer, there may be justification for the provision of supportive care interventions that is essential to offspring development and parent coping (Weisman & Worden, 1976; Worden, 1996). Further, population-based data will provide critical information to describe the population in terms of their key characteristics, in order to ascertain what factors contribute to poorer cancer related outcomes and to identify at-risk offspring and parents. For example, these data would describe these families' geographic remoteness and socioeconomic status, both of which are associated with poorer cancer-related survival rates in Australia (Heathcote & Armstrong, 2007; Yu, O'Connell, Gibberd, & Armstrong, 2008). Therefore, in the event that families are geographically isolated and of low socioeconomic status, there may be offspring who face premature parental bereavement due to cancer, highlighting the need for better bereavement care.

Overall, quantifying and describing the population of adolescent and young adult offspring (12 – 24 years) and their parents with cancer in Australia will provide much needed information regarding these families, and respond to a precedent set by international research regarding the impact of parental cancer in other jurisdictions (Chen, Sjölander, et al., 2015; Inoue et al., 2015; Niemelä et al., 2012; Syse et al., 2012). Furthermore, obtaining such data would assist in identifying factors that contribute to poorer outcomes in relation to cancer to better identify at-risk groups, so as to better support offspring and parents who are at risk.

1.2.4 Preoccupation with psychopathology

Another major limitation in the research to date is the overwhelming focus on the psychopathology of offspring whose parents have cancer (Mosher & Danoff-Burg, 2005). Although such investigations have contributed to better understanding the consequences of parental cancer, this research has overshadowed capacity to understand what positive outcomes might occur for offspring (Phillips, 2014; Sidhu, Passmore, & Baker, 2005). Although limited, there is evidence of positive outcomes that occur as a result of parental cancer (Phillips, 2014). Research has demonstrated that adult offspring (24 – 52 years) exhibit gains following their parent’s cancer in terms of improved family values, appreciation, empathy, and reorientation of priorities (Levesque & Maybery, 2012). Children and young-adolescents (7 – 13 years) have demonstrated adaptive functioning in terms of their mental health (Howell et al., 2016); and children and adolescents (8 – 18 years) have reported positive outcomes in terms of increased gratitude and appreciation, and positive incidences relating to personal growth and maturation, prioritising family, and strengthening relationships (Kennedy & Lloyd-Williams, 2009; Kissil, Niño, Jacobs, Davey, & Tubbs, 2010).

Relatedly, offspring affected by parents’ chronic illness, chronic pain, mental illness, and disability have reported positive outcomes in terms of personal growth, such as increased maturity, independence, helpfulness, tolerance, understanding, and responsibility (Armistead et al., 1995; Banks et al., 2001; Johnston, Martin, Martin, & Gumaer, 1992; Pakenham & Cox, 2015; Umberger & Risko, 2016); and closer family relationships (Armistead et al., 1995; Banks et al., 2001). Such findings, albeit resulting from few studies within the scope of parental cancer, demonstrate the need to consider alternatives to the psychopathology approach with respective to exploring offspring outcomes (Howell et al., 2016).

1.2.4.1 Coping as a predictor of adaption to parental cancer

Besides investigating what adaptive outcomes can occur as a result of parental cancer, it is also important to consider what processes result in advantageous outcomes, thereby establishing what factors may offset the negative effects of a parent's cancer diagnosis (Howell et al., 2016). One process that can be modified to achieve more favourable outcomes is coping (Lazarus, 1993; Taylor & Stanton, 2007), definable as cognitive and behavioural efforts to manage stress (Lazarus, 1993). Coping strategies can promote desirable or undesirable outcomes depending on the extent to which they are utilised (Carver, Scheier, & Weintraub, 1989). Within the context of parental cancer, offsprings' problem-focused and approach-oriented coping (resolving or managing the cause of stress) are linked to better mental health whereas avoidant coping (e.g. distraction, withdrawal) are linked to poorer mental health (Krattenmacher et al., 2013). Further, emotion-focused coping (palliating emotions caused by stress) are linked to both better (Krattenmacher et al., 2013) and worse mental health (Compas, Worsham, Ey, & Howell, 1996; Krattenmacher et al., 2013). In addition, offspring's maladaptive coping (e.g. denial, behavioural disengagement) are a significant risk factor for psychological morbidity (Costas-Muniz, 2012) and posttraumatic stress disorder (PTSD) (Wong, Looney, Michaels, Palesh, & Koopman, 2006).

Results of these empirical studies support the notion that outcomes are dependent on the type of coping used (Carver et al., 1989). However, these studies are limited in that they too focus on negative consequences that arise in response to parental cancer. Coping processes can be modified in order to maximise desirable outcomes (Lazarus, 1993; Taylor & Stanton, 2007). Therefore, it is important to establish what type of coping is linked to positive outcomes.

1.2.4.2 Adaption to parental cancer through posttraumatic growth, resilience, and emotion

1.2.4.2.1 Posttraumatic Growth

One way in which offspring may adapt to their parent's cancer is through posttraumatic growth (PTG), which is defined as positive growth or adaption occurring as a result of trauma (Tedeschi & Calhoun, 2004; Zoellner & Maercker, 2006). PTG presents as outcomes including improved personal strength and greater appreciation of life (Tedeschi & Calhoun, 1996). PTG does not imply that distress and growth occur separately in result of trauma, but accompany one another (Tedeschi & Calhoun, 2004). Indeed, it is postulated that distress is a prerequisite of PTG (Tedeschi & Calhoun, 2004), and that stress as a result of trauma may assist or hinder PTG (Meyerson, Grant, Carter, & Kilmer, 2011). Investigating PTG as a function of coping among offspring is warranted because of its adaptive significance in terms of psychological and physical functioning (Meyerson et al., 2011; Tedeschi & Calhoun, 2004). PTG has received attention in psycho-oncological research, such as that focused on adolescents and young adults with cancer (e.g. Sansom-Daly & Wakefield, 2013; Zebrack et al., 2015), but few studies were identified that investigated PTG among offspring affected by parental cancer. However, in the three identified studies, offspring did exhibited PTG (Hirooka, Fukahori, Akita, & Ozawa, 2016; Levesque & Maybery, 2012; Wong, Cavanaugh, Macleamy, Sojourner-Nelson, & Koopman, 2009).

1.2.4.2.2 Resilience

A closely related but separate construct to PTG is that of resilience (Duan, Guo, & Gan, 2015; Tedeschi & Calhoun, 2004), which is defined as a positive adaption following adversity (Windle, Bennett, & Noyes, 2011; Wright & Masten, 2005), as well as a process of avoiding negative outcomes (Luthar, Cicchetti, & Becker, 2000). It is suggested that resilience exists on a continuum (Pietrzak & Cook, 2013). In light of this, it can be argued that resilience is both a protective factor as well as a positive outcome. Offspring affected by parental cancer have demonstrated resilience, such as by choosing to remain positive (Ashurst, Hans, & Smith, 2009; Spira & Kenemore, 2000). Additionally, among families affected by parental cancer, higher resilience has been linked to offspring reporting less stress and better communication (Chen et al., 2017), indicating the adaptive significance of resiliency for offspring experiencing parental cancer. Akin to PTG, investigating resilience as a function of coping will assist understanding as to whether certain styles of coping maximise adaption to parental cancer in terms of resilience.

1.2.4.2.3 Positive emotion

It is posited that resiliency is fuelled by positive emotion (Fredrickson, 2004), and that positive emotion is critical in helping individuals find positive meaning (Tugade & Fredrickson, 2004) and achieve growth (Donaldson, Dollwet, & Rao, 2015; Fredrickson, 2004; Garland et al., 2010). Barbara Fredrickson's Broaden and Build theory suggests the experience of positive emotions broadens one's momentary thought-action repertoires, which in turn builds their enduring personal resources (Fredrickson, 1998, 2004). In other words, positive emotion broadens momentary thought and behaviour, which builds on enduring psychological, social, intellectual, and physical resources. Such resources are argued to be adaptive and durable (Fredrickson, 2004). Furthermore, Fredrickson suggests that where positive emotions lessen the resonance of a negative event, negative emotions do the opposite (Fredrickson, 2004; Fredrickson & Joiner, 2002) .

The role of positive emotion has been investigated in the literature concerning parental cancer, where offspring who made a conscious effort to think positively in response to their parent's cancer enhance their response to uncertainty and anticipatory grief, and facilitate psychosocial development (Ashurst et al., 2009). Conversely, offspring's negative emotions (uncertainty and loneliness) in the wake of a parents' cancer have been linked to their dysfunction (Gazendam-Donofrio et al., 2011). In these examples, it appears that offspring's emotions enable or hinder their adaption to their parent's cancer.

Outside of parental cancer, positive emotion has led to adaptive outcomes in terms of improved physical (Cohen, Alper, Doyle, Treanor, & Turner, 2006; Cohen & Pressman, 2006; Richman et al., 2005) and mental health (Diehl, Hay, & Berg, 2011; Ong, Bergeman, Bisconti, & Wallace, 2006). Specifically, studies have demonstrated that positive emotion is linked to a decreased likelihood of developing a disease (Richman et al., 2005) or illness (Cohen et al., 2006), increased longevity (Cohen & Pressman, 2006) and reporting fewer symptoms when unwell (Cohen et al., 2006). Additionally, research has shown a link between higher levels of positive emotion and improved mental health (Diehl et al., 2011), as well as a moderating effect on stress reactivity and stress recovery (Ong et al., 2006).

The role of positive emotion on outcomes has also been investigated in cancer patients, where low levels of positive affect are recognised as a key cause of psychological distress as demonstrated in a cross-sectional study (Voogt et al., 2005). A randomised control trial involving breast cancer patients demonstrated that induced positive emotional expression reduced hospital visits for cancer related morbidities (Stanton et al., 2002). Furthermore, women with breast cancer who used positive appraisal to cope with their cancer reported improved positive mood and perceived health at 3 and 12 months post diagnosis, and posttraumatic growth at 12 months (Sears, Stanton, & Danoff-Burg, 2003).

Arguably, resilience, posttraumatic growth, and positive emotion are salutogenic constructs, meaning they are factors that support health and wellbeing (Levine, Laufer, Stein, Hamama-Raz, & Solomon, 2009). Investigating these constructs among offspring affected by a parent's cancer will assist in understanding the degree to which offspring adapt to parental cancer in terms of protective factors (i.e. resilience and positive emotion) and positive outcomes (i.e. PTG). These forms of adaption will be investigated as a function of coping, because coping can be modified through intervention (Taylor & Stanton, 2007), thus demonstrating what coping styles are conductive to improved offspring outcomes.

1.2.5 Aims of thesis

As demonstrated in the reviewed literature, offspring are significantly impacted by their parent’s cancer. Although there is understanding around how offspring are impacted, three major gaps in the literature are evident. These include a lack of evidence pertaining to offspring in their adolescence and young adulthood at the time of their parent’s cancer diagnosis or treatment; an absence of data concerning the number of adolescent and young adult offspring impacted by parental cancer in Australia; and overwhelming focus on psychopathology (Mosher & Danoff-Burg, 2005), and little understanding of adaption to parental cancer. These three gaps underpin the studies described in this thesis. Specifically, the thesis examines the impact of a parent’s cancer on young people aged 12 – 24 years through a three-part investigation:

i. Study 1: a systematic literature review of peer-reviewed studies regarding the impact of a parent’s cancer on offspring;

ii. Study 2: a data linkage investigation using the Western Australia Data Linkage System (WALDS) to determine the number and characteristics of these offspring in Western Australia; and

iii. Study 3: an online survey study exploring how coping predicts adaption to parental cancer in terms of resilience, positive emotion, and posttraumatic growth in the cohort.

These projects will contribute to the scientific literature by focusing on offspring who are traditionally underrepresented in this area due to their age and provide much needed evidence that will contribute to effective support strategies that is essential for offspring development (Weisman & Worden, 1976; Worden, 1996).

A chapter is now presented that provides an explanation of definitions and terms used in the thesis (i.e. “offspring” instead of “children”), and provides a rationale for decisions made regarding the three studies. Following on from this, an overview of the methods is provided, prior to the respective studies.

CHAPTER 2. RATIONALE FOR DECISIONS MADE IN THE THESIS

2.1 Preamble

The following chapter aims to help the reader understand how the thesis was developed by providing rationale for definitions, terminology and methodologies used. This includes explanation regarding definitions and parameters developed in relation to each of the studies in the dissertation.

2.2 Defining the study population of offspring

This thesis focuses on offspring in their adolescence and young adulthood at the time of their parent's cancer. Regarding terminology, 'offspring' was utilised throughout the dissertation as it refers to a person's child, irrelevant of age, and was a term consistent with that used in other research in the area (e.g. (Kim & Park, 2014; Niemela et al., 2016; Patterson et al., 2013; Patterson et al., 2011; Verkooijen et al., 2013)). Terminology not used in this thesis included the acronym 'AYA' (adolescents and young adults) because of its connotation as a term to describe young people *with* cancer (Cancer Australia & CanTeen, 2008; Lewis et al., 2014; Medlow & Patterson, 2015; National Cancer Institute, 2015; Patterson & McDonald, 2015; Patterson, McDonald, Zebrack, & Medlow, 2015).

Regarding age, adolescents and young adults were defined as those aged 12 – 24 years. This age range was selected as it closely aligns with the World Health Organisation (WHO) definition of adolescents and young adults (10 – 24 years) (World Health Organisation, 1986); whilst adopting the same age delineation set by Australian government (Australian Institute of Health and Welfare, 2011) and cancer support organisations (CanTeen, 2016).

2.2.1 Population age change between Study 1 and Studies 2 and 3

At the conception of the thesis, adolescent and young adult offspring were defined as offspring aged 10 – 24 years. This original age delineation was selected because it mirrored WHO definitions of age (World Health Organisation, 2016), which was deemed suitable as it is an internationally recognised source. This 10 – 24 age range was applied to Study 1 (Chapter 4), in that studies satisfied one inclusion criteria if they considered offspring 10 – 24 years at the time of their parent's cancer diagnosis.

The systematic review was submitted and subsequently rejected from the journal Psycho-Oncology. A reason for the rejection that was frequently cited in reviewer comments was that the 10 – 24 year age range was problematic. Specifically, it was noted that the lower limit of 10 years was too young and not representative of adolescence. The feedback was discussed with the supervisory team and it was agreed that progressing with the original age range of 10 – 24 years may lead to future journal rejections. It was decided that the most suitable action was changing the offspring age range to coincide with developmental literature that states adolescence begins at age 12 (Graber, Brooks-Gunn, & Petersen, 1996; Hoffnung et al., 2015; Venning, Eliott, Kettler, & Wilson, 2013), and adopt the same age range for adolescents and young adults as the Australian government (Australian Institute of Health and Welfare, 2011) and the leading cancer support organisation for adolescence and young adults (CanTeen, 2016). Thus, the age range of 12 – 24 years was utilised for Studies 2 and 3, and the introductory and discussion chapters of the thesis (Chapters 1 – 3; Chapter 7).

2.3 Defining families

Another consideration was regarding who could be defined as offspring, given that parent-child relationships vary by definition, and the changing structure of the nuclear or traditional family (Cohen, 2013; de Vaus, 2004; Dempsey, 2013). Nationally, this change has seen the increase of single parent, step, blended, and same-sex parented families (Australian Bureau of Statistics, 2015; Dempsey, 2013). Recent data has identified that 71% of children (≤ 15 years) live with two biological or adoptive parents, and 1 – 4 % lived with a step-parent and biological or adoptive parent (Baxter, 2016). Separate data has identified that 0.1% of Australian children have same-sex parents (Dempsey, 2013). Given the changing dynamics of families and nuclear families becoming less dominant (Cohen, 2013; de Vaus, 2004), it is important that contemporary families are not excluded or marginalised from research (Forster-Jones, 2007). Also, it is important to consider how family dynamics may impact outcomes, as children within non-traditional families may have unique experiences as a result of living with one or more non-biological parents (Forster-Jones, 2007). Thus, offspring may be differentially affected by a parent's cancer depending on the nature of the relationship with the ill parent.

In order to respond to the changing dynamics of families in Australia and include non-biological offspring, research in this thesis considered offspring to be of single-parent, step-parent, blended, and same-sex parented families. This definition of offspring was applied where possible in Study 3 (Chapter 6).

In Studies 1 and 2 (Chapter 4 and Chapter 5), the inclusion of non-biological offspring was restricted. In Study 1, all but one study that met inclusion criteria for review failed to specify the type of relationship between parents and offspring (i.e. biological, adoptive, or step); and no studies offered information beyond whether offspring were of single or partnered parents. In Study 2, the population was limited to biological offspring as recorded on birth certificates because current data linkage has no capacity to link to adoptive, step or surrogate offspring. Given these limitations, it was unclear the extent to which non-biological offspring were represented in Studies 2 and 3, and demonstrated the challenges that arise in investigating contemporary family structures.

2.4 Parent disease factors as parameters

A final consideration made in regard to the thesis was establishing parameters based on parent's disease factors. First, the inclusion of bereaved offspring was debated and it was decided that both bereaved and non-bereaved offspring would be included. Research has demonstrated that bereaved offspring are impacted differently to non-bereaved offspring (Howell et al., 2016), which suggests that combining these offspring may bias results. However, a more relaxed inclusion criteria that considered bereaved and non-bereaved offspring was adopted in order to maximise sample representativeness and facilitate understanding of the impact of parental cancer at different disease stages. In addition, combining these groups set the research apart from other work, which often focuses on one of either group.

Similar to the inclusion of bereaved and non-bereaved offspring, no other restrictions were placed on parental cancer status in terms of disease stage or severity in Studies 1 and 3. In Study 1, no restrictions were placed on parent's disease stage so as to avoid relevant evidence being discarded. This approach was adopted after a preliminary reading of literature confirmed that few studies specified parent's cancer data in detail. In Study 3, no restrictions were applied to parent's disease as it was presumed few offspring would know precise details concerning their parent's cancer staging or severity, and that asking such questions may deter offspring from participating.

2.5 Summary

This brief chapter provided an overview of key decisions made in relation to the whole thesis. These decisions included definitions of the study population of offspring, their age, and terminology; the definition of family, and establishing study parameters in regards to parental cancer. Against the backdrop of these justifications, an overview of the methods of each study is now provided.

CHAPTER 3. OVERVIEW OF METHODOLOGY, SAMPLES, AND MEASURES

3.1 Preamble

The aim of this chapter is to provide a more detailed description of the methods used in the three research papers comprising this thesis. Specifically, this chapter provides further information on data sources, materials and analyses that were omitted in Chapters 4 – 6 due to the confines of journal article length and to provide additional context on the approaches underlying the research report in subsequent chapters. An outline of each study and its methods is presented in turn.

3.2 Study One – Systematic literature review

The experiences of adolescent and young adult offspring have been largely overlooked in the current literature concerning offspring affected by a parental cancer. Although some studies have claimed to focus on adolescents and young adults, many of these have been methodologically limited in terms of not defining the age of their sample, or by excluding offspring in their adolescence or young adulthood at the time of their parent's cancer (see Table A1, page 161). As a result, what is ostensibly understood about how adolescent and young adult offspring are impacted by parental cancer is largely based on non-representative samples. The first study of this thesis sought to rectify this issue by systematically reviewing the evidence regarding the impact of parental cancer on offspring in their adolescence or young adulthood (10 – 24 years) at the time of the parent's diagnosis.

3.2.1 Study design

For the first study in this thesis, a systematic review was conducted in order to identify, select, and summarise the relevant evidence (Moher et al., 2015) regarding the impact of parental cancer on adolescent and young adult offspring. This approach was deemed advantageous because it provides a reliable basis from which conclusions can be drawn (Oxman & Guyatt, 1993) by facilitating unbiased and critical appraisal of various primary studies (Stone, 2002). For a review to be considered 'systematic', it must have a structured methodology that is clearly stated, comprehensive, and replicable (Stone, 2002). A systematic literature review is defined by features that include a rigorous and transparent search protocol; inclusion and exclusion criteria; and data extraction, appraisal and synthesis (Khan, Kunz, Kleijnen, & Antes, 2003; Stone, 2002).

3.2.2 Search strategy

Electronic databases were selected for their focus on health and psychology disciplines and included PubMed, PsycINFO, Embase and The Cumulative Index to Nursing and Allied Health Literature (CINAHL). Predefined key search terms were developed in collaboration with a School of Psychology Research Librarian at the University of Adelaide and included: (neoplasms OR neoplasm* OR cancer* OR oncolog* OR malignan* OR tumor* OR tumour* OR carcinoma) AND (parents OR parent-child relations OR child parent relation OR mother* OR parent* OR father*) AND (child of impaired parents OR child OR adolescent OR young adult OR son OR sons OR daughter* OR child* OR adolescen* OR young adult* OR teen* OR youth) NOT (childhood neoplasms OR Children with cancer* OR child with cancer* OR childhood cancer* OR pediatric oncolog* OR paediatric oncolog* OR pediatric cancer* OR paediatric cancer*). Asterisks (i.e. *) signified truncation, and were applied to the end of words to find variants of that word.

Detailed search algorithms and indexing language (e.g. PubMed’s Medical Subject Headings (MeSH)) for each database are outlined in Table 1. Electronic database searches ran for a period of three months (02 June 2016 – 01 September 2016); with a final search conducted in March 2017 to ensure no articles published since September 2016 were missed.

Table 1

Database search terms, algorithms and indexing language

Database	Algorithms and indexing language
PubMed	(Neoplasms[mh] OR Neoplasm*[tiab] OR Cancer*[tiab] OR Oncolog*[tiab] OR Malignan*[tiab] OR Tumor*[tiab] OR Tumour*[tiab] OR carcinoma*[tiab]) AND (Parents[mh] OR "Parent-Child Relations"[mh] OR mother*[tiab] OR parent*[tiab] OR father*[tiab]) AND ("child of impaired parents"[mh] OR child[mh:noexp] OR adolescent[mh] OR "young adult"[mh] OR son[tiab] OR sons[tiab] OR daughter*[tiab] OR child*[tiab] OR adolescen*[tiab] OR young adult*[tiab] OR teen*[tiab] OR youth[tiab]) NOT (children with cancer*[ti] OR child with cancer*[ti] OR childhood cancer*[ti] OR pediatric oncolog*[ti] OR paediatric oncolog*[ti] OR pediatric cancer*[ti] OR paediatric cancer*[ti])
PsycINFO	(Neoplasms.sh OR Neoplasm*.ti,ab OR Cancer*.ti,ab OR Oncolog*.ti,ab OR Malignan*.ti,ab OR Tumor*.ti,ab OR Tumour*.ti,ab OR carcinoma*.ti,ab) AND (Parent child relations.sh OR mother*.ti,ab OR parent*.ti,ab OR father*.ti,ab) AND (Daughters.sh OR Sons.sh OR Son.ti,ab OR Sons.ti,ab OR daughter*.ti,ab OR child*.ti,ab OR adolescen*.ti,ab OR young adult*.ti,ab OR teen*.ti,ab OR youth.ti,ab) NOT (Children with cancer*.ti OR child with cancer*.ti OR childhood cancer*.ti OR pediatric oncolog*.ti OR paediatric oncolog*.ti OR pediatric cancer*.ti OR paediatric cancer*.ti)
Embase	("Cancer diagnosis"/exp OR Neoplasm/exp OR Neoplasm*:ti,ab OR Cancer*:ti,ab OR Oncolog*:ti,ab OR Malignan*:ti,ab OR Tumor:ti,ab OR Tumour:ti,ab OR Carcinoma*:ti,ab) AND ("child parent relation"/exp OR mother*:ti,ab OR parent*:ti,ab OR father*:ti,ab) AND (Child/exp OR sons:ti,ab OR daughter*:ti,ab OR child:ti,ab OR adolescen*:ti,ab OR "young adult*":ti,ab OR teen:ti,ab OR youth:ti,ab) NOT ("childhood cancer"/exp OR "children with cancer*":ti,ab OR "child with cancer*":ti,ab OR "childhood cancer*":ti,ab OR "pediatric oncolog*":ti,ab OR "paediatric oncolog*":ti,ab OR "pediatric cancer*":ti,ab OR "paediatric cancer*":ti,ab)

CINAHL	((MH neoplasms) OR TI Neoplasm* OR AB Neoplasm* OR TI Cancer* OR AB Cancer* OR TI Oncolog* OR AB Oncolog* OR TI Malginan* OR AB Malginan* OR TI Tumor* OR AB Tumor* OR TI Tumour* OR AB tumour* OR TI carcinoma* OR AB carcinoma*) AND ((MH “parent-child relations”) OR TI mother* OR AB mother* OR TI parent* OR AB parent* OR TI father* OR AB father*) AND ((MH ”Children of impaired parents”) OR TI sons OR AB sons OR TI son OR AB son OR TI daughter* OR AB daughter* OR TI child* OR AB child* OR TI adolescen* OR AB adolescen* OR “TI young adult*” OR “AB young adult*” TI teen OR AB teen OR TI youth OR AB youth) NOT ((MH “childhood neoplasms”) OR TI “children with cancer” OR TI “child with cancer” OR “AB childhood cancer” OR “ TI pediatric oncolog*” OR “TI paediatric oncolog*” OR “TI pediatric cancer*” OR “TI paediatric cancer*”)

Key: TI= Title; AB= Abstract; tiab= title and abstract; mh=MeSH; noexp=No explode.

3.2.3 Inclusion and exclusion criteria

Studies met the inclusion criteria if they reported on the impact of parental cancer on offspring aged 10 – 24 years at the time of the parent’s incident cancer diagnosis, were written in English, published in a peer-reviewed journal, and constituted original research (i.e. not review articles). Studies could consider offspring of parents with any type or stage of cancer, and include bereaved or non-bereaved offspring. Studies that considered parenting experiences were included if they investigated the impact of parenting on offspring. No restrictions were placed on date of publication or study design. Reference lists of relevant studies (e.g. reviews) and studies that met the inclusion criteria were screened for additional articles.

Studies were included if they sampled offspring in the target age range (10 - 24 years) at their parent’s *incident* cancer diagnosis in order to control for age-related differences (e.g. differences in functioning (Visser et al., 2004), coping and support needs (Ellis et al., 2016), psychological issues (Compas et al., 1994) and comfort (Mosher & Danoff-Burg, 2005)). Studies were excluded if offspring age at diagnosis was not specified. Further, studies were excluded if they focused on adolescent and young adult offspring (10 – 24 years) at a parent's recurrent diagnosis because recurrence is a predictor of offspring's distress (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005; Phillips, 2014; Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2006). Commentaries, reports, book chapters or dissertations were excluded due to not having undergone peer-review and thus having undetermined methodological quality. Studies were also excluded if they focused on health professionals, school staff, or the impact on parents as the cohort(s) of observation, as these were not pertinent to the purpose of the review or focus of this thesis.

3.2.4 Data extraction

This study followed the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines (Moher et al., 2015) because it is an essential component of the systematic review process (Moher, Tetzlaff, Tricco, Sampson, & Altman, 2007) and a minimal requirement for publication by several journals (Mandrekar & Mandrekar, 2011). The PRISMA protocol establishes careful planning and documentation throughout the review process, and ensures bias and arbitrariness are reduced (Moher et al., 2015). The guidelines consist of a 17-item checklist that specifies essential components for a systematic review and a four-phase flow diagram in which the review process is documented (Liberati, Altman, Tetzlaff, & et al., 2009; Moher et al., 2015); details of which are displayed in Figure 1.

A total of 12,541 potential publications were initially identified using the above search criteria and were exported to Endnote X7. Duplicates identified and removed leaving 10,893 records upon which screening of references was undertaken. One investigator screened titles and abstracts, and a second investigator independently reviewed a subset of excluded titles.

Where there was disagreement between investigators, a third arbitrator was consulted. Through this process, consensus was reached on which studies to include.

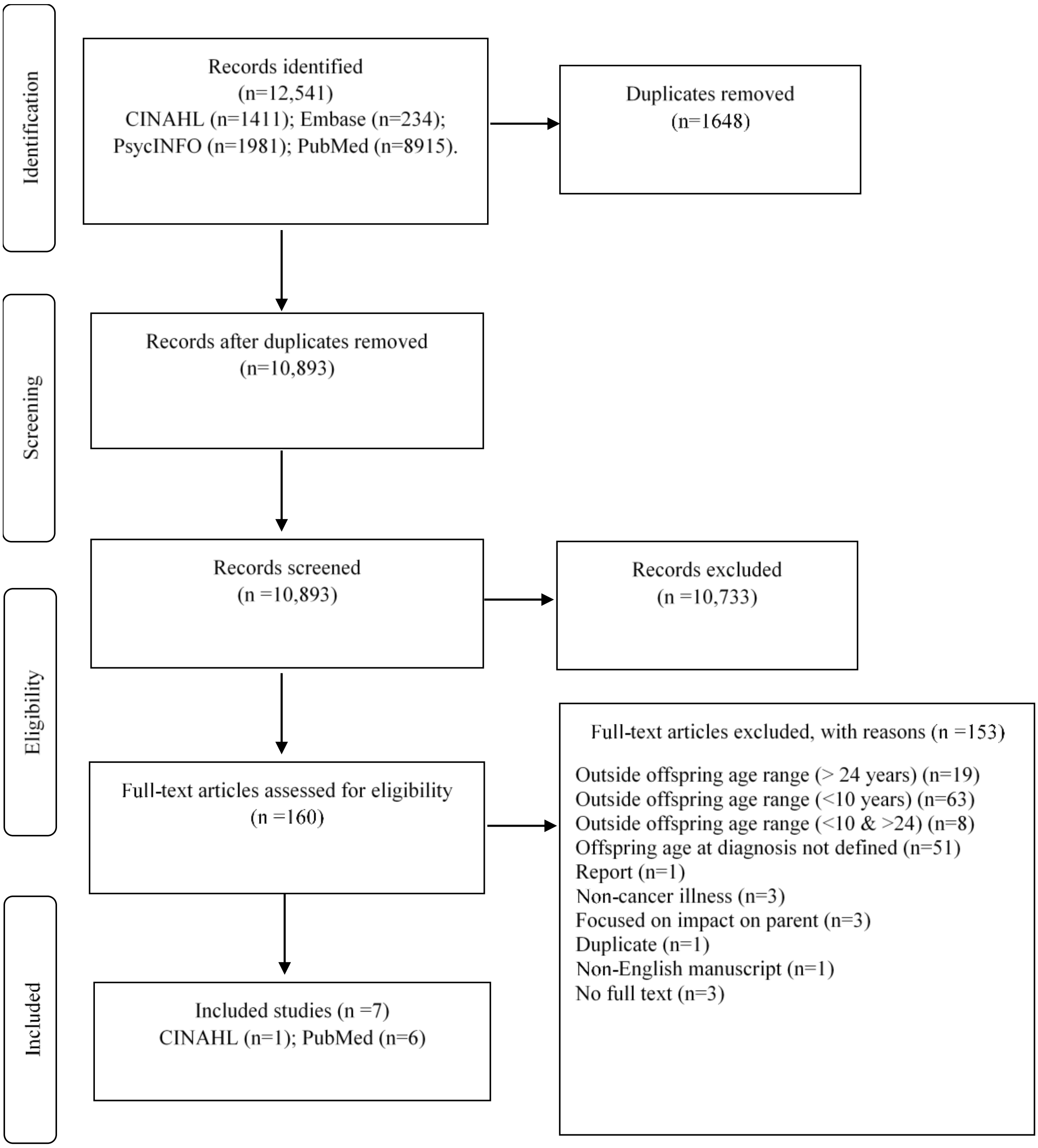


Figure 1 Article selection and exclusion process

3.2.5 Data appraisal

The Mixed Method Appraisal Tool (MMAT) (Pluye et al., 2011) was selected to assess the methodological quality of included studies. The MMAT has demonstrated good reliability (Pace et al., 2012; Souto et al., 2015). The tool assesses studies against set criteria specific to their methodology and includes mixed-method, qualitative, and quantitative (divided into randomised-controlled trials, non-randomised trials, and descriptive studies). Under each methodology, four criteria must be met for the study to be deemed as 'high' methodological quality. If only one criteria is met, the study will receive a score of 25% (low quality), if two are met, 50%, if three are met, 75%, and if all are met, the study will receive a score of 100% (high methodological quality).

3.2.6 Data synthesis

Studies that met the inclusion criteria underwent thematic analysis, which involves identifying features or ‘codes’ within the data that contribute to patterns of meaning called ‘themes’ (Clarke & Braun, 2017). The themes established in the data make up the framework for organising and reporting on observations within the data (Clarke & Braun, 2017). For this review, thematic analysis was undertaken using the qualitative data analysis software, NVivo [19]. Key findings were coded into subthemes, which were grouped into one of five master themes: learning about the cancer and its impact on the family and normality; offspring communication; behavioural and psychological impact; gender differences; and sources of support. These five emergent themes guided the results section. Results of this study are presented in Chapter 4.

3.3 Study Two – data linkage

The second study in this thesis responded to a precedent set by international research regarding the impact of parental cancer by enumerating and describing the population of adolescent and young adult offspring (12 – 24 years) and their parents with cancer in Western Australia. A comparison of sociodemographic and health economic indicators across Australian states and territories demonstrated that Western Australia is representative of

Australian jurisdictions overall (Clark, Preen, Ng, Semmens, & Holman, 2010). Specifically, Western Australia was among the three jurisdictions closest to the jurisdictional average across all but two indicators (proportion privately insured and per capita health expenditure) (Clark et al., 2010). In light of this, findings from this study may be nationally relevant. To the knowledge of the research team, this was the first study to quantify parental cancer in Australia using reliable whole-population linked administrative data

3.3.1 Study design

A retrospective cohort study was conducted using routinely-collected linked whole-population administrative health data. Data linkage can be defined as a technique for creating links within and between different sources of data for information related to the same entity (Boyd et al., 2015; Eitelhuber, 2016). This method is effective for longitudinal evaluation of health outcomes in whole-populations and provides increased statistical power (Haggar, 2016). Compared to primary data collection, data linkage is more time- and cost- effective (Kelman, Bass, & Holman, 2002), and minimises response, reporting and recall bias as well as practical barriers such as those related to attrition (Haggar, 2016). This method is less intrusive as no direct contact with participants is required (Boyd et al., 2015). In addition, data linkage is based on rigorous privacy protection standards (Kelman et al., 2002) and data remains de-identified. Thus, participant privacy is ensured.

3.3.2 Data sources

Data utilised in this project were obtained through the Western Australia Data Linkage System (WADLS). Data from the WADLS are based on a relatively stable population of approximately 2.6 million people (Australian Bureau of Statistics, 2016). Datasets routinely linked by the WADLS are included in Figure 2.

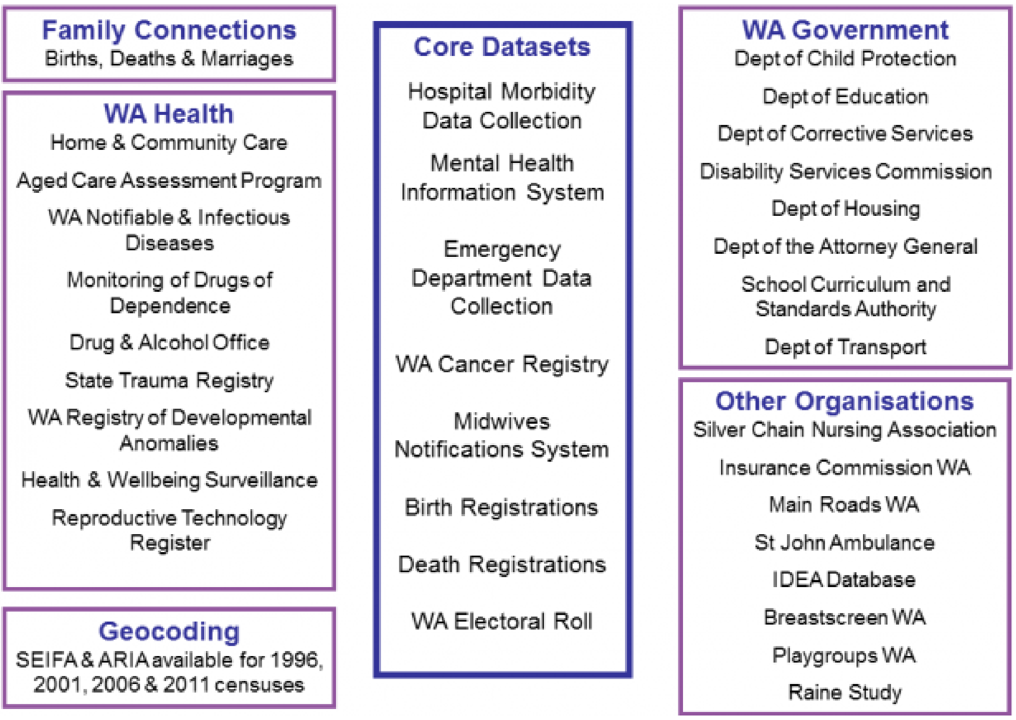


Figure 2 Western Australia Data Linkage Branch data collection

The following section describes the datasets used in this study. Detailed information on the variables available under each dataset, and those utilised in this research, is available in Appendix B.

3.3.2.1 Western Australia Cancer Registry (WACR)

The WACR was established in 1981 by the Western Australia Department of Health following regulations requiring cancer diagnoses be reported by pathologists, haematologists and radiation oncologists (Threlfall & Thompson, 2015). Electronic WACR records start from January 1982 and are sourced through treating practitioners, laboratory reports, hospital files and discharge records, and clinical information systems (Threlfall & Thompson, 2015). The Registry's data are linked monthly and include detailed information concerning an individual’s tumour(s) (Western Australia Data Linkage, 2016). It also contains information concerning deaths that occur outside of Western Australia by periodically linking to the National Death Index (NDI).

The accuracy of WACR records is strengthened by its lack of ‘death certificate only’ (DCO) records, which are created in the event where no supporting information other than a death certificate mentioning cancer is available (Western Australia Department of Health, 2018). These records are often inaccurate compared with those obtained from clinical or pathology records (Bray & Parkin, 2009). However, in this study only 0.09% of parental cancer records obtained through the WACR were DCO registered. Accuracy of WACR data is also ensured if the diagnosis is determined by histological examination (Western Australia Department of Health, 2018), which was the case for 89.5% of parental cancer records in this thesis. Detailed information on variables available in the WACR and those variables selected for this study are available in Appendix B.

3.3.2.2 Death Registrations

The Western Australia Death Registry (also referred to as the Mortality Registry) contains records of all recorded deaths occurring in Western Australia every month since 1969. Death records must be registered within 14 days from the date of death under the Births, Deaths, and Marriages Registration Act (Department of the Attorney General, 2017). A death registration is made by a funeral director following receipt of a medical certificate of cause of death from a doctor, except in the event that the death is reportable to the Coroner (Department of the Attorney General, 2017). Causes of deaths are updated annually, except in the event that the death is under investigation (Western Australia Data Linkage, 2016). Further information on the Death Registrations is available in Appendix B.

3.3.2.3 Births Registrations

The Births Registry contains all recorded Western Australia birth records since 1974 and is linked monthly. The Registry is routinely updated through the provision of Birth Registration Forms by the hospital or attending midwife (Department of the Attorney General, 2017). Regardless of relationship status, both parents must complete and sign the

Birth Registration Form. If only one parent is available to sign the Birth Registration, they must explain in a letter the reason why the other parent has not signed. In certain circumstances, a father's details can be included on behalf of both parents. Since 2002, the 'Same Sex Parents Birth Registration Form' was made available for same sex female partners to record the names of both women on their child's birth certificate (Department of the Attorney General, 2017). Further information regarding the Births Registrations is available in Appendix B.

3.3.2.4 Midwives Notification System (MNS)

The MNS is regulated by the 1911 Western Australia Health Act and 1994 Health Regulations Act and holds records dating back to 1980 (Western Australia Data Linkage, 2016; Western Australia Department of Health, 2018). It includes births of at least 20 weeks gestation or, if gestational age in not known, at least 400 grams in weight. Registrations are completed by the attending midwife or medical officer. In the absence of an attending midwife or medical officer at the birth, the first qualified midwife or medical officer to attend the mother and baby (postpartum) will complete the registration (Downey & Gee, 2006). Before 2005, records were made through paper based submission. Now, births are predominately submitted electronically through 'feeder systems' that include Stork, Ramsay System, or SJOG System (Western Australia Data Linkage, 2016). Data from the MNS are used for perinatal statistics and perinatal, infant and maternal mortality in Western Australia and can be used to inform the Department of Health on matters such as obstetrics, neonatal care and community health centres (Downey & Gee, 2006). Further information regarding the MNS is available in Appendix B.

3.3.3 Sample parameters

Parents were identified in the WACR by having a first record malignant cancer diagnosis (excluding Basal cell carcinoma (BCC) and Squamous cell carcinoma (SCC), as these are precursors to skin cancer, rather than cancer per se (Sober & Burstein, 1995)) between 01 January 1982 and 31 December 2015; and at least one child aged 12-24 years at the time of that diagnosis who was not dead or whose date of death was after their parent's cancer diagnosis date.

An application for data was made to the Western Australia Department of Health Data Linkage Branch (DLB) based on the sampling parameters and variables from the aforementioned data sources. From this application, data were linked and extracted by the Western Australia DLB.

3.3.4 Linkage and extraction

The process of probabilistic data linkage occurs across five steps: preparation, blocking, matching, storage, and merging (Eitelhuber, 2016; Preen, 2016). Preparation of data is a type of data cleaning that occurs before other technical steps. At this stage, data are formatted into the same structure, and any incorrect or missing entries corrected. A common data preparation technique used by the WADLS is phonetic compression. This process is carried out using software such as Automatch (Holman, Bass, Rouse, & Hobbs, 1999), followed by the New York State Intelligence Information System's (NYSIIS) and Soundex software (Holman et al., 1999). The NYIIS performs phonetic compression by running an algorithm to identify possible matches based on confounding letter groups and by removing vowels. Soundex then identifies similar sounding consonants. The consequential groups of sounds are weighted depending on their frequency in the population. Lastly, checks are performed to check on possible matches that fall between definite matches and non-matches (Boyd et al., 2015). The second phase of the linkage process is blocking, which refers to the ordering of records to increase efficiency of searching for matches (Preen, 2016). Blocking is a way of filtering down the data to a subset, either by sorting files by unique identifier, or undertaking compression algorithms on name and date of birth records.

The third phase is matching, in which records that could be linked are systematically compared against all other records to determine whether or not they relate to the same person. This technique matches records by calculating a likelihood score that is based on the similarity of one or more identifiers. In the WADLS common identifiers used for matching primarily include medical record numbers, full names and initials, date of birth, sex, and full residential address. Data linkage across multiple sources for the same entity is performed using probabilistic matching techniques. Probabilistic matching allows for realistic variations in the data, and is thus more flexible. It is different from the less common technique of deterministic matching, in which exact matches of identifiers are made (Eitelhuber, 2016). This deterministic matching technique is commonly done in countries with universal identifiers for each individual. The result of matching is a file of accepted links between various data sources.

The forth phase is storage, and involves storing the links from the matched phase for future extraction and merging. The fifth and final stage of data linkage is merging, and involves assembling the data in a format for analysis. A diagram of these linkage steps is displayed in Figure 3.

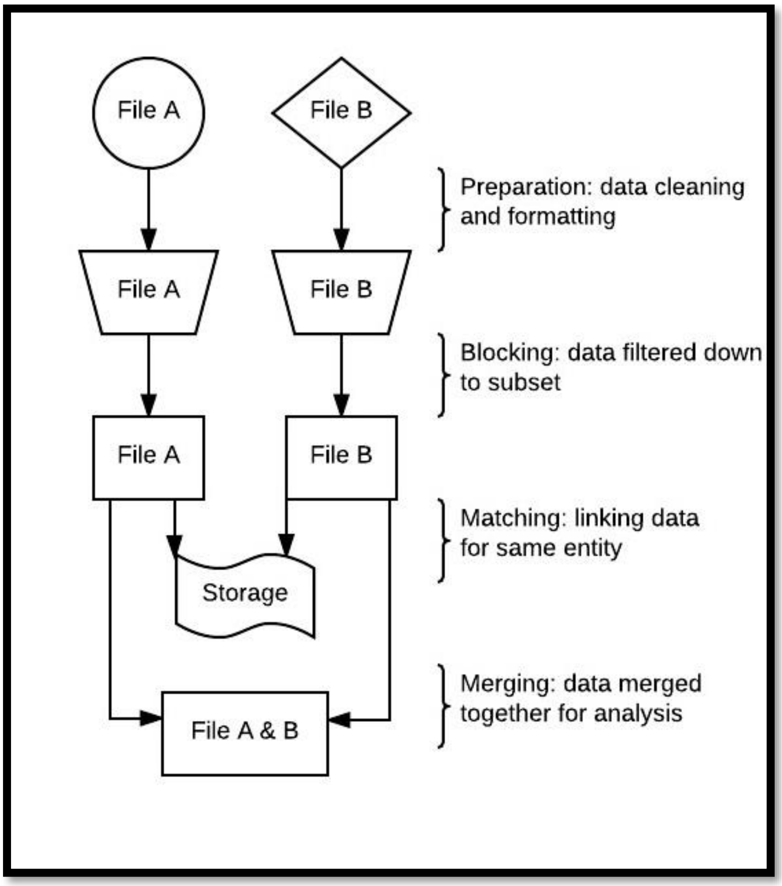


Figure 3 Process of data linkage

Once the data are linked, the extraction process begins. This stage involves trained data linkage officers producing a ‘linkage key file’ (Kelman et al., 2002). This file establishes mapping between local identifiers used by each data custodian and a new ‘linkage key’. The linkage key enables extraction of data by custodians in order to supply that data to the researchers, and is consistent across all datasets for the research project (Kelman et al., 2002). Files used to produce the linkage key do not include any clinical or health data, and any demographic data are destroyed once the linkage is complete. Following the creation of the linkage key, data custodians extract the data relevant to the project. These data are then provided by the WADLS to the researchers in de-identified format for analysis.

3.3.5 Data cleaning

Data were obtained through the WADLS in a series of Microsoft Notepad files, and manually converted to SPSS (version 24, IBM) format for data cleaning. Each data file was initially considered in turn where any necessary variable transformations were run to ensure all variables were in a consistent format for future analysis. Once each data file had been considered, parent and offspring variables were linked together using each individual's unique identifier and a genealogical identifier matching parents with their children. Following this process, the cohort was screened to ensure they met inclusion criteria (i.e. parent's incident diagnosis (excluding BCC and SCC) between 1982 and 2015 with at least one living offspring aged 12 – 24 years at the time of diagnosis). A diagrammatic representation of this screening process is presented in Figure 4.

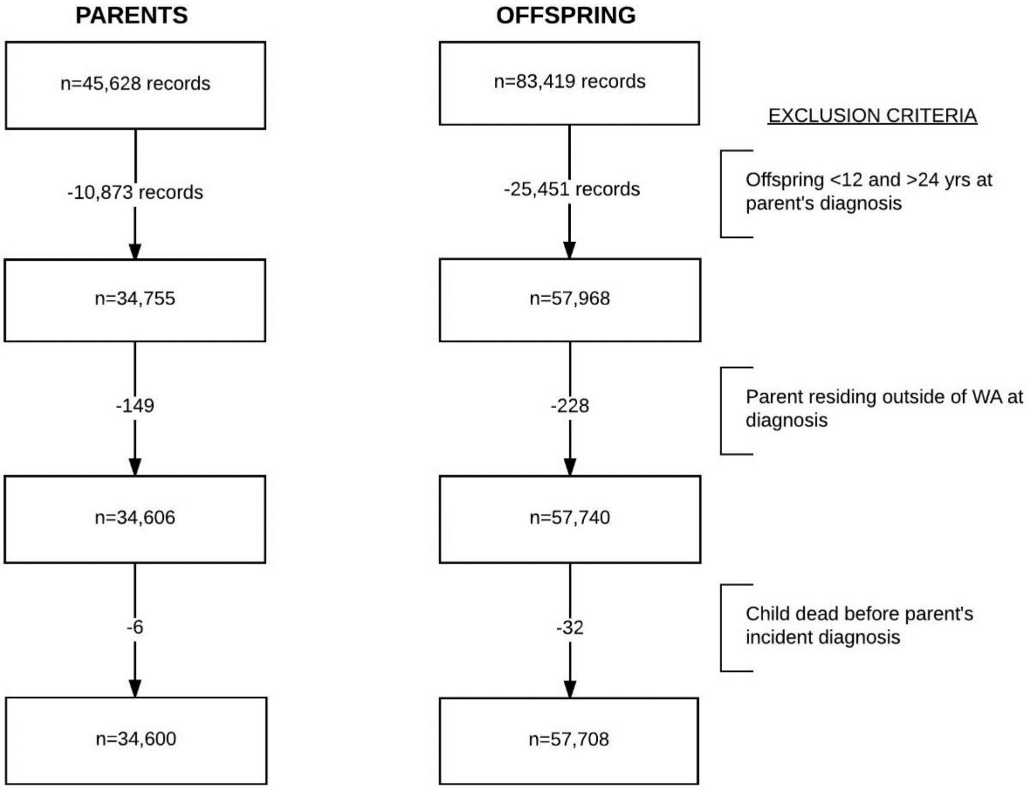


Figure 4 Process of screening participants for inclusion

3.3.5.1 Assigning values to coded data

Cause of death and tumour topography were classified according to the Tenth Revision of the World Health Organisation's (WHO) International Classification of Diseases (ICD-10) (World Health, 2005). Tumour morphology was classified according to the WHO's Third Edition of The International Classification of Diseases for Oncology (ICD-O-3) (World Health Organisation, 2018). Parents' country of birth was categorised according to United Nations geographic regions (United Nations, 2018).

To measure geographic remoteness and socioeconomic status, Remoteness Area (RA) (Australian Bureau of Statistics, 2011) and Socioeconomic Index for Areas (SEIFA) (Australian Bureau of Statistics, 2013) values from each national Census year (1986, 1991, 1996, 2001, 2006 and 2011) were requested from the WADLS. RA and SEIFA values were attached to the offspring cases based on their postcode at birth.

When examining RA and SEIFA values provided by the WADLS, it was apparent that between 39 – 96% of offspring were missing an RA or SEIFA record, and only 41% of cases had a postcode on which to base a SEIFA or RA score. The first attempt at rectifying the missing data involved imputing SEIFA and RA based on parent's postcode at diagnosis for each Census year. The degree to which the newly imputed scores compared to the pre-existing SEIFA and RA data was checked through Pearson's correlations. The weak relationship ($r = 0.35$) between imputed scores based on parent postcode and those provided by the WADLS demonstrated that this method of addressing the missing cases was insufficiently robust to apply in this instance. Thus, it was decided to manually impute all SEIFA and RA scores based on parent postcode at diagnosis instead of utilising the pre-existing offspring SEIFA and RA data provided by the WADLS. This method was preferred as it addressed the missing cases, maximised consistency by basing scores on only the parent postcode, and minimised inaccuracies resulting from the possibility that families moved the residence they occupied at the time of their child's birth.

In terms of geographic remoteness, RA scores by postcode were only imputed for the 2006 Census because remoteness is a relatively stable measure. Further, selecting only one Census year would minimise discrepancies that may arise between the previous Australian Standard Geographical Classification (ASGC) and the new Australian Statistical Geography Standard (ASGS) that assign geographic remoteness (Australian Bureau of Statistics, 2011). SEIFA scores were imputed for each Census year based on parent postcode at diagnosis based on Australian Bureau of Statistics data (Australian Bureau of Statistics, 2013). Where there was no SEIFA score for a postcode, the average SEIFA score of the Local Government Area (LGA) under which that postcode was classified was imputed. As raw SEIFA scores are ambiguous and their value within the distribution changes between Census years, scores were classified into one of three categories – low, middle and high socioeconomic status SES. To achieve this, the 33% lower and 66% upper cut-off points across state-wide SEIFA scores for every Western Australia postcode were identified for each Census year. Scores were then classified as low SES if they fell below the 33% cut off, middle SES if they fell at or between 33% and 66%, and high SES if they fell above 66%. The low, middle or high SES value was then selected based on the closest Census to time of diagnosis. Offspring were assigned their mothers' SES and RA or, in the case of same-sex parents, the earlier diagnosis SES and RA. Separately, if a child had two parents who experienced an incident cancer diagnosis in the WACR, offspring age at diagnosis was calculated at the earlier diagnosis date.

3.3.6 Data analyses

Data analyses were conducted using SPSS statistical software (version 24, IBM). Descriptive statistics were used to report on the offspring and parent cohort demographics and key characteristics, specifically: age, sex, country of birth, family relations (number of parents per offspring; number of children per parent), SES (SEIFA), place of residence (remoteness), and date and cause of death. Descriptive statistics were also used to report on parent's cancer data, specifically: cancer type, date of diagnosis and age at diagnosis, and tumour characteristics.

Negative binomial regression analysis was used to determine whether the number of offspring whose parents had cancer changed between 1982 and 2015; and whether the number of offspring experiencing parental cancer was different in terms of their age. The natural logarithm of the Western Australia population size from 1982 and 2015 was derived from Australian Bureau of Statistics Census data, and added to the model as an offset variable.

Multivariate Cox proportional hazards regression modelling was used to determine what characteristics were associated with time to parent's cancer-related death (the hazard or risk of dying), or offspring's rate of bereavement. Log minus log plots were examined to ensure they met the assumptions of proportional hazards required for Cox modelling. The start of the follow up was the date of the parent's cancer diagnosis; and follow up ended at the date of parent's cancer related death; or censored at the date of non-cancer related death for parents who died within the observation period, or at 31 December 2015 for those who did not die within the observation period. Parents were excluded if they had died but were missing a date of death record (n = 69), missing a date of birth record (n = 3), or missing a postcode at diagnosis (n = 89) (from which their SEIFA and RA scores were derived). Covariates were added to the model using forward selection. The final model regressed the rate of bereavement against parent age at diagnosis, total offspring at incident diagnosis, mean age of offspring, SES, and remoteness. Results of this study are presented in Chapter 5.

3.4 Study Three – survey

The third study of the thesis sought to contribute a better understanding offspring's adaption to parental cancer and shift focus away from psychopathology that dominates much of the published research (Mosher & Danoff-Burg, 2005). To achieve this aim, Study Three considered how offspring's coping impacts upon adaption to parental cancer in terms of posttraumatic growth, resilience, and positive emotion. In addition, this study explored how coping differed between offspring in order to understand what variables (e.g. parent's disease duration) predicted adaptive or maladaptive coping.

3.4.1 Study design

For this study, an online survey was developed and hosted via the online platform SurveyGizmo (www.surveygizmo.com). The survey was activated in May 2017 and remained active for a period of six months. The structure, format and phrasing of survey questions were guided by previous studies of bereaved (Bylund-Grenklo et al., 2013) and non-bereaved offspring (Davey, Tubbs, Kissil, & Nino, 2011; Patterson et al., 2013); people with cancer (Zaid et al., 2014); as well as findings from the systematic review (Study One). Demographic questions were developed through consulting Australian Bureau of Statistics published data (Australian Bureau of Statistics, 2016). For example, the Family Characteristics and Transitions Survey (Australian Bureau of Statistics, 2015) indicated that between 2012 and 2013, 31% of children had face-to-face contact with their parent at least once a week; 25% of children saw their parent at least fortnightly or monthly; 16% of children saw their parent at least once a year (but not monthly; and 28% of children saw their parent less than once a year or never. These data were then used to develop the question that asked offspring how often they typically saw their parent during their cancer, and the response options: at least once a week; at least fortnightly or monthly; at least once a year; and less than once a year or never.

The survey questions were then grouped into sections relating to demographics, cancer information, family information, and relationship with parent. A dummy question was placed at the beginning of the survey ("*How did you hear about this survey?*"), in order to ease participants into the survey by providing them with a non-invasive question (Krosnick & Presser, 2010). Following the dummy question, the item *"Which describes your parent's cancer?"* was included to which respondents could answer either *"my parent currently has cancer"* or *"my parent had cancer in the last 10 years"*. This question was used to confirm eligibility and to direct them to the questions that were phrased in either present or past tense. Some questions were not tense specific (e.g. "*What type of support (if any) have you used to help you with your parent's cancer*?"; *"What was your parent's marital status at the time of their cancer diagnosis?"*).

Disqualification rules were created on the Survey Gizmo interface in order to ensure participants met eligibility criteria and moved through the questionnaire depending on their previous responses. A custom disqualification script, was applied to the question "*What is* *your date of birth?*" which disqualified participants if they were under 18 years of age. Questions requiring a numeric answer used a Regression Expression (RegEx) pattern (Crowe, 2016) in order to validate a two-digit numeric response. A copy of the survey is available in Appendix C, with a table in Appendix D demonstrating how participants were moved through the differently phrased questions depending on whether their parent had cancer at the time of the survey, or in the past 10 years. Demographics were placed at the end of the survey, as their inclusion at the beginning of a questionnaire can deter participants from engaging (Krosnick & Presser, 2010). Also, questions about the parent's cancer was divided across two sections in order to alleviate participant burden that may have arisen due to their sensitive nature.

3.4.2 Instruments

Besides survey questions pertaining to demographics, cancer information, and family relationships, the survey included online versions of the instruments to measure coping (Brief COPE), resilience (Ego-Resiliency Scale (ER-89)), posttraumatic growth (Posttraumatic Growth Inventory (PTGI)) and emotion (Positive and Negative Affect Schedule (PANAS)). Participants were directed to tense-specific phrasing depending on whether they indicated their parent had cancer at the time of the survey, or had cancer in the previous 10 years.

3.4.2.1 Brief COPE

The 14-item Brief COPE (Carver, 1997) was used to investigate how offspring coped with their parents cancer. For this study, participants indicated on a 4-point Likert scale the degree to which they used a coping strategy (e.g. '*I turned to work or other activities to take my mind off things'*) in direct response to their parents cancer (1 = *I haven't been doing this at all* to 4 = *I have been doing this a lot*). For this study, items were summed into one of two major subscales, conceptualised as *coping style*: adaptive coping (comprised of active coping, use of emotional support, use of instrumental support, positive reframing, planning, humour, acceptance, religion); and maladaptive coping (self-distraction, denial, substance use, behavioural disengagement, venting, self-blame). Cronbach's alpha for the subscales demonstrated acceptable reliability (maladaptive coping α = 0.67; adaptive coping α = 0 .69) (Brownlow, 2005).

3.4.2.2 PTGI

The 21 item PTGI was used to measure posttraumatic growth, as it had previously demonstrated good internal reliability (Cronbach's alpha = 0.90) and test-retest reliability (α = 0.71) (Tedeschi & Calhoun, 1996). Respondents indicated on a 5-point Likert scale the degree to which they experienced change as a result of their parent's cancer (0 = *I did not experience this change as a result of my crisis,* to 5 = *I experienced this change to a very great degree as a result of my crisis*). The degree to which respondents experienced change was measured across five domains: Relating to Others; New Possibilities; Personal Strength; Spiritual Change; and Appreciation of Life. Within the context of this study, participants were asked to indicate the degree of change they experienced as a result of their parent's cancer. A total PTG score was then obtained by summing the subscale scores (Steffens & Andrykowski, 2014). Internal consistency was high for each of the five factors of the PTGI (between α = 0.77 and α = 0.85), and for the overall PTGI score (α = 0.82).

3.4.2.3 PANAS

The 20-item PANAS (Watson, Clark, & Tellegen, 1988) was used to measure emotion. Participants indicated on a 5-point Likert scale (1 = *Very Slightly or Not at All,* to 5 = *Extremely*) the degree they experienced positive affect (attentive, interested, alert, excited, enthusiastic, inspired, proud, determined, strong, active) or negative affect (distressed, upset, hostile, irritable, scared, afraid, ashamed, guilty, nervous, jittery) *generally*. The scale provides measures of positive affect and negative affect that are each based on items. Higher scores on each domain indicating higher levels of that affect. Internal consistency was high for the PANAS Positive Affect (PA) (α = 0.88) and Negative Affect (NA) (α = 0.91) scales.

3.4.2.4 ER-89

Block and Kremen's 14-item scale ER-89 (Block & Kremen, 1996) was used to measure resilience. This measure received the highest psychometric rating for a resilience-measure directed at young adults (18 – 23 years) in a review of resilience scales (Windle et al., 2011). Participants indicated on a 4-point Likert scale (1 = *Does not apply at all*, to 4 = *Applies very strongly*) the degree to which an item applied to them (e.g. *"I like to do new and different things"*). Scores were summed for an overall resilience score, with higher scores indicating higher trait resiliency. The 14-item resiliency inventory (ER-89) was highly reliable (α = 0.82).

3.4.3 Pilot phase

Once the study survey was created, a pilot phase was carried out in order to improve and refine the survey (Conrad, Blair, & Tracy, 1999; Drennan, 2002; Rattray & Jones, 2005; Van Teijlingen & Hundley, 2002) by identifying and resolving any issues such as readability or understanding (Conrad et al., 1999; Dillman, Smyth, & Christian, 2014). First, the survey was reviewed by two subject matter experts who work extensively within the area of parental cancer and psycho-oncology, as this is an identified method of refining surveys (DeVellis, 2011). Each item was assessed by the experts in terms of its clarity and conciseness (DeVellis, 2011). Both subject matter experts were satisfied with the questionnaire, thus no changes were made following their review.

The survey was then piloted using a think-aloud procedure and observation with one individual of the intended survey population. The think-aloud procedure involved the individual articulating their thinking as they answered all questionnaire items (Conrad et al., 1999; Dillman et al., 2014; Drennan, 2002). During this time, the principal researcher observed the individual respondent’s visual behavioural cues (e.g. skipping questions) (Drennan, 2002). The respondent took 11 minutes to complete the survey, and appeared to spend the same amount of time on each item with no significant change in disposition. The respondent described the items as “fine” in terms of its acceptability and readability.

Changes made in relation to the pilot stage included (1) adding the response category option of “*If less than a year, please enter 1*” to all questions that required a numeric response in terms of time (as indicating months was not an option to questions such as *“how long has your parent had cancer?”*); (2) changing response options from ‘Melanoma’ and ‘Non-melanoma skin’ ‘Skin (melanoma)’ and ‘Skin (non-melanoma)’ respectively, for the item that asked about parent’s main or primary diagnosis; and (3) changing the colours of scales and increasing font size to improve readability.

3.4.4 Sample

Participants included biological, adoptive, and step offspring aged 12 – 24 years at the time of their parent’s cancer. Participating offspring were adults (≥ 18 years), to promote ethical consent and reduce the possibility of harm. Participants met the inclusion criteria if their parent had cancer within the past 10 years, which was implemented in order to control for memory bias. Furthermore, this timeframe was within the range (3 – 20 years) that related studies used in assessing offspring’s outcomes (Ashurst et al., 2009; Bylund-Grenklo et al., 2015; Bylund-Grenklo et al., 2013; Edwards et al., 2008; Krattenmacher et al., 2013; Küçükoğlu & Çelebioğlu, 2013; Visser et al., 2006; Wong et al., 2006). Finally, this timeframe was of sufficient length for PTG to occur in response to a parent’s cancer, as there is no prescribed timeline across which PTG develops (Helgeson, Reynolds, & Tomich, 2006; Teixeira & Pereira, 2013; Zoellner & Maercker, 2006). No restrictions were placed on parent’s cancer type, stage, or disease duration, and multiple offspring from the same family could participate.

3.4.5 Recruitment

Participants were recruited via email or social media promotion through Australian cancer support organisations, health organisations, and universities. The study was also promoted through social media via a Facebook ‘page’ incorporating a public profile to attract ‘fans’, who are people who choose to ‘like’ or follow the page. The Facebook page detailed the background, aims, and eligibility criteria of the questionnaire, and specified the hyperlink to the external SurveyGizmo URL for the questionnaire. The page was made public, so that study information and the Survey Gizmo hyperlink were accessible to anyone. The Facebook page was launched on May 2017, on the same day as the survey went live. Monthly status updates were made to the Facebook page in order to increase the visibility of the study. The survey was activated in May 2017 and remained active for a period of six months.

3.4.6 Data analyses

Statistical analyses were conducted using SPSS (version 24; IBM). Descriptive statistics described demographics (gender, ethnicity, and age), offspring’s relationship with their parent (e.g. biological, adoptive, or step relationship) and family characteristics (e.g. number of siblings, marital status of parent with cancer etc.). Coping style was derived from responses to the two major coping subscales (adaptive and maladaptive coping) which were median-split to reflect high and low scores on each dimension. Individuals were then classified as using one of four-types of coping: high adaptive, low maladaptive coping; high adaptive, high maladaptive coping; low adaptive, high maladaptive coping; and low adaptive, low maladaptive coping. The collective use of adaptive and maladaptive coping was used (i.e. high adaptive, low maladaptive coping style) rather than independent coping approaches (i.e. adaptive versus maladaptive coping) because individuals use contradictory forms of coping in almost all encounters (Folkman & Lazarus, 1988; Folkman & Lazarus, 1988; Folkman, Lazarus, Gruen, & DeLongis, 1986). One way univariate ANOVA was used to compare the effects of the four coping styles on PTG, resilience, and emotion. Multinomial logistic regression was used to explore individual predictors of reported coping style whilst controlling for appropriate covariates (e.g. offspring sex, support accessed (whether offspring accessed formal support for their parents cancer), parent death from cancer, cancer duration, offspring residing with parent at time of cancer (yes or no), and the degree of worry offspring experienced in response to their parent's cancer) which were added to the final model using backwards selection ($p > .05$). Results of this study are available in Chapter 6.

3.5 Summary

This chapter has provided detailed information regarding the methods of each study under the thesis. The information provided in this chapter extends upon the methods section in each study, which was restricted within the confines of journal-length articles. The three studies are now presented in turn.

CHAPTER 4. STUDY ONE

Statement of authorship

Title of Paper	The psychological, social, and behavioural impact of a parent’s cancer on adolescent and young adult offspring aged 10 - 24 at time of diagnosis: A systematic review.
Publication Status	Published
Publication Details	Morris, J., Turnbull, D., Preen, D., Zajac, I., & Martini, A. (2018). The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10–24 at time of diagnosis: A systematic review. Journal of Adolescence, 65, 61-71. doi: 10.1016/j.adolescence.2018.03.001

Principal Author

Name of Principal Author (Candidate)	Julia Morris		
Contribution to the Paper	Formulated aims with supervisors. Undertook data analysis and interpretation. Wrote manuscript and revised in response to reviewer comments. Acted as corresponding author.		
Overall percentage (%)	85		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	26/07/2018

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

Name of Co-Author	Professor Deborah Turnbull		
Contribution to the Paper	Supervised development of work. Assistance in article selection. Provided feedback on manuscript.		
Signature		Date	26/07/2018
Name of Co-Author	Professor David Preen		
Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		
Signature		Date	02/08/2018
Name of Co-Author	Dr Ian Zajac		
Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		

Signature		Date	31/07/2018
Name of Co-Author	Dr Angelita Martini		
Contribution to the Paper	Supervised development of work. Assistance in article selection. Provided feedback on manuscript.		
Signature		Date	27/07/2018

Published paper

Abstract

This study reviewed the literature regarding the psychological, social, and behavioural impact of parental cancer on offspring aged 10 – 24 years, at the time of the parent’s first diagnosis. A systematic literature review was conducted following 2015 PRISMA guidelines. Seven studies met inclusion criteria. Offspring were impacted by their parent’s cancer and experienced psychological and behavioural problems. Daughters and offspring who experienced more problems at their parent’s diagnosis appeared to be most impacted. Offspring refrained from communicating their disease-related concerns, but expected their parents to communicate openly. Turning to oneself and peer-support were coping strategies used by offspring. The majority of offspring were significantly impacted by their parent’s cancer. The paucity of literature focussing on offspring aged 10 – 24 years at the time of their parent’s incident cancer diagnosis indicates that research has overlooked offspring age at their parent’s cancer onset as a factor that may influence their future outcomes.

Keywords: Adolescent, Young Adult, Parental Cancer; Offspring; Systematic Review.

Background

A parent’s cancer is experienced as stressful (Compas et al., 1994) and disruptive by offspring (Lewis, 2011). As a result of parental cancer, offspring face increased emotional and behavioural problems (Möller et al., 2014). Longitudinal data has demonstrated offspring whose parents are diagnosed with cancer access more psychiatric services and do so at an earlier age compared to offspring of healthy parents (Niemelä et al., 2012). They are also found to have an increased rate of death due to cancer and non-cancer related causes (Chen et al., 2015).

Offspring respond differently to parental cancer as a result of their age (Hauken, Senneseth, et al., 2017) in terms of variability in functioning (Visser et al., 2004), coping and support needs (Ellis et al., 2016), psychological issues (Compas et al., 1994) and comfort (Mosher & Danoff-Burg, 2005). Research has demonstrated adolescents and young adults have higher levels of anxiety and depression than preadolescent children (Compas et al., 1994). Furthermore, older offspring tend to experience greater household and caregiving responsibilities as a result of their parent’s illness, and report more activity restrictions, isolation, daily hassles and stress than offspring of healthy parents (Houck et al., 2007; Sieh et al., 2013). Older children with a parent affected by cancer are also found to struggle at school, where they have a lower grade point average compared to the norm (Sieh et al., 2013).

The stress and coping theory posits that the threat of parental illness is a continuous stressor that can exceed children’s coping resources and increase problematic behavior (Sieh et al., 2010). The perceived stress of parental illness depends on child related factors, including age (Lazarus, 1974). As children experience puberty and adolescence, they make significant advances in cognitive and physical development (Sieh et al., 2010). During this time, they also learn to acquire appropriate emotional regulatory skills to deal with stressors (Silvers et al., 2012). Given that the overall impact of a parent’s illness on their offspring varies with offspring’s age (Korneluk & Lee, 1998; Su & Ryan-Wenger, 2007), it is plausible that offspring age at the time of a parent’s incident (i.e., first) cancer diagnosis may have significant and unique implications for their ability to respond and cope with their parent’s illness. Younger children may be shielded by a lack of understanding whereas older children possess advanced cognitive and empathetic capacities that increase their awareness of potential loss and their parent’s physical and emotional pain (Christ et al., 1994). Therefore, older children might experience greater and potentially more prolonged impact because of their ability to critically appraise the situation and its implications. Additionally, adolescent and young adult offspring are concurrently contending with developmental challenges. Specifically, adolescence represents a critical period of transition (Spear, 2000; World Health Organisation, 2016) underpinned by heightened vulnerability (Steinberg, 2005); and young adulthood represents a period of instability as one establishes independence and structure (Arnett, 2000). Experiencing a parent’s cancer diagnosis during adolescence or young adulthood could potentially impact these normative milestones and lead to developmental ramifications.

Currently, there is a dearth of literature that systematically considers what impact a parent’s cancer has on offspring in their adolescence and young adulthood at their parent’s incident diagnosis. Studies to date that claim to have focused on the impact of parental cancer on adolescent and young adult offspring have suffered significant limitations, including not-specifying the age of participants in their sample, or adopting a broad approach and exploring the impact across all ages- a methodological weakness identified as far back as 15 years ago (Nelson & While, 2002). For example, reviews with prescribed adolescent and young adult offspring samples have included children as young as infants (e.g. Walczak, McDonald, Patterson, Dobinson, & Allison, 2017), toddlers (e.g. Osborn, 2007) or young children (e.g. Phillips 2014); or have included children whose age is not explicitly stated in the original research (e.g. Grabiak, Bender, & Puskar, 2007). Thus, what is assumedly known regarding the impact of parental cancer on adolescent or young adult offspring is arguably based on skewed interpretations. Maintaining focus on adolescent and young adult offspring impacted by parental cancer can only be achieved if the sample consists of adolescents and young adults. This can be achieved by focusing on offspring in their adolescence or young adulthood at their parent's incident cancer diagnosis. This approach would control for the varying responses to parental cancer that occur as a function of age (Korneluk & Lee, 1998; Su & Ryan-Wenger, 2007). Therefore, the aim of this current study was to systematically review the evidence regarding the psychological, social, and behavioural impact a parent's cancer has on adolescent and young adult offspring aged 10 – 24 years at their parent's incident cancer diagnosis. This age span was chosen because it aligns with the World Health Organisation (WHO) definitions of young people and adolescence (World Health Organisation, 2016).

Methods

Search Strategy

Electronic databases were selected for their focus on health and psychology disciplines and included PubMed, PsycINFO, Embase and The Cumulative Index to Nursing and Allied Health Literature (CINAHL). Predefined key search terms were developed in collaboration with a Research Librarian at the University of Adelaide's School of Psychology. Detailed search algorithms and indexing language used under each database are outlined in Table 1 (page 47). Electronic database searches ran for a period of nine months (02 June 2016 – 15 February 2017) and targeted original research in English language that was published in peer-reviewed journals. No time restrictions on publication date were applied. Reference lists of relevant studies (e.g. reviews) and studies that met inclusion criteria were screened for additional articles.

Inclusion and exclusion criteria

Studies met inclusion criteria if they reported on the impact a parent's cancer has on offspring aged 10 – 24 years at the time of the parent's diagnosis, were written in English, published in a peer-reviewed journal, and constituted original research (i.e. not review articles). This review did not consider offspring 10 – 24 years at the time of a recurrent diagnosis because recurrence is itself a predictor of offspring distress (Huizinga et al., 2005; Phillips, 2014; Visser et al., 2006), thus may bias results. Separately, as time from diagnosis impacts adjustment (Huang, O'Connor, & Lee, 2014), offspring younger than 10 years at the time of their parent's first diagnosis would arguably experience their parent's recurrent or ongoing cancer differently. Therefore, this review excluded offspring who were outside the target age range (10 – 24 years) at their parent's first cancer diagnosis. Studies could consider offspring of parents with any type of cancer and at any stage, and include bereaved or non-bereaved offspring. Studies considering parenting experiences were included if they investigated the impact of parenting on offspring. No restrictions were placed on date of publication or study design.

Studies were excluded if offspring age at diagnosis was not specified, as the purpose of this review was to evaluate the impact of parental cancer on offspring aged 10 – 24 years at the time of the incident diagnosis. Offspring outside of this age at the time of the incident cancer diagnosis have arguably different experiences relating to their parent's cancer due to the developmental trajectory associated with being of latency-age or in adulthood. Thus, eliminating studies that did not define offspring age at the time of the incident diagnosis was a means for controlling offspring age. It was decided among the research team that methodological quality would be the highest among studies which had undergone peer-review. Therefore, studies were excluded if they were commentaries, reports, book chapters or dissertations. Studies were also excluded if they focused on health professionals, school staff, or the impact on parents, as these were not pertinent to the purpose of the review.

Methodological quality

Due to the small body of literature concerning offspring aged 10 – 24 years at the time of their parent's cancer diagnosis, studies of qualitative, quantitative and mixed-method designs were included. Methodological quality was assessed using the Mixed Method Appraisal Tool (MMAT) (Pluye et al., 2011). Studies were assessed under three MMAT methodological domains: mixed-method, qualitative, and quantitative. Under each domain, relevant criteria must be met for the study to be deemed high methodological quality (see http://mixedmethodsappraisaltoolpublic.pbworks.com for criteria). Each criterion is worth 25%, such that if all four are met, the study will receive a score of 100% (high methodological quality). The majority of studies (*n* = 5) had high methodological quality with the exception of one study scoring 75% and another scoring 50% (see Table 2, page 93).

Data analysis

A total of 12,906 records published between 1915 and 2017 were captured across the database searches. Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines were followed; details of which are presented in Figure 1 (page 50). Records were exported to citation management software Endnote X7, in which duplicates were identified and removed, and screening of references was undertaken. One investigator screened titles and abstracts for inclusion suitability, and a second investigator reviewed a subset of excluded titles. Through this process, consensus was reached on which studies to include.

Given the heterogeneity of data across studies, a narrative approach was taken. Studies that met inclusion criteria underwent thematic analysis: a systematic process for analysing and interpreting data that identifies features or 'codes' within the data that contribute to overarching ‘themes’ or patterns of meaning (Clarke & Braun, 2017). Studies were exported to the qualitative data analysis software, NVivo (QSR International Pty Ltd., 2012). Each study was manually coded to reveal elements and key features. The codes were then classified and reassembled in terms of similarity into a coherent order of subthemes. Following this, the subthemes were grouped into one of five master themes: Learning about the cancer and its impact on the family and normality; Offspring communication; Behavioural and psychological impact; Gender differences; and Sources of Support. These five themes guide the results section.

Results

Seven studies met inclusion criteria for the review. Study designs were quantitative (*n* = 4), qualitative (*n* = 2), and mixed method (*n* = 1). All studies were from different countries, with research originating from Malaysia, Iran, the United States of America, the United Kingdom, the Netherlands, Norway, and Germany. Offspring age at their parent’s diagnosis was ranged from 10 to 20 years. Four studies observed the impact of a parent’s cancer from the perspective of the offspring, and the other three included perspectives of offspring, parents with cancer, and their partners. Across the studies, the most common parental cancer was breast (*n* = 6), followed by gynaecological (*n* = 2). Studies focused on health-related quality of life (HRQoL) (Jeppesen et al., 2016), overall quality of life (QoL) (Ainuddin, Loh, Low, Sapihis, & Roslani, 2012), and QoL following a supportive-educative program (Azarbarzin, Malekian, & Taleghani, 2015). Studies also focused on offspring coping (Clemmens, 2009), stress response symptoms (Huizinga et al., 2010), and how offspring learn about their parent’s cancer (Finch & Gibson, 2009). Details of included studies and their key findings are outlined in Table 2 (page 93). Through thematic analysis, five themes were identified from the included papers.

Learning about the cancer and its impact on the family and normality. The diagnosis of a parent's cancer was experienced as a loss (Finch & Gibson, 2009) and distressing (Clemmens, 2009) by offspring. Fear of parental death was connected to offspring first learning of their parent's diagnosis and was perceived as a real and constant threat (Finch & Gibson, 2009). Thirty percent of offspring in one study experienced clinically elevated stress response symptoms in the first few months of their parent's diagnosis (Huizinga et al., 2010). Offspring felt fear jointly for their parent and for themselves (Clemmens, 2009). They saw themselves and their family members as vulnerable (Finch & Gibson, 2009) and perceived the uncertainties associated with the disease as life threatening (Finch & Gibson, 2009). As a result of the cancer, offspring's normal patterns of life had changed (Clemmens, 2009). Offspring expressed family roles had also changed (Finch & Gibson, 2009) but parents reported more role dysfunction than offspring (Kühne et al., 2013). Offspring reported their ill parent was noticeably absent and their parenting was affected (Clemmens, 2009). Offspring attempted to normalise the cancer within their lives (Finch & Gibson, 2009) and believed life would return to normal if their ill parent had a good day or when their treatments had finished (Clemmens, 2009). Notably, offspring whose parents had been diagnosed 12 months prior fared better in terms of intrusion, avoidance, and total distress than offspring whose parents were diagnosed 1 – 5 years previously (Huizinga et al., 2010).

Offspring reported that their parents needed looking after (Finch & Gibson, 2009). They had an intense desire to stay close to their ill parent (Clemmens, 2009), and stayed home more, or selected colleges closer to home upon finishing high school (Clemmens, 2009). The desire to stay close to their parent was especially important among offspring whose parents were in palliative disease stages (Kühne et al., 2013). Families whose parents were in palliative disease stages had more consistent reports regarding family functioning than those in non-palliative disease stages (Kühne et al., 2013). Offspring desired closeness to their parent, but found it challenging as it drew attention to the illness, its severity, and potential loss (Clemmens, 2009).

Offspring communication. Communication among family members was dependent on the family's attitudes, beliefs, and comfort in discussing the cancer (Finch & Gibson, 2009). Offspring encouraged open and honest family communication about their parent's cancer (Clemmens, 2009; Finch & Gibson, 2009), which fostered understanding (Clemmens, 2009; Finch & Gibson, 2009), helped offspring make sense of the disease (Finch & Gibson, 2009), and increased their feelings of security (Clemmens, 2009). However, offspring reported more dysfunctional family communication than their parents (Kühne et al., 2013). Offspring used open communication to cope with their parent's cancer and reported that talking about the cancer was essential (Clemmens, 2009). In contrast, offspring refrained from discussing their own fears about the disease (Finch & Gibson, 2009) and hid their emotional reactions (Clemmens, 2009) in order not to burden their ill parent. Offspring were careful not to contribute to their parent's problems or worry them and thus would be self-reliant or turn inward (Clemmens, 2009). Offspring believed they needed to modify their behaviour and stay emotionally strong for the sake of their parent (Finch & Gibson, 2009).They moved their attention away from their parent's cancer (Clemmens, 2009) or did not think about it to reduce their stress (Finch & Gibson, 2009). Parents interpreted their offspring's withdrawal to mean they were unaffected by their diagnosis (Clemmens, 2009) and consequently also reported less emotional and behavioural problems in offspring than in offspring self-report (Huizinga et al., 2010). Offspring sensed their parent's misinterpretation of this behaviour and felt misunderstood if they tried to cope independently or normalise their daily life (Clemmens, 2009).

Behavioural and psychological impact. Prior to engaging in a support program, offspring had normal QoL scores on the dimensions physical functioning, role limitation due to physical health, and role limitation due to emotional problems and pain (Azarbarzin et al., 2015). Also, parental cancer only appeared to have a moderate effect on their offspring's HRQoL (Jeppesen et al., 2016). Although 42% of offspring reported a low score on at least one HRQoL dimension, corresponding normative data were missing, thus its comparative significance was undetermined (Jeppesen et al., 2016). At the individual level, a parent's cancer diagnosis impacted school functioning (i.e. performance; truancy (Varni, Seid, & Kurtin, 2001)) if their mother had cancer (Ainuddin et al., 2012). Also, offspring reported a diminished capacity to focus or concentrate (Clemmens, 2009). Stress response symptoms were associated with emotional and behavioural problems, and future emotional and cognitive problems (Huizinga et al., 2010). In the first year following diagnosis, the relationship between stress response and somatic complaints increased (Huizinga et al., 2010). Ill parents and partners observed more emotional and behavioural problems in offspring with higher stress response symptoms, but these were to a lesser degree than offspring reported for themselves (Huizinga et al., 2010). Offspring age, parent gender, and treatment intensity and length was unrelated to offspring stress response symptoms (Huizinga et al., 2010). Offspring self-esteem was significantly correlated with HRQoL (Jeppesen et al., 2016). Offspring had poor emotional functioning scores (i.e. negative emotional affect) (Ainuddin et al., 2012) but normal emotional wellbeing (Azarbarzin et al., 2015). Lastly, the lower the household income, the poorer the emotional, school, and psychosocial HRQoL, and total QoL (Ainuddin et al., 2012).

Gender differences. Daughters whose parents had cancer had significantly lower self-esteem (Jeppesen et al., 2016), physical functioning, and QoL (Ainuddin et al., 2012) than sons. More daughters reported clinically elevated stress response symptoms at 4 months following diagnosis, and daughters also reported higher rates of intrusion than sons at 6 months following diagnosis (Huizinga et al., 2010). Compared to sons whose parent had been diagnosed 1 – 5 years earlier (reference group), sons whose parent had been diagnosed 12 months earlier had less intrusion, avoidance and total distress (Huizinga et al., 2010). Compared to the reference group, daughters reported significantly less intrusion and less total distress at 12 months (Huizinga et al., 2010). Female family members and partners reported more family dysfunction regarding problem solving and general functioning (Kühne et al., 2013).

Sources of support. Offspring sought support from friends (Finch & Gibson, 2009). Although offspring engaged less with their friends than they had prior to their parent's diagnosis, participating in activities with their peers assisted their coping (Clemmens, 2009). Daughters reported significantly poorer HRQoL in terms of social support and peers than sons, but over time, this score improved for both genders (Jeppesen et al., 2016). At 4 and 6 months following diagnosis, offspring who experienced more stress-response symptoms reported more problems on all self-report scales except for social problems (Huizinga et al., 2010). Offspring turned inward and relied on themselves for problem solving, decision making, and to escape (Clemmens, 2009), thus being their own source of support. For other offspring, one study found that religious faith and church affiliations were helpful (Clemmens, 2009). In regard to healthcare support, offspring felt they had no role within the hospital environment and believed it offered no emotional or psychosocial component of care (Finch & Gibson, 2009). Offspring preferred to speak to friends or family about the cancer than seek support from medical staff (Finch & Gibson, 2009). One supportive educative program, developed by oncologists and researchers, reported a significant increase on almost all QoL scores among offspring (Azarbarzin et al., 2015). In terms of their school, offspring felt that they received little support from their teachers. Rather, a teacher's acknowledgement was limited to their asking after the offspring's parent (Finch & Gibson, 2009). However, offspring had mixed views on the level of support they would have liked from their teachers (Finch & Gibson, 2009).

Discussion

Each of the reviewed studies demonstrated that offspring aged 10 – 24 years at their parent’s incident diagnosis are significantly impacted in some way by their parent’s cancer. In regard to which offspring are most impacted by parental cancer, the literature to date suggests that daughters struggled more than sons (Ainuddin et al., 2012; Huizinga et al., 2010; Jeppesen et al., 2016); a finding echoed in other research focusing on different age groups (McDonald et al., 2016; Morris et al., 2016; Osborn, 2007; Visser et al., 2004). There is evidence to suggest that daughters fare worse if their mother has cancer (Morris et al., 2016), and one reviewed study supported this (Ainuddin et al., 2012), but this finding may demonstrate a response bias resulting from the large number of mothers in the study (45 mothers; 5 fathers). Parental cancer research is dominated by the impact of maternal breast cancer, and is likely due to the commonality of breast cancer during child-rearing years. In this review, most included studies ($n = 6$) had more mothers affected by cancer than fathers (one study failed to mention parents’ gender). It is speculated that offspring may suffer more if their father has cancer, because the nature of a father’s prognosis is poorer than that of a mother’s breast cancer diagnosis (Thastum et al., 2009). Future research should attempt to recruit larger samples of both male and female offspring to establish whether parent gender impacts offspring.

In terms of the degree of impact parental cancer had on offspring, some reviewed evidence suggested that offspring showed little affect to their parent’s cancer (Azarbarzin et al., 2015; Jeppesen et al., 2016). This has been reiterated in other research, which found offspring whose parents have cancer display no more psychological problems (Jeppesen, Bjelland, Fossa, Loge, & Dahl, 2013) risk behaviours, externalising behaviours (Jantzer et al., 2013), or psychiatric problems (Niemela et al., 2016) than the norm. Other reviewed evidence suggested that offspring were impacted by their parent's cancer, but only in terms of acute reactions to the time of diagnosis (Clemmens, 2009; Huizinga et al., 2003; Kühne et al., 2013), and overall, they adjusted well (Jantzer et al., 2013; Kühne et al., 2013). On the contrary, evidence also suggested that the impact of a parent's cancer was more pervasive (Ainuddin et al., 2012; Clemmens, 2009; Huizinga et al., 2010). The lingering impact of a parent's cancer diagnosis was apparent in offspring experiencing more problems if their parent was diagnosed farther back in time (Huizinga et al., 2010). It also suggests that offspring may be affected by uncertainty and fear of recurrence in the aftermath of the disease: a phenomena reported in cancer survivors (Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006).

Evidence suggested that offspring may be predisposed to future problems if they experience more problems at the time of their parent's diagnosis. For example, through the increasing association between somatic complaints and stress response symptoms (Huizinga et al., 2010). Gazendam-Donforio et al. (Gazendam-Donofrio et al., 2011) found that emotional reactions were unrelated to later emotional or behavioural problems, but total problems were related to later dysfunction. This is similar to findings that offspring's total burden of illness predicted future problems (Visser et al., 2007). These findings contribute to the notion that only some offspring experience severe strain as a result of their parent's cancer (Jantzer et al., 2013). Conversely, other research indicates that compared to the norm, parental cancer impacts all offspring to some degree. Longitudinal population-based studies have reported that offspring whose parents have cancer have a higher rate of injury (Chen, Regodón, et al., 2015), access more psychiatric support (Niemelä et al., 2012), and have an increased rate of death due to all causes (Chen, Sjölander, et al., 2015) compared to the norm.

The inconsistencies around which offspring are impacted by parental cancer may be due to the significant variation in research design across studies, child-characteristics (e.g. age, perceived maturity), or even family characteristics (e.g. single versus coupled-parent families) that either protect or exacerbate the impact of parental cancer. Given the inconsistencies around which offspring are impacted by parental cancer, further research is warranted to better understand if a subgroup of offspring are vulnerable, or if all offspring are at risk.

Adolescence and young adulthood is a time in which offspring acquire more independence and are seen to move away from the family. A parent's cancer resulted in offspring sacrificing this independence by staying home more or by choosing colleges nearer to their home (Clemmens, 2009). Arguably, this is akin to 'parentification', a coping strategy in which offspring compromise their own needs or emotions for the sake of their parent (Davey et al., 2003; Phillips & Lewis, 2015; Thastum et al., 2008). Parentification can be destructive for offspring as it can indicate an absence of reciprocity, acknowledgement, and support within the family (Thastum et al., 2008). Parents reported more role dysfunction than offspring (Kühne et al., 2013), meaning they perceived more dysfunction in relation to established behaviour patterns, assigned tasks and responsibilities. This may reflect that parents sensed their offspring had assumed a role beyond that of being the child because of the cancer. Alternatively, it may reflect parent's feelings of guilt about failing to be a 'good parent' (Morris et al., 2016). Overall, it appeared that the cancer drew offspring towards their parents, but this closeness did not necessarily imply a stronger or more supportive relationship between parents and their children.

Open and honest communication is not only encouraged (Clemmens, 2009; Finch & Gibson, 2009) but is essential in minimising their suffering and supporting offspring (Morris et al., 2016). Thus, communication is key to minimising the impact of a parent's cancer on children. The evidence illustrated a problematic dynamic in which offspring's expectations juxtapose their own communicative behaviours. In other words, offspring expected their parents to communicate, but were unwilling to reciprocate in terms of open and honest communication, out of fear of upsetting their parent. This led to parents underestimating the impact that their cancer had on their children (Clemmens, 2009; Huizinga et al., 2010); a finding which is reiterated in the literature (Morris et al., 2016; Osborn, 2007). Offspring in one of the reviewed studies reported more dysfunctional communication than their parents, (Kühne et al., 2013), which may reflect parent's misunderstanding that offspring need to communicate. It is important that offspring are supported to communicate with their parents (Ellis et al., 2016), and families may benefit from receiving guidance about how to support and communicate with their children.

The deficit in support strategies for offspring was evident in this review. Offspring perceived no emotional or psychosocial support for themselves in their parent's care (Finch & Gibson, 2009), and only one study reported on the outcome of a supportive care program (Azarbarzin et al., 2015). Health professionals have an obligation to support the coping and wellbeing of offspring (Jeppesen et al., 2016), and offspring are in need of such support (Ellis et al., 2016). Positive outcomes were reported as a result of the aforementioned supportive care program, which demonstrates the benefit of small group or one-on-one support to minimise the burden of cancer (Azarbarzin et al., 2015). One study indicated that there was less dysfunction in families affected by palliative parental cancer (Kühne et al., 2013), which may be a result of palliative support strategies. However, this outcome may also be due to a natural progression resulting from these families spending more time together as the disease became more dominant (Kühne et al., 2013), and their main concern being a lack of time together (Sheehan & Draucker, 2011). Regardless, support must be tailored and provided to families affected by palliative and non-palliative parental cancer and on a long-term basis, to counteract any pervasive impact of parental cancer. It should also be made available to families of lower socioeconomic status, where offspring quality of life was reported to be lower (Ainuddin et al., 2012); a finding which is reiterated across research concerning children of chronically ill parents (Sieh et al., 2010). Besides support from healthcare, a school can play a helpful role in helping offspring facing a parent’s cancer (Chalmers et al., 2000) as it can offer ongoing and stable support. This is especially important given that offspring struggle in terms of their focus, concentration (Clemmens, 2009), and school functioning (Ainuddin et al., 2012).

The included studies were somewhat limited in the extent to which they identified what part of a parent’s cancer impacts their offspring. A parent’s cancer has many facets but research has largely approached parental cancer as a single event. Rolland’s (1987) psychosocial typology of illness describes dimensions of illness that exist on a continuum: onset (acute versus gradual); course (episodic/relapse, constant, or progressive); outcome (terminal or not); and degree of incapacitation (e.g. cognitive, sensation, movement, energy etc.) (Rolland, 1987). Depending on the dimension, the family must perform different adaptive behaviours and face various psychosocial demands (Chen, 2017; Korneluk & Lee, 1998). Where the two included qualitative studies approached parental cancer on a continuum and explored the impact on offspring as a function of diagnosis as well as the ensuing illness (Clemmens, 2009; Finch & Gibson, 2009), the quantitative and mixed-method studies were restricted by their design. Two of these latter studies did investigate course and outcome (treatment duration and type; palliative versus non-palliative) on their outcome variables (stress response symptoms and family functioning, respectively) (Huizinga et al., 2010; Kühne et al., 2013), but the other studies were limited by only describing dimensions of the illness (e.g. type and stage, treatment, palliation or non-palliation) and analysing the impact of a parent’s cancer as the outcome of an all-encompassing event (Ainuddin et al., 2012; Azarbarzin et al., 2015; Jeppesen et al., 2016). From the available research, one can imply that offspring are first impacted at the parent’s diagnosis, and are challenged by ongoing exposure to the illness, incapacitation of their parents, and uncertainty regarding their parents’ mortality. Reasonably, offspring are also impacted by the flexibility they must proffer in adapting to these challenges, all whilst negotiating their normal developmental milestones. Approaching parental cancer as a whole is, in some ways, demonstrating that all elements of the illness are equivalent in their impact on parents and their offspring. However, identifying at what point and for what reason offspring experience negative consequences as a result of parental cancer may be of significance for supportive care strategies so as to identify offspring at risk and know when is necessary to intervene.

The studies which met the inclusion criteria largely described the negative impact of parental cancer, which contributes to the overwhelming focus on psychopathology (Mosher & Danoff-Burg, 2005) or negative incidents in this research area. Conversely, there was little investigation of positive or protective factors that may mediate the burden of a parent’s cancer. One study indicated that self-esteem was related to better HRQoL (Jeppesen et al., 2016), thus self-esteem may be a protective factor for wellbeing. Interestingly, one study found scores for social support improved over time (Jeppesen et al., 2016), and another study found that stress response symptoms were related to all other problems but social issues (Huizinga et al., 2010). Such findings indicate that offspring may place great significance on social support and it may offset the negative impact of parental cancer. Similarly, offspring in one study found solace in religious or spiritual connections (Clemmens, 2009). However, this finding may be reflective of religion being more culturally significant within an American sample. Research should attempt to better understand the presence of positive or protective factors that attribute to improved wellbeing for these offspring.

Limitations of current research

Through undertaking this review, shortcomings in the extant research were apparent. The exclusion of a large number of studies due to offspring age (see Figure 1) highlights the extent to which research has failed to address the experiences of offspring in their adolescence and young adulthood *at the time* of their parent's incident cancer diagnosis. No studies in this review considered young adults aged 21 to 24 years, and papers (*n* = 19) were excluded because they were limited to adults above 24 years. Additionally, 73 studies were excluded for including dependent offspring below 10 years. The paucity of research relating to this cohort (10 – 24 years) exposes the need for further investigation.

Many studies (*n* = 56) were excluded from this review because they failed to define offspring age at diagnosis. Omitting such key information undermines the usability of study outcomes, as offspring developmental stages are overlooked. This limitation calls for consideration in regards to the age of offspring at the time of the parent's incident cancer diagnosis as a factor that may affect the degree to which they are impacted by their parent's illness. It also calls for contemporary methods of research to assess offspring on a longitudinal basis.

Studies were limited by their definition of family. All but one study failed to define the type of relationship parents and their offspring had (i.e. biological, adoptive, or step). Also, studies considered parents in partnered relationships (*n* = 1), a mix of two-parent and one-parent families (*n* = 4), or failed to define the family structure (*n* = 2). Given the nuclear family is becoming less dominant (Cohen, 2013; de Vaus, 2004), it is important that non-traditional families are better researched. This includes same-sex parents, and biological, adoptive, and step-offspring. However, this may only be suitable to Western countries.

Limitations of this review

This review had some limitations. In order to accurately summarise the impact that a parent's incident cancer diagnosis has on their adolescent and young adult offspring, a stringent inclusion criteria was created. The WHO’s definition of adolescents and young adults was adopted, thus studies were excluded if offspring were outside the ages of 10 and 24 at first diagnosis, or if they failed to specify offspring age at diagnosis. The reason for this latter criteria was to control for developmentally different responses due to being offspring being latency-aged (< 10 years) or in adulthood (> 24 years) at the time diagnosis. Subsequently, few studies met the offspring age requirement for inclusion, and a significant number of studies (*n* = 56) were excluded because they failed to specify offspring age at the incident diagnosis.

Although most studies originated from Western countries, two studies were based in Iran and Malaysia, respectively. This has implications for the findings, as strategies such as open communication to support offspring may be less applicable outside of Western culture.

In this type of research, parents are often concerned about creating more distress for their child. Therefore, findings may be based on offspring who have accustomed well to the disease, rather than those who are struggling. In three studies, offspring included sibling informants, which may have biased findings. In another three studies, it was not defined whether sibling informants were used. Also, one study was limited to only using families with partnered parents, thus not representing single-parent households.

Conclusions

To our knowledge, this was the first review that specifically considered the impact of a parent’s cancer on offspring in their adolescence or young adulthood (10 – 24 years) at the time of their parent’s incident diagnosis. These offspring represent an age range characterised by turbulence resulting from increasing independence and maturity. Significantly, the paucity of studies uncovered in this systematic literature review demonstrated a methodological weakness in the extant literature related to the oversight of offspring age at the time of a parent’s first cancer diagnosis.

Given the small number of studies uncovered in this review and differences that may have arisen from cross-cultural comparisons, findings should be treated with caution. This review illustrated that almost all offspring in the included studies were impacted by their parent’s cancer diagnosis, but daughters and offspring who reported more initial problems appear to be most impacted. Reviewed studies focused on the psychopathological or negative impact that a parent’s cancer has on offspring, rather than protective or positive factors. Future research may benefit by establishing what components of the parents cancer impacts offspring to better inform supportive care strategies.

Table 2

Studies considering the impact of a parent's cancer on offspring (10 - 24 years)

Author (year) Country	Aim	Participants	Offspring age at (i) study, (ii) diagnosis	Parent cancer types; stage	Study design Data collection method/ tool	Key findings	MMAT Score (Limitations)*
Ainuddin et al., (2012) Malaysia	Cancer impact on offspring QoL	95 offspring	(i) 13 – 18 yrs) (ii) 13 – 18 yrs	Colorectal, lung, breast; Stage I – IV	Quantitative PedsQL	- Offspring scored lowest on emotional and school functioning domains. - Sons had better physical functioning and total QoL. - Offspring whose mothers had cancer had worse school functioning. - Household income was negatively associated with emotional	75% (4.2)*

						functioning, school functioning, psychosocial HRQoL, and total QoL.	
Azarbarzin et al., (2015) Iran	Effect of supportive-educative program on offspring QoL	30 offspring	(i) 11 – 20 yrs (ii) 10 – 20 yrs	Not specified	Quantitative SF-36	- Following the program, there were statistically significant differences in physical functioning, energy/fatigue, emotional wellbeing, social functioning, pain, general health, and psychological and physical health subcategories. - No statistically significant differences in role limitation due to physical or	100%

						psychosocial health following program.	
Clemmens (2009) United States	Offspring coping	11 offspring	(i) 13 – 19 yrs (ii) 12 – 19 yrs	Breast	Qualitative In depth, semi-structured interviews	- All offspring experienced distress. - Five main themes identified: life changed; turning to self (self-reliance and coping behaviours); learning to be with my mother (new ways of being close to the parent); needing to normalise; speaking openly- the importance of communication.	50% (1.3; 1.4)*
Finch & Gibson (2009)	How offspring learn of	7 offspring	(i)14 - 18 yrs	Breast, acute myeloid leukaemia, non-	Qualitative	- Offspring advocated for	100%

United Kingdom	parent’s cancer		(ii) 14 - 18 yrs	Hodgkin’s lymphoma	Semi-structured interviews	open and honest communication - Six themes identified: first hearing about diagnosis; vulnerability of self and others (family roles and relationships were threatened); communication within the family (dependent on attitudes, beliefs and comfort); feeling supported in experience; experience and support of school; experience and support of hospital.	
Huizinga et al., (2010) Netherlands	Offspring stress response symptoms	49 offspring	(i) 11 – 18 yrs	Breast, testicular, gynaecological, sarcoma,	Quantitative IES YSR	- Offspring SRS were at clinical levels for 29% of offspring at T1,	100%

		37 parents with cancer 37 partners	(ii) 10 – 18 yrs	melanoma, haematological, rectal, renal, thyroid	CBCL	16% at T2, 14% at T3. - Moderate to large correlations were found between initial SRS and future emotional and cognitive problems. - Parents observed less SRS in offspring than in offspring self-report. - Daughters experienced more SRS. - Offspring age, patient gender, treatment intensity and duration were unrelated to SRS.	
Jeppensen et al., (2016)	Offspring QoL	29 offspring	(i) 13 – 19 yrs	Breast, lymphoma,	Quantitative	- Offspring had significantly	100%

Norway		26 parents with cancer 19 partners	(ii) 12 – 19 yrs	Hodgkin’s lymphoma.	KIDSCREEN Rosernberg self-esteem questionnaire-short form SCL-5 FAD	poorer physical wellbeing score than norms. - Social support and peers scores improved over time. - Daughters scored significantly lower on the HRQoL psychological wellbeing subscale. - Self-esteem had a significant and positive association with HRQoL.	
Kühne et al., (2013) Germany	Family functioning in families by disease stage (palliative, other)	Palliative: 31 offspring 46 parents with cancer 59 partners	(i) 11 – 18 yrs (ii) 10 – 18 yrs	Breast, gynaecological, digestive organs (unspecified).	Mixed-method FAD	- 15 – 26% of family members reported dysfunctional general functioning.	100%

	Non-palliative 33 offspring 89 parents with cancer 65 partners		- Offspring observed more dysfunctional communication than parents - Patients and partners observed more role dysfunction than offspring - Palliative-parent families had higher scoring agreement than non-palliative families.

Note: CBCL: Child Behaviour Checklist; FAD: Family Assessment Device; HRQoL: Health Related Quality of Life; IES: Impact of Events Scale; PedsQL: Paediatric Quality of Life Inventory; QoL: Quality of Life; SCL-5: Hopkin's Symptoms Checklist; SF-36: Short Form Health Survey; T1: 4 months after parent's diagnosis; T2: 10 months after parent's diagnosis; T3: 16 months after parent's diagnosis; YSR: Youth Self Report.

MMAT Limitations*: 1.1 Source of data; 1.3 Consideration of data collection context; 1.4: Consideration of researchers' influence; 3.1: Participant recruitment; 4.2: Sample representativeness

NB: Key findings in quantitative and mixed-method study based on statistical significance (*p* < .05).

CHAPTER 5. STUDY TWO

Statement of authorship

Title of Paper	Profiling adolescents and young adults and their parents with a cancer diagnosis in Western Australia: a population-based data linkage investigation.
Publication Status	☐ Published ☐ Accepted for Publication ☑ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	Morris, J.N., Zajac, I., Turnbull, D., Preen, D., Patterson, P. & Martini, A. (2018). *Profiling adolescents and young adults and their parents with a cancer diagnosis in Western Australia: a population-based data linkage investigation*. Manuscript submitted for publication.

Principal Author

Name of Principal Author (Candidate)	Julia Morris		
Contribution to the Paper	Contributed to linked data applications. Analysed and interpreted data. Wrote manuscript and revised in response to reviewer comments. Acted as corresponding author.		
Overall percentage (%)	80		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	13/09/2018

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Ian Zajac		
Contribution to the Paper	Supervised development of work. Assisted with statistical analysis. Provided feedback on manuscript.		
Signature		Date	31/07/2018
Name of Co-Author	Professor Deborah Turnbull		

Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		
Signature		Date	26/07/2018
Name of Co-Author	Professor David Preen		
Contribution to the Paper	Supervised development of work. Provided linked data support. Provided feedback on manuscript.		
Signature		Date	02/08/2018
Name of Co-Author	Dr Pandora Patterson		
Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		
Signature		Date	06/08/2018
Name of Co-Author	Dr Angelita Martini		
Contribution to the Paper	Advised on research design and planning. Supervised development of work. Contributed to linked data applications. Provided feedback on manuscript.		
Signature		Date	27/07/2018

Paper

Abstract

Objective: Parental cancer is a significant problem for adolescent and young adult offspring, whose developing cognitive and empathetic capacities result in increasing awareness of their parent's physical and emotional pain. This study responded to a precedent set by international research regarding the impact of parental cancer by enumerating and describing the population of adolescent and young adult offspring (12 – 24 years) and their parents with cancer in Australia.

Methods: A retrospective cohort study was conducted using linked whole-population data from the Western Australia Data Linkage System, which provided results generalisable at a national level.

Results: Between 1982 and 2015, 57,708 offspring were impacted by 34,600 parents' incident malignant cancer diagnoses. The most common parent diagnosis was breast cancer. Of the 36.4% of parents who died, this was mostly a result of cancer. Most families resided in regional areas and were of high or middle socioeconomic status. Significant predictors of earlier parent death included low socioeconomic status, remoteness, age, having more children, and having older children.

Conclusion: This research contributes to better understanding which adolescents and young adults are affected by a parent's cancer in Australia.

Implications for Public Health: These results may be useful for planning and implementation of Australian supportive services.

Keywords: Cancer, Parental cancer, Adolescent, Young adult, Linked data

Objectives

A parent's cancer is the cause of considerable distress for their children (Morris et al., 2016). Offspring of parents with cancer experience a variety of psychological and physical health problems (Chen, Sjölander, et al., 2015; Huizinga et al., 2003; Krattenmacher et al., 2013; Niemelä et al., 2012; Phillips, 2014). For example, compared to the norm, these children access more psychiatric services (Niemelä et al., 2012) and have an increased rate of death (Chen, Sjölander, et al., 2015). Parents with cancer not only endure the physical and emotional strain of the disease and its treatment, but are burdened with feelings of guilt about the impact that their illness has on their children (Turner et al., 2007).

Research has demonstrated that offspring respond differently to parental cancer depending on their age (Hauken, Senneseth, et al., 2017), with older offspring experiencing greater disruption as a result of parental cancer than younger children. Compared to children of healthy parents, adolescent and young adult offspring of ill parents are tasked with more household and caregiver responsibilities (Patterson et al., 2017; Sieh et al., 2013) that impede on their leisure activities, and impair their academic achievement (Sieh et al., 2013) and normative development (Pederson & Revenson, 2005). Research also shows that compared to preadolescents who experience parental cancer, adolescent and young adult offspring experience higher levels of anxiety and depression (Compas et al., 1994). Recent findings have demonstrated that adolescent and young adult offspring facing a family member's cancer experience levels of distress comparable to that experienced by young people seeking treatment for mental health issues (Patterson et al., 2017). Additionally, adolescents and young adults report higher levels of distress, and higher levels of unmet needs if they have a parent with cancer, compared to those with a sibling with cancer (Patterson et al., 2017).

Support for families experiencing a parent's cancer is essential to offspring development and parent coping (Weisman & Worden, 1976; Worden, 1996). However, there are large service gaps in the provision of support for this group (Semple & McCaughan, 2013; Su & Ryan-Wenger, 2007). Offspring affected by a parent’s cancer may be overlooked by supportive care services (Rauch & Moore, 2010) as they themselves are not the patient . For offspring in their adolescence and young adulthood, this is particularly problematic. These offspring possess a unique vulnerability in that their developing cognitive and empathetic capacities mean they are more aware of a parent’s physical and emotional pain than younger children (Christ et al., 1994). Further, these young people are contending with the developmental challenges and milestones that come with adolescence and young adulthood. It is imperative that adolescents and young adults experiencing a parent’s cancer diagnosis are appropriately supported. A first step in achieving this aim is to seek to better understand the prevalence of parent cancer in households with adolescent and young adult children, as well as identify factors which are contributing to poorer outcomes in relation to cancer to better identify at-risk groups.

Outside of Australia, parental cancer has been quantified in an effort to understand the extent of this problem. Parental cancer is estimated to affect 6.6% of Finnish offspring (0 – 21 years) (Niemelä et al., 2012); 1.4% of Norwegian offspring (0 – 25 years) (Syse et al., 2012); and 0.38% of Japanese offspring (0 – 18 years) (Inoue et al., 2015). In Sweden, over 100,000 of 2,871,242 children (≤ 18 years) followed between 1991 and 2009 had a parent diagnosed with cancer (Chen, Sjölander, et al., 2015). Further, United States based estimates indicated that in 2007, 562,000 dependent children (≤ 18 years) lived with a parent in the early phases of cancer (Weaver et al., 2010) and 200,000 children were newly impacted by a parent’s incident cancer diagnosis (Lewis, 2007).

It is estimated that every year in Australia, 10,000 parents are diagnosed with cancer (Camp Quality, 2014), affecting 21,000 adolescents and young adults (12 – 24 years) (Walczak et al., 2017). Besides these projections, there is a dearth of evidence that identifies the number of Australian offspring affected by parental cancer and the characteristics of these families in terms of demographics and other key variables. Identifying the number and characteristics of Australian families with adolescent and young adult offspring affected by parental cancer is essential to appropriately respond to this vulnerable population by providing evidence essential to service development and implementation. The purpose of this study was to enumerate and describe the characteristics of adolescent and young adult offspring (12 – 24 years) and their parents with cancer in Western Australia using whole-population linked administrative health data.

Ethics

Approval for the project was received from the Western Australia Department of Health (WADoH) (#2016/31); Western Australia Data Linkage Branch (#201604.07); University of Western Australia Human Research Ethics Council (HREC) (RA/4/1/8660) and University of Adelaide HREC (#32198).

Methods

Definitions of offspring and parents

For the purpose of this project, adolescents and young adults were defined as young people aged 12 – 24 years. This age range closely aligns with the World Health Organisation’s definition of adolescents and young adults (10 – 24 years) (World Health Organisation, 1986); whilst encompassing developmental perspectives of age 12 years constituting the start of adolescence (Hoffnung et al., 2015), and adopting the same age delineation for adolescent and young adults as provided by Australian government (Australian Institute of Health and Welfare, 2011) and cancer support organisations (i.e. CanTeen).

In this project, parents were defined as biological mothers and fathers as current data linkage is limited in its capacity to link family members outside of biological relationships.

Data sources

A retrospective cohort study was conducted using routinely-collected linked whole-population data from the Western Australia Data Linkage System (WADLS). Parents were identified in the Western Australia Cancer Registry (WACR) as having an incident malignant cancer diagnosis (excluding benign or in-situ cancers, Basal cell carcinoma (BCC) and Squamous cell carcinoma (SCC)) between 1 January 1982 and 31 December 2015; and at least one child aged 12 - 24 years and alive at the time of diagnosis. Offspring (12 – 24 years) were identified via Family Connections (a system that genealogically links individuals) through the Midwives Notification System, Birth Registrations, and Mortality Registry. WACR records provided demographic information (sex, date of birth, residential postcode at diagnosis), cancer information (date of diagnosis, tumour topography) and cancer-related death data (date of death, cause of death). Birth Registrations and Midwives Notification System data provided further demographic information on the parent and offspring cohorts (sex, age, birth place, postcode of residence). The Mortality Registry provided death data (date of death, cause of death). Cause of death and tumour topography were classified according to the International Classification of Diseases (ICD-10). Socioeconomic status (SES) was assigned based on parent postcode at diagnosis, or Local Government Area at diagnosis where postcode was unavailable, using the Socioeconomic Index for Areas (SEIFA) Index of Relative Socioeconomic Disadvantage (Australian Bureau of Statistics, 2013). SEIFA was assigned according to the most recent Census to time of diagnosis. Parents were categorised into one of three SEIFA groups (low, middle and high SES) depending on their SEIFA score relative to the state-wide tertiles for that Census period. Remoteness was assigned based on parent postcode at diagnosis using the Australian Statistical Geography Standard Remoteness Area (RA) structure (Australian Bureau of Statistics, 2011). Offspring were assigned their mother’s SEIFA and RA scores. In the case of offspring having two mothers in the dataset, offspring were assigned SEIFA and RA scores of the parent with the earlier cancer diagnosis.

Data analysis

Data analysis was conducted using SPSS statistical software (version 24, IBM) (SPSS Inc., 2017). Descriptive statistics were used to report on the offspring and parent cohort demographics and characteristics, specifically: age, sex, ethnicity, country of birth, family relations (number of parents per offspring; number of children per parent), SES (SEIFA), place of residence (remoteness), and date and cause of death. If a child had more than one parent who experienced an incident cancer diagnosis in the WACR, their age was calculated at the date of first diagnosis. Descriptive statistics were also used to report on parent's cancer data, specifically: year of diagnosis and age at diagnosis, as well as tumour information (behaviour, morphology, topography).

Negative binomial regression analysis was used to determine whether the number of offspring impacted by parental cancer changed from 1982 to 2015, and whether the number of offspring experiencing parental cancer varied in terms of their age. The adolescent and young adult (12 – 24 years) WA population from 1982 to 2015 was derived from ABS Census data, and added to the model as the offset variable.

Multivariate Cox Proportional Hazards regression modelling was used to determine the characteristics associated with earlier parent cancer-related death, thus establishing the rate at which offspring were bereaved. Covariates included parent's Indigenous status, age at diagnosis, total offspring at incident diagnosis, mean age of offspring, SES, and remoteness. Hazard ratios (HRs) with 95% confidence intervals were adjusted for the aforementioned covariates. The start of the follow up was the date of the parent's cancer diagnosis; and follow-up ended at the date of parent's cancer related death; or censored at the date of non-cancer related death or at 31 December 2015. Parents were excluded if they had died but were missing a date of death record (0.2%), a date of birth record (0%), or a postcode at diagnosis (0.3%).

Results

Offspring & Parents

Between 1982 and 2015, a total of 57,708 adolescent and young adult offspring (12 – 24 years of age) experienced their 34,600 parents' incident cancer diagnosis in WA. The cumulative number of adolescent and young adults in WA within this timeframe (~33 years) was 12,314,577, and the proportion of offspring affected by parental cancer was estimated to be 0.47%, with an average of 0.46% of offspring newly affected by a parent's malignant cancer each year (95% CI: 0.43, 0.49). Of this, 29,606 sons and 28,102 daughters were affected; and 18,265 fathers and 16,335 mothers received an incident cancer diagnosis. The mean age of offspring at their parents diagnosis was 18.8 years (SD = 3.7), and the mean age of parents was 51.3 years (SD = 7.9). Visual inspection of the data indicated that older offspring were more affected by parental cancer (5), but this difference was not statistically significant (X^2 (1) = .50, p = .48). The mean number of offspring per parent at their diagnosis was 1.71 (SD = 0.85), with the range of offspring per parent varying from 1 to 9.

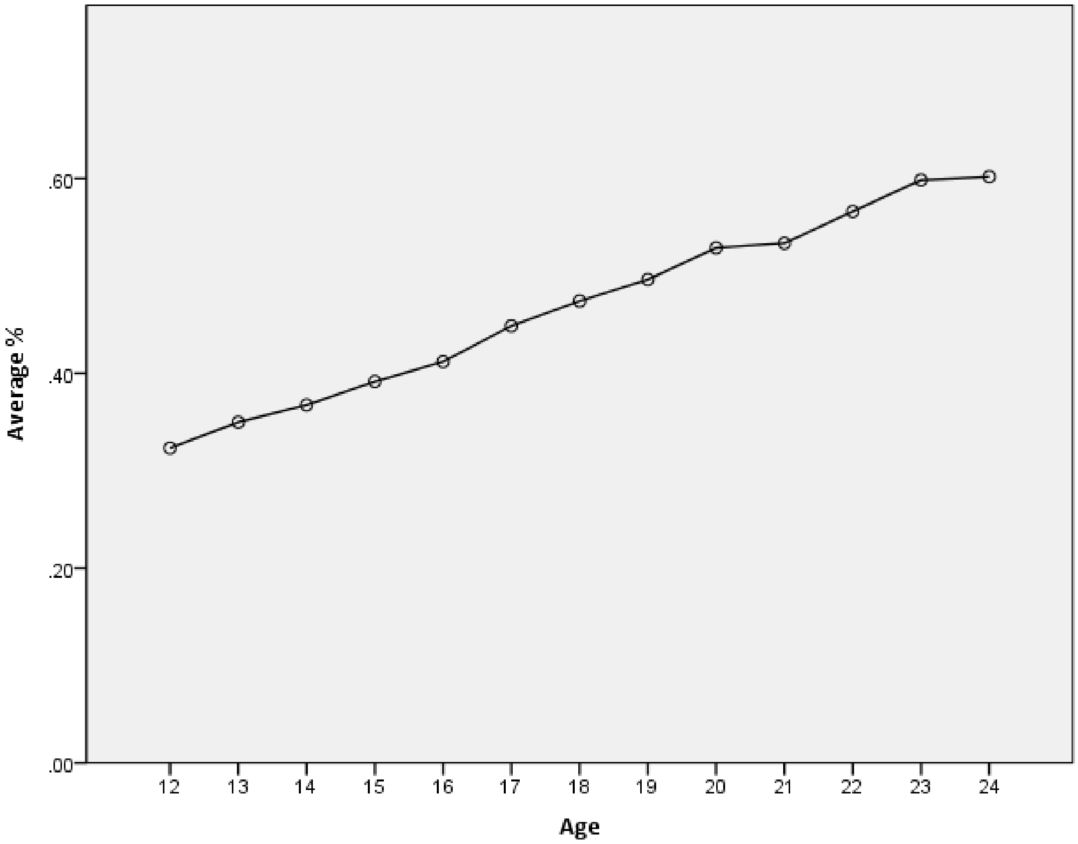


Figure 5 Average percentage of offspring affected annually by age (in years)

The number of diagnoses and offspring affected increased between 1982 and 2015 (Table 3) but negative binomial regression modelling demonstrated no statistically significant association between number of offspring and time, adjusting for the WA population aged 12 – 24 years (X^2 (1) = 1.36, *p* = .24). Analyses indicated that 97.5% of offspring had only one parent diagnosed with cancer between 1982 and 2015. Of the 2.5% who had both parents diagnosed, two offspring had same-sex parents. The mean time between parent's cancer diagnoses for this group was 3.4 years (SD = 3), and mothers were generally diagnosed first (52.5%).

Table 3

Parent cancer diagnosis and offspring affected between 1982 and 2015

Year of parent diagnosis	Parent diagnoses	%	Offspring affected	%	Total	%
1982 to 1985	2272	6.6	4164	7.2	6436	7
1986 to 1990	3358	9.7	5824	10.1	9182	9.9
1991 to 1995	4309	12.5	7056	12.2	11365	12.3
1996 to 2000	4522	13.1	7399	12.8	11921	12.9
2001 to 2005	5790	16.7	9625	16.7	15415	16.7
2006 to 2010	6740	19.5	11103	19.2	17843	19.3
2011 to 2015	7609	22	12537	21.7	20146	21.8
Total	34600	100	57708	100	92308	100

Note: for offspring with two parents with cancer, count was considered at the earliest diagnosis.

Socioeconomic status and geographic remoteness

Most families (parents and offspring) resided in Inner (48.2%) or Outer Regional (11.3%) areas of WA (Table 4). More families were of high (44.5%) or middle SES (31.8%). Most offspring (99.9%) were born in WA, as were the majority of parents (69.1%). The remaining parents were born in the United Kingdom (13.3%), and a further 14.3% born in New Zealand, Europe, Asia, Africa, the Americas, and Antarctica. An additional 2.3% had no place of birth record.

Table 4

Socioeconomic Status and Remoteness Area

	Offspring	%	Parents	%	Total	%
Total	57708		34600		92308	
SES[a]						
Low	13562	23.5	8068	23.3	21630	23.4
Mid	18410	31.9	10931	31.6	29341	31.8
High	25579	44.3	15512	44.8	41091	44.5
NFA[b]	157	0.3	89	0.3	246	0.3
Remoteness Area						
Major cities	19550	33.9	12128	35.1	31678	34.3
Inner Regional	27902	48.4	16626	48.1	44528	48.2
Outer Regional	6619	11.5	3774	10.9	10393	11.3
Remote	891	1.5	4894	1.4	1380	1.5
Very Remote	2589	4.5	1494	4.3	4083	4.4
NFA[b]	157	0.3	89	0.3	246	0.3

[a] ‘Low’ indicates relatively greater disadvantage and a lack of advantage, and ‘high’ indicates relatively greater advantage and a lack of disadvantage.

[b] NFA = No fixed address.

Cancer information

Parent’s first cancer diagnoses included invasive and lymphohaematopoietic malignancies (Table 5). The most common cancer diagnoses among mothers was breast (40.7%) and among fathers, cancer of the male genital organs (22.4%). Melanoma and skin cancers were the second most common cancer for mothers and fathers (16.3% and 21.1%, respectively).

Table 5

Topography of parent's incident malignant cancer diagnosis

Topography	ICD10	Mothers	%	Fathers	%	Total	%
Lip, oral cavity and pharynx	C00 – C14	281	1.7	1170	6.4	1451	4.2
Digestive organs	C15 – C25	1894	11.6	3533	19.3	5427	15.7
Respiratory and intrathoracic organs	C30 – C34; C37 – C38	637	3.9	1618	8.9	2255	6.5
Bone and articular cartilage	C40 – C41	24	0.1	40	0.2	64	0.2
Melanoma and skin	C43 – C44	2660	16.3	3862	21.1	6522	18.8
Mesothelial and soft tissue	C45 – C49	120	0.7	363	2	483	1.4
Breast	C50	6643	40.7	27	0.1	6670	19.3
Female genital organs	C51 – C54; C56 – C57	1616	9.9	0	0	1616	4.7
Male genital organs	C60 – C63	0	0	4092	22.4	4092	11.8
Urinary tract	C64 – C68	352	2.2	929	5.1	1281	3.7
Eye, brain and other parts of central nervous system	C69 – C72	259	1.6	471	2.6	730	2.1
Thyroid and other endocrine glands	C73 – C75	652	4	207	1.1	859	2.5
Unknown primary site	C80	175	1.1	355	1.9	530	1.5
Hodgkin lymphoma	C81	57	0.3	80	0.4	137	0.4
Follicular lymphoma	C82	168	1	192	1.1	360	1
Non-follicular lymphoma	C83	190	1.2	308	1.7	498	1.4

Mature T/NK-cell lymphomas	C84	26	0.2	54	0.3	80	0.2
Other/unspecified types of non-Hodgkin lymphoma	C85	126	0.8	189	1	315	0.9
Other specified types of T/NK-cell lymphoma	C86	5	0	14	0.1	19	0.1
Malignant immunoproliferative diseases	C88	7	0	6	0	13	0
Multiple myeloma and malignant plasma cell neoplasms	C90	116	0.7	194	1.1	310	0.9
Lymphoid leukaemia	C91	75	0.5	236	1.3	311	0.9
Myeloid leukaemia	C92	147	0.9	161	0.9	308	0.9
Monocytic leukaemia	C93	7	0	15	0.1	22	0.1
Other leukaemias of specified cell type	C94	5	0	7	0	12	0
Leukaemia of unspecified cell type	C95	5	0	5	0	10	0
Other/unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue	C96	7	0	6	0	13	0
Polycythaemia vera	D45	12	0.1	29	0.2	41	0.1
Myelodysplastic syndromes	D46	27	0.2	43	0.2	70	0.2
Lymphoid, haematopoietic and related tissue	D47	42	0.3	59	0.3	101	0.3

Deaths

Between 1982 and 2015, 610 offspring died (1.1%). Offspring died at a mean age of 34 years (SD = 9.6), and the mean time to death from their parent's diagnosis was 13 years (SD = 8.7). In the study period, 12,595 parents died (36.4%) at a mean age of 58.3 years (SD = 10.7), and mean time to death from diagnosis was 4.6 years (SD = 6.6). More fathers died overall (60.5%) and more fathers died of both cancer-related (58.8%) and non-cancer related or unknown causes (71.0%) than mothers. Among parents who died, more died of cancer-related deaths (86.4%) than non-cancer deaths (13.6%).

Rate of offspring bereavement due to parent's cancer related death

Cox Proportional Hazards Regression models revealed a statistically significant relationship between parent's age at diagnosis and time to death, ($p < .001$, Table 6), where parents aged 50 years and younger had a hazard of dying 34% lower than parents aged 51 – 94 years. Fewer children in the family was also associated with lower hazard of dying ($p < .01$). Parents with 4 or more children had the lowest survival rate.

A statistically significant association was found between child's age and time to parent's death ($p < .05$). Parents with younger offspring had a lower hazard of dying than parents with older offspring. A statistically significant association was found between SES and time to death ($p < .001$). Compared to those of high SES, parents of low SES had a 49% increased rate of dying, and parents of moderate SES had a 30% increased rate. Lastly, there was a statistically significant association between remoteness and time to death ($p < .05$), with parents living in major cities and regional areas having a 9% lower risk of death than parents living in remote areas.

Table 6

Characteristics influencing rate to parent's cancer related death

Variable	Adj. HR	Hazard Ratios (95% CI)	p-value
Parent age at diagnosis (26 – 50 years)	0.66	(.63 – .69)	.000
Parent age at diagnosis (51 – 94 years)			
Total offspring			
1 offspring	0.87	(.79 – .97)	.01
2 offspring	0.80	(.72 – .89)	.000
3 offspring	0.81	(.73 – .90)	.000
4 or more offspring			
Mean offspring age[a]			
Early adolescence (12 – 14 years)	0.88	(.82 – .93)	.000
Late adolescence (15 – 19 years)	0.95	(.91 – .99)	.02
Young adulthood (20 – 24 years)			
SEIFA			
Low	1.49	(1.42 – 1.56)	.000
Middle	1.30	(1.24 – 1.36)	.000
High			
Remoteness[b]			
Major cities	0.91	(.84 – .99)	0.02
Regional	0.92	(.85– .99)	0.03
Remote			

[a] Offspring age categorised according to Patton et al. definitions of adolescent and young adult age.

[b] Remoteness collapsed into Major Cities, Regional (Inner and Outer Regional) and Remote (Remote and Very Remote).

Discussion

To our knowledge, this is the first study to describe the Australian population of adolescent and young adult offspring (12 – 24 years) impacted by parental cancer; responding to a precedent set by international research regarding the impact of parental cancer in other jurisdictions (Chen, Sjölander, et al., 2015; Inoue et al., 2015; Niemelä et al., 2012; Syse et al., 2012). WA has been shown to be representative of the wider Australia population in terms of sociodemographic and health economic indicators (Clark et al., 2010). As such, findings are likely generalisable at a national level. Results demonstrated that an estimated 0.47% (equating to 57,708) of adolescents and young adults experienced their parent's incident cancer diagnosis between 1982 and 2015 in WA. Importantly, this percentage reflects *incident* parent diagnoses over the 33-year period as opposed to overall prevalence of parental cancer and so likely underestimates the true burden from parental cancer. Regardless, this study confirms that on average, approximately 1697 adolescents and young adults are impacted by a parent's incident cancer diagnosis each year.

Although these results provide a reference point for the extent of incident parental cancer diagnoses in Australia, drawing comparisons between countries is complicated by methodological variations in the published literature. Where our study excluded first record cancer diagnoses of BCC and SCC (as these are precursors to skin cancer, rather than cancer per se (Sober & Burstein, 1995)) other studies did not comment on such exclusion criteria. Further, our study was limited to malignant diagnoses and excluded benign or in-situ records. This criteria was consistent with that of Niemelä et al. (Niemelä et al., 2012), but different to other population-based studies that focused on malignant and in-situ diagnoses (Chen, Sjölander, et al., 2015), malignant and benign neoplasms of the brain (Syse et al., 2012), or one study that mentioned exclusion of in-situ cases, but did not specify their inclusion criteria(Inoue et al., 2015). Notably, other studies may not have excluded BCC and SCC as they are less commonly diagnosed in Japan (Inoue et al., 2015) and Scandinavia (Chen, Sjölander, et al., 2015; Syse et al., 2012). Our study focused on adolescents and young adults defined as 12 – 24 years, where others have focused on dependent offspring (0 – 8 years)

(Chen, Sjölander, et al., 2015; Inoue et al., 2015) or children through to young adults (0 – 25 years) (Syse et al., 2012). Other variations relate to differences in observation periods ranging from 4 years (Inoue et al., 2015), 18 years (Chen, Sjölander, et al., 2015), 21 years (Niemelä et al., 2012) and 48 years (Syse et al., 2012). These methodological differences mean that comparisons between countries should be attempted with caution, both in regard to the number of families affected by parental cancer, and in terms of comparing the extent of the problem that is parental cancer. For example, by focusing on malignant cancers, we do not imply that in-situ or benign diagnoses are less distressing. In fact, research has demonstrated that false-positive cancer diagnoses are experienced as psychologically distressing (Renzi, Whitaker, & Wardle, 2015). Thus, whilst this research is a necessary contribution elucidating the number of offspring affected by parental cancer in Australia, the nuances of each study of this nature must be considered for global estimates or national comparisons.

Across the sample, most cancer diagnoses were among mothers for breast cancer. Daughters experience their mother’s cancer as particularly distressing (Inbar, Ety, Ayala, & Tamer, 2013). In response to a mother’s breast cancer diagnosis, daughters report increased concerns about their body image, sexual functioning (Adelson, 2012), future health and their genetic susceptibility to the disease (Cappelli et al., 2005). Seperately, results demonstrated that more fathers were diagnosed with cancer and died because of the disease. Longitudinal research has demonstrated that sons have an increased likelihood of being diagnosed with a psychosocial disorder if they experienced paternal cancer during childhood (Niemelä et al., 2016). Furthermore, a cross-sectional study found that fathers with cancer reported difficulties in accessing practical and psychosocial support resources, which they believed was due their needs being minimised due to the social construction of gender roles and masculinity (Lundquist, 2017). Such findings indicate that depending on which parent is diagnosed, offspring and their parents encounter different problems. In light of this, healthcare professionals should be prepared to support families affected by parental cancer, as well as offer support relevant to the disease, such as genetic counselling in the case of a parent's breast cancer diagnosis (Cappelli et al., 2005).

Notably, the majority of families in this study resided in regional areas, which is higher than the general WA population, who mostly reside in major cities (78.1%) (Australian Bureau of Statistics, 2018). Furthermore, a substantial proportion of families (23.4%) were of low socioeconomic status, although this was consistent with population norms (Clark et al., 2010). In Australia, people with cancer who are socioeconomically disadvantaged or geographically isolated are less able to access care; both in terms of screening and treatment (Hall, Holman, & Sheiner, 2004; Vinod, Hui, Esmaili, Hensley, & Barton, 2004). Rurality and socioeconomic disadvantage is consistently linked to poorer cancer survival in Australia, (Australian Institute of Health and Welfare, 2008); a finding echoed in this study, where parents characterised by these demographics had an increased rate of death. In other words, offspring were parentally bereaved at a faster rate if their family was socioeconomically disadvantaged or geographically isolated. Socioeconomic disadvantage and geographic isolation is consistently linked to under-utilisation of mental health services in Australia (Booth et al., 2004; Meadows, Enticott, Inder, Russell, & Gurr, 2015). Results indicated that offspring most at risk of bereavement due to parental cancer are also the least likely to access psychosocial support because of their sociodemographic profile. As most parent deaths were cancer-related there is a clear need for effective bereavement support regardless of offspring's socioeconomic or geographic position.

Parental cancer was more commonly experienced by older offspring (mean age of ~18). In most Australian States, this age corresponds to the final year of secondary school, and represents a major transitional point in children's lives characterised by greater independence and responsibilities. Plausibly, this age is a time of acute vulnerability triggered by the disappearance of structure they have received through formal schooling. If the young person is in school or university at the time of their parent's diagnosis, they may struggle academically (Sieh et al., 2013), or even be at risk of withdrawal (Hoyt & Winn, 2004). Besides academic obligations, the older a child is at their parent's cancer diagnosis, the more responsibilities they likely adopt (Patterson et al., 2017; Sieh et al., 2013). This includes adopting the role of caregiver (Patterson et al., 2017), which may disrupt their developmental trajectory. To counteract this, families must be mindful of balancing offspring's needs with the needs of the parent with cancer (Patterson et al., 2017), and it is important that healthcare professionals support families to achieve such a balance. In addition, support strategies should consider the age of offspring at the time of their parent's diagnosis and the offspring's needs.

In this sample, 2.5% of offspring who experienced parental cancer had both parents diagnosed with cancer. Although a minority, this cohort are potentially at significant risk. A parent's illness may compromise the quality of the parent-child relationship as the ability to fulfil parenting obligations is challenged (Pederson & Revenson, 2005). If offspring have two parents with cancer, they will likely endure the deterioration of two essential relationships and supports. In response to parental illness, families endure a redistribution of roles that see offspring adopting the role of a parent (Pederson & Revenson, 2005) or caregiver (Patterson et al., 2017). Such responsibilities would be exacerbated for offspring if both their parents were affected by cancer. Long-term parental illness may significantly disrupt the family structure and as a result compromise the family's capacity to meet their children's developmental needs (Pederson & Revenson, 2005). Plausibly, this may also be the case if parents are diagnosed sequentially across the child's life.

Strengths and Limitations

A strength of this study was that it involved whole-population routinely-collected data linked through the WADLS, thereby increasing statistical power and reducing reporting bias. This method identified people otherwise underrepresented in cancer research, as focus is predominately placed on mothers with cancer, coupled parents, those belonging to an ethnic majority, and people of middle to high socioeconomic status who not geographically isolated. Current data linkage has no capacity to link to adoptive, step- or surrogate offspring, as Family Connections data are limited to biological relationships as recorded on birth certificates. Therefore, there was underrepresentation of non-traditional families in this study; and no method of discerning the nature of the relationship for the (n = 2) same-sex parent families. No staging information is currently available in the WACR, which meant the acuity of offspring's experience of their parent's cancer was not thoroughly understood in terms of disease severity or treatments received. Offspring cause of death was provided by the Cancer Registry, and therefore only available for offspring who had a cancer diagnosis and subsequently died within WA. Also, there were no data that described the relationships between offspring and their parents. In other words, some offspring may be estranged from their parents and potentially not affected by their parent's cancer, but this would not be represented in the data.

Conclusion

Results show that a considerable number of offspring and their parents were impacted annually. Offspring would be sooner parentally bereaved if their parent was older, of low socioeconomic status, or residing in non-metropolitan regions. The considerable number of parental deaths due to cancer identified in this study and factors associated with time to death highlights the need for greater attention to be placed on bereavement support for offspring affected by parental cancer. Adolescent and young adult offspring are being affected by parental cancer at an age that makes them vulnerable, given the other challenges they are facing as part of their developmental trajectory. This research brings to attention the significant number of offspring affected by a parent's cancer. More attention must be given to these offspring, and in particular, those affected by both parent's cancer and those experiencing bereavement due to parental cancer.

Implications for Public Health

Parental cancer is a problem in Australia, as family members who encounter the burden of the illness are often overlooked by support services. This study is the first to report the number of adolescents and young adults (12 – 24 years) affected by a parent's incident cancer diagnosis in an Australian setting. These results are useful for the planning and implementation of supportive care services for these families, whose offspring are potentially at risk due to their developmental vulnerabilities.

Acknowledgements

This research was supported by grant funding from the University of Western Australia's School of Population and Global Health and CanTeen Australia; and through an Australian Government Research Training Program Scholarship.

CHAPTER 6. STUDY THREE

Statement of authorship

Title of Paper	Coping and its relationship to posttraumatic growth, emotion, and resilience among adolescents and young adults (12 - 24 years) impacted by parental cancer.
Publication Status	☐ Published ☐ Accepted for Publication ☑ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	Morris, J.N., Turnbull, D., Martini, A., Preen, D. & Zajac, I. (2018). *Coping and its relationship to posttraumatic growth, emotion, and resilience among adolescents and young adults (12 - 24 years) impacted by parental cancer.* Manuscript submitted for publication.

Principal Author

Name of Principal Author (Candidate)	Julia Morris		
Contribution to the Paper	Formulated aims with supervisors. Collected, analysed and interpreted data. Wrote manuscript and revised in response to reviewer comments. Acted as corresponding author.		
Overall percentage (%)	85		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	27/07/2018

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Professor Deborah Turnbull		
Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		
Signature		Date	26/07/2018
Name of Co-Author	Dr Angelita Martini		
Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		
Signature		Date	27/07/2018

Name of Co-Author	Professor David Preen		
Contribution to the Paper	Supervised development of work. Provided feedback on manuscript.		
Signature		Date	02/08/2018
Name of Co-Author	Dr Ian Zajac		
Contribution to the Paper	Supervised development of work. Assisted with statistical analysis. Provided feedback on manuscript.		
Signature		Date	31/07/2018

Paper

Abstract

Purpose: This study investigated how offspring coping impacts on adaption to parental cancer in terms of posttraumatic growth, resilience, and positive emotion; and how coping differs between offspring.

Methods: Participants (18 – 34 years) completed an online survey, results of which were analysed using generalised linear modelling and multinomial regression.

Findings: Among participating offspring (*n* = 244), higher levels of adaptive coping was associated with increased posttraumatic growth, resiliency, and positive affect; whereas maladaptive coping was associated with decreased resiliency and greater negative affect. Females and offspring who did not access support for their parent's cancer reported higher adaptive coping. Offspring bereaved by parental cancer reported higher levels of maladaptive coping, whilst those whose parents' cancer was of shorter duration and those who lived with their ill parent had lower adaptive and maladaptive coping.

Conclusions/Implications: Adaptive coping appeared beneficial to offspring. Supportive interventions may benefit from focusing on increasing adaptive coping, particularly among bereaved offspring.

Keywords: Psycho-oncology, Coping, Emotion, Parental cancer, Posttraumatic Growth, Resilience

Background

Children who are impacted by a parent's cancer experience a variety of psychological, behavioural, and physical problems. Naturally, offspring will attempt to manage their distress by drawing on their available coping strategies. Coping is defined as the cognitive and behavioural processes used to manage internal or external demands that are appraised as taxing or exceeding one's personal resources (Folkman & Lazarus, 1988). Some coping strategies promote desirable outcomes but others may result in undesirable outcomes (Carver et al., 1989). Within the context of parental cancer, offsprings' problem- and approach-oriented coping (resolving or managing the cause of stress) have been linked to better mental health (Krattenmacher et al., 2013). Conversely, avoidance coping (e.g. distraction) is linked to poorer mental health (Krattenmacher et al., 2013) and maladaptive coping (e.g. denial, behavioural disengagement) is a significant risk factor for psychological morbidity (Costas-Muniz, 2012) and posttraumatic stress disorder (PTSD) (Wong et al., 2006). Further, emotion-focused coping (palliating emotions caused by stress) have been linked to both better and worse mental health (Compas et al., 1996; Krattenmacher et al., 2013).

Results of various empirical studies (Compas et al., 1996; Costas-Muniz, 2012; Krattenmacher et al., 2013) support the notion that offspring's psychological outcomes are somewhat dependent on the coping they use (Carver et al., 1989). Indeed, a component of supportive programs for families affected by parental cancer with dependent children (0 – 18 years) (e.g. Enhancing Connections (Lewis et al., 2015); Child of Somatically Ill Parents (COSIP) (Romer, Kühne, Bergelt, & Möller, 2011)) involve addressing offspring coping as a means to improving adjustment to their parent's illness. Although the aforementioned research (Compas et al., 1996; Costas-Muniz, 2012; Krattenmacher et al., 2013) has contributed to understanding the link between coping and psychopathology or maladjustment, it has overshadowed understanding of a broader range of outcomes that offspring may experience.

Although the research is limited, there is unexpected evidence of offspring experiencing positive gains despite a parent’s cancer (Phillips, 2014) relating to personal development and priorities, improved family relationships (Levesque & Maybery, 2012), increased gratitude and appreciation, and positive incidences relating to personal growth and maturation, prioritising family, and strengthening relationships (Kennedy & Lloyd-Williams, 2009; Phillips, 2014). Since coping processes are purportedly modifiable (Lazarus, 1993), investigating which coping strategies are linked to favourable outcomes in offspring affected by parental cancer may provide important evidence to help offspring achieve such outcomes.

One way in which offspring may experience positive gain after a parent’s cancer is through posttraumatic growth (PTG), defined as positive growth following a traumatic event (Tedeschi & Calhoun, 1996). Investigating PTG as a function of coping is warranted because PTG has adaptive significance in terms of psychological and physical functioning. PTG has been exhibited among offspring affected by parental cancer (Hirooka et al., 2016; Levesque & Maybery, 2012; Wong et al., 2009). In each of these studies, growth experiences emerged alongside adversities, highlighting that distress and growth co-occur (Tedeschi & Calhoun, 1996). In other words, whilst offspring who experience a parent’s cancer may encounter significant distress, many also demonstrate positive growth.

Similar to PTG, resilience is defined as a process of negotiating, managing and adapting to significant stress or trauma (Windle et al., 2011). Studies have demonstrated that offspring exhibit resilience (Ashurst et al., 2009; Spira & Kenemore, 2000). Further, higher resilience among families affected by parental cancer has been linked to offspring reporting reduced stress and better communication (Chen et al., 2017).

It is suggested that resiliency is fuelled by positive emotion, and that positive emotion is a means of achieving growth (Fredrickson, 2004). Where positive emotions are thought to lessen the resonance of a negative event, negative emotions do the opposite (Fredrickson, 2004). This has been demonstrated among offspring impacted by parental cancer, where offspring who made a conscious effort to think positively in response to their parent's cancer enhanced their response to uncertainty and anticipatory grief, and psychosocial development (Ashurst et al., 2009). Conversely, results of retrospective and prospective studies found that offspring's negative emotions in the wake of parental cancer were linked to their dysfunction (Gazendam-Donofrio et al., 2011). In these examples, it appears that offsprings' emotion enabled or hindered their adaption. Outside of parental cancer, positive emotion has led to adaptive outcomes in terms of improved physical (Cohen & Pressman, 2006) and mental health (Diehl et al., 2011). Moreover, among cancer patients, positive emotions are linked to less psychological distress (Voogt et al., 2005), and reduced hospital visits for cancer-related morbidities (Stanton et al., 2002).

Overall, it can be argued that positive emotion is a salutogenic construct in the same way as resilience and PTG are (Levine et al., 2009), and that adaption to parental cancer may be more attainable among offspring with more positive than negative emotions, and higher levels of resilience and PTG. It is posited that coping and emotion share a reciprocal relationship, in which coping is not only a response to emotion, but also mediates emotional response (Folkman & Lazarus, 1988). Therefore, adaptive coping which promotes positive emotion may potentially promote future adaptive coping, creating a cycle that is beneficial to overall wellbeing. In addition to this, adaptive coping processes (e.g. positive reappraisal) have been demonstrated to be a catalyst for PTG (Tedeschi & Calhoun, 1996) and a predictor of resilience (Campbell-Sills, Cohan, & Stein, 2006). This indicates that considering these constructs as a function of coping may demonstrate what coping is conducive to lessening negative emotion, and increasing positive emotion, resilience and PTG among offspring affected by parental cancer. This is of particular significance given evidence that coping can be modified through intervention (Antoni et al., 2001; Chesney, Chambers, Taylor, Johnson, & Folkman, 2003; Kennedy, Duff, Evans, & Beedie, 2003).

The present study investigates how coping impacts emotion, resilience, and PTG among offspring affected by a parent's cancer; and how coping differs between offspring in order to understand what variables predict adaptive or maladaptive coping.

The study focusses on offspring in their adolescence and young adulthood (12 – 24 years) as coping depends upon development (Skinner & Zimmer-Gembeck, 2016) and one's cognitive and psychological resources (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). As a child transitions into adolescence, their coping capacity increases, as does their ability to discriminate between effective and non-effective coping (Skinner & Zimmer-Gembeck, 2016). Thus, by investigating adolescents and young adult offspring, we can establish what cognitive and behavioural processes can be taught to, or enhanced in, offspring who are at a developmentally appropriate age, in order to maximise favourable outcomes for offspring facing a parent's cancer.

Ethics

Approval for the project was received from the University of Western Australia Human Research Ethics Council (HREC) (RA/4/1/8660) and University of Adelaide HREC (#32198).

Methods

Participants

Participants were biological, adoptive, or step offspring (≥ 18 years) whose parents had cancer within the past 10 years, and who were aged 12 – 24 years at the time of their parent’s cancer diagnosis. No restrictions were placed on parent’s cancer type, stage, or disease duration. Multiple offspring from the same family could participate.

Recruitment and Procedure

Participants were recruited via email correspondence or social media promotion through Australian cancer support and health organisations, and universities. The study was promoted through social media via a Facebook ‘page’ created to promote the study, as well as paid advertisements across Facebook and Instagram. Participants were directed from email or social media to an online self-report survey, hosted through the online platform SurveyGizmo. The survey was activated on 07 March 2017 for six months. Survey questions were phrased in present tense for participants whose parents had cancer at the time of completing the survey; and in past tense for those whose parents’ previously had cancer. No data were collected regarding participants’ residential location for confidentiality reasons. Questions included in the survey are described below.

Demographics and characteristics. Participants reported demographic characteristics and parent’s cancer characteristics (e.g. diagnosis, duration, recurrence). They also completed questions regarding family characteristics (i.e. birth order), and questions regarding their relationship with their parent at the time of the cancer (i.e. degree of communication with parent).

Coping. Carver’s Brief COPE (Carver, 1997) was used to investigate how offspring coped with their parent’s cancer. The Brief COPE consists of 14 subscales, each derived from 2-items. Respondents indicated on a 4-point Likert scale (1 = I haven’t been doing this at all to 4 = I have been doing this a lot) the degree to which they used a coping strategy (e.g. *“I turned to work or other activities to take my mind off things”*) in direct response to their parent’s cancer. The subscales were summed into one of two major subscales, conceptualised as *coping style*: adaptive coping (comprised of active coping, use of emotional support, use of instrumental support, positive reframing, planning, humour, acceptance, religion) and maladaptive coping (self-distraction, denial, substance use, behavioural disengagement, venting, self-blame). Cronbach's alpha for the subscales demonstrated acceptable scale reliability (maladaptive coping α=.67; adaptive coping α= .69).

Emotion. Emotion was measured through the 21-item Positive and Negative Affect Scale (PANAS) (Watson et al., 1988). Participants indicated on a 5-point Likert scale the degree they generally experience positive affect (attentive, interested, alert, excited, enthusiastic, inspired, proud, determined, strong, active) or negative affect (distressed, upset, hostile, irritable, scared, afraid, ashamed, guilty, nervous, jittery). The scale provides measures of positive affect (PA) and negative affect (NA), with higher scores on each domain indicating higher levels of that affect. Internal consistency was high for each subscale (PA α=0.88; NA α=0.91).

Resilience. The 14-item ER-89 (Block & Kremen, 1996) was used to measure resilience. Respondents indicated on a 4–point Likert scale (1 = Does not apply at all, to 4 = Applies very strongly) the degree to which they agree with a statement (e.g. *"I enjoy dealing with new and unusual situations"*). Items were summed for an overall score, with higher scores indicating higher resiliency. The overall score was highly reliable (α=0.82).

PTG. The 21-item Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996) was used to measure posttraumatic growth. Respondents indicated on a 6-point Likert scale the degree to which they experienced change as a result of their parent's cancer (0 = I did not experience this change, to 5 = I experienced this change to a very great degree). The degree to which respondents experience change is measured across five domains: Relating to Others; New Possibilities; Personal Strength; Spiritual Change; and Appreciation of Life, with higher scores indicating greater PTG. A total PTG score was obtained by summing the five subscale scores, which had high internal consistency (α=0.82).

Statistical Analysis

Statistical analyses were conducted using SPSS (version 24; IBM). Descriptive statistics were calculated for demographics (gender, ethnicity, and age) and characteristics (e.g. parent's cancer).

Coping style was derived from responses on the two major coping subscales (adaptive and maladaptive coping) which were median-split to reflect high and low scores on each dimension. Individuals were then classified as using one of four coping styles: high adaptive, low maladaptive coping; high adaptive, high maladaptive coping; low adaptive, high maladaptive coping; and low adaptive, low maladaptive coping. The collective use of adaptive and maladaptive coping was used (i.e. high adaptive, low maladaptive coping style) rather than independent coping approaches (i.e. adaptive versus maladaptive coping) because individuals use contradictory forms of coping in almost all encounters (Folkman & Lazarus, 1988).

Generalised linear modelling was used to compare the effects of the four coping styles on PTG, resilience, and emotion. Multinomial logistic regression was used to explore individual predictors of reported coping style whilst controlling for appropriate covariates.

Results

A total of 244 eligible participants responded, of whom the majority were female (82%), born in Australia (91%) and identified as neither Aboriginal nor Torres Strait Islander (98%). More offspring were affected by maternal (69%) than paternal (31%) cancer and the mean duration of their parent's illness was 2.2 years (SD = 1.8). Offsprings' mean age at their parent's cancer diagnosis was 18.8 years (SD = 3.4) and the mean time since their parent's cancer was 5.5 years (SD = 2.9). Further information regarding demographics and characteristics is in Table 7.

Table 7

Demographics and characteristics

Variable	Frequency (%)
Ethnicity	
Aboriginal or Torres Strait Islander	3 (1.2)
Neither Aboriginal nor Torres Strait Islander	238 (97.5)
Unanswered	3 (1.2)
Birth order	
Only child	18 (7.4)
Firstborn child	99 (40.6)
Middle child	50 (20.5)
Youngest child	77 (31.6)
Lived with parent (at time of cancer)	
Full time	138 (56.6)
Part time	38 (15.6)
Lived elsewhere	68 (27.9)
Parent contact (at time of cancer)	
At least once a week	193 (79.1)
At least fortnightly or monthly	36 (14.8)
At least once a year	14 (5.7)
Less than once a year or never	1 (0.4)
Open communication with parent about their cancer	
Strongly disagree	23 (9.4)
Somewhat disagree	33 (13.5)
Neither agree nor disagree	14 (5.7)
Somewhat agree	109 (44.7)
Strongly agree	65 (26.6)
Frequency of worry (about cancer)	
Never	1 (0.4)
Rarely	8 (3.3)
Sometimes	38 (15.6)
Often	102 (41.8)
All the time	95 (38.9)
Cancer recurrence	
Recurrent	90 (36.9)
Not recurrent	139 (57)
Unsure	15 (6.1)
Death	
Cancer-related death	90 (36.9)
No cancer-related death	119 (48.8)
Unanswered	35 (14.3)

Table 8 presents the result of generalised linear models exploring the impact of coping style on PTG, resilience, and positive and negative affect (emotion). The presence of high adaptive coping resulted in significantly higher PTG, regardless of the level of maladaptive coping. Resilience also appeared to be significantly greater among those with higher adaptive coping and lower maladaptive coping. Separately, high adaptive, low maladaptive coping was linked to greater positive emotion; whereas the inverse was related to greater negative emotion. High adaptive, high maladaptive coping was linked to significantly higher positive and negative emotion.

Results of multinomial logistic regressions exploring predictors of coping style classification are presented in Table 9. Variables that were not statistically significant in predicting coping style included age, birth order, parent sex, and degree of communication (about cancer). Daughters were more likely to have a high adaptive coping style, regardless of the level of maladaptive coping also experienced. Offspring who did not access support for their parent's cancer were more likely to have a high adaptive, low maladaptive coping style. Compared to offspring whose parents survived their cancer, bereaved offspring were more likely to report a low adaptive, high maladaptive coping style. Offspring whose parent's cancer was of shorter duration (< 1 year) were more likely to have a low adaptive, low maladaptive coping style than any other coping style. Offspring who lived with their parent with cancer compared to those who did not were more likely to have a low adaptive, low maladaptive cope style. Also, compared to offspring who worried about their parent's cancer all of the time, those who occasionally worried reported using fewer coping strategies.

Table 8

Coping style as a predictor of PTG, resilience, and emotion

	M	SD	*B*	*SE B*	95% CI
			High adaptive, low maladaptive (*n* = 56)		
PTG	50.68	20.48	18.86***	3.22	12.51, 25.20
Resilience	42.38	6.70	3.55**	1.18	1.23, 5.88
Positive emotion	32.52	6.11	4.78***	1.37	2.09, 7.47
Negative emotion	21.29	6.70	0.36	1.46	-2.51, 3.23
			High adaptive, high maladaptive (*n* = 57)		
PTG	53.37	16.10	25.55***	3.20	19.24, 31.86
Resilience	40.35	6.00	1.53	1.18	-0.79, 3.84
Positive emotion	30.96	7.59	3.23*	1.36	0.55, 5.91
Negative emotion	30.32	8.41	9.39***	1.45	6.53, 12.24
			Low adaptive, high maladaptive (*n* = 63)		
PTG	34.41	17.28	2.59	3.12	-3.56, 8.73
Resilience	36.46	6.25	-2.36*	1.14	-4.62, -0.11
Positive emotion	25.43	7.45	-2.31	1.32	-4.92, 0.30
Negative emotion	29.87	9.50	8.95***	1.41	6.17, 11.73
			Low adaptive, low maladaptive (*n* = 68)		
PTG	31.82	17.40	-	-	-
Resilience	38.82	7.09	-	-	-
Positive emotion	27.74	8.68	-	-	-
Negative emotion	20.93	7.33	-	-	-

Note: Reference category is low adaptive, low maladaptive (*n* = 68)

*p < .05; **p <. 01; ***p < .001

Table 9

Predictors of coping style

	High adaptive, low maladaptive		High adaptive, high maladaptive		Low adaptive, high maladaptive	
Predictor	Adjusted OR	(95% CI)	Adjusted OR	(95% CI)	Adjusted OR	(95% CI)
Sex						
Female	4.96*	(1.31, 18.81)	3.54*	(1.00, 12.57)	2.72	(0.91, 8.11)
Male						
Support						
Accessed support	6.12***	(2.16, 17.35)	2.69	(0.97, 7.42)	0.75	(0.30, 1.87)
Did not access support						
Death						
Parent died from cancer	1.00	(0.33, 3.02)	2.61	(0.93, 7.30)	4.74***	(1.86, 12.11)
Parent did not die						
Cancer duration						
≤1 year	0.30*	(0.11, 0.82)	0.18***	(0.07, 0.48)	0.37*	(0.15, 0.92)
≥2 years						
Lived with parent						
Yes	0.20**	(0.07, 0.64)	0.26*	(0.08, 0.84)	0.54	(0.19, 1.59)
No						
Worry						
Occasionally	1.04	(0.26, 4.18)	0.13*	(0.02, 0.71)	0.45	(0.13, 1.52)
Often	3.13	(0.99, 9.85)	0.77	(0.28, 2.16)	1.18	(0.46, 3.08)
All of the time						

Note. Reference category is: Low adaptive, low maladaptive. Odds ratios (OR) with 95% confidence intervals (CI) adjusted for covariates. **p* < .05; ***p* < .01; ****p* < .001. Cases excluded if cancer duration unknown (*n* = 6). Covariates in the final model included offspring sex, support accessed (whether offspring accessed formal support for their parents cancer), parent death from cancer, cancer duration, offspring residing with parent at time of cancer (yes or no), and the degree of worry offspring experienced in response to their parent's cancer. Covariates excluded from the model due to non-statistical significance included birth order, parent sex, degree of communication (about cancer), offspring age at diagnosis and degree of contact (with parent during cancer).

Discussion

Consistent with the wider literature (Rajandram, Jenewein, McGrath, & Zwahlen, 2011), adaptive coping was linked to PTG. This occurred regardless of the level of concurrent maladaptive coping, indicating that adaptive coping may be a factor that facilitates PTG. Interestingly, PTG was highest among offspring who experienced high maladaptive coping alongside high adaptive coping. This suggests that maladaptive coping did not compromise offspring's capacity to experience PTG but potentially served some function for PTG. Indeed, growth following trauma supposedly requires contemplation of that trauma (Tedeschi & Calhoun, 1996). Such consideration may mobilise certain adaptive coping strategies (i.e. planning), but also implies a degree of rumination: a type of maladaptive coping. In other words, significant posttraumatic growth requires psychological distress, and maladaptive coping may better facilitate engagement with distress than adaptive coping, which is largely solution-oriented. Regardless of whether maladaptive coping increased offspring's capacity to experience PTG, high adaptive coping appeared necessary for supporting PTG.

Offspring with high adaptive and high maladaptive coping had increased negative and positive emotions. This indicates that using multiple and divergent coping strategies may be of detriment to offspring in terms of inflated negative emotion. Where resiliency and positive emotion required more adaptive and less maladaptive coping, the inverse of this—low adaptive, high maladaptive—predicted decreased resilience and more negative emotion. The connection between adaptive coping and resilience has been demonstrated in other populations (Campbell-Sills et al., 2006; Gloria & Steinhardt, 2016) and likely occurs as resilience relies on a process of effective negotiation, adaption, and management of significant stress or trauma (Windle et al., 2011): a process conceivably similar to adaptive coping, which is active in its approach and task-oriented (Campbell-Sills et al., 2006). Regarding emotion, the aforementioned findings likely reflect that coping is not only a response to emotion, but also mediates emotional response (Folkman & Lazarus, 1988). In other words, positive emotion facilitates adaptive coping, and facilitates future positive emotion. This is like resilience, insofar as the propensity to adaptively cope is greater among people with high personal resilience (Gloria & Steinhardt, 2016). It is suggested that positive emotion and resilience share a reciprocal relationship in that they build upon one another to promote wellbeing (Fredrickson, 2004). Also, dependent children (2 – 18 years) perceived learning to actively cope (a type of adaptive coping) as the most useful component of a family-based support program for parental cancer (Paschen et al., 2007), next to other components such as improving family communication and parenting skills (Romer et al., 2011). Therefore, interventions that aim to increase adaptive coping and positive emotion, and consequently increase resilience (Gloria & Steinhardt, 2016) may be applicable in offspring affected by parental cancer.

In terms of how coping varied between offspring, those who did not access support for their parent’s cancer used more adaptive and less maladaptive coping. Presumably, those offspring do not require support as they are coping well independently. Females were more likely to cope adaptively, and significantly less likely to use fewer coping strategies (i.e. low adaptive, low maladaptive coping) than males. Taken together, these results indicate that daughters may be more inclined to take a proactive approach to coping with their parent’s cancer than sons, highlighting the need for tailored services to target the latter. Alternatively, this finding could reflect that in response to trauma, women commonly report higher emotional distress (Matud, 2004) and thus have a greater need to apply coping strategies, and are more practised in doing so. Separately, compared to offspring whose parents survived their cancer, bereaved offspring used a higher level of maladaptive coping; a result seen elsewhere (Hoeg et al., 2017). Offspring bereaved by parental cancer report high levels of maladaptive grief and posttraumatic stress (Kaplow et al., 2014). Therefore, bereaved offspring engaging in more maladaptive coping strategies likely reflects the toll of their parent’s death and their response to unresolved grief.

Fewer coping strategies were used by offspring whose parent’s cancer was of shorter duration (< 1 year). Lengthy disease duration is linked to offspring’s poorer adjustment (Ireland & Pakenham, 2010), but is also believed to facilitate better adjustment as offspring have longer to acclimatise (Armistead et al., 1995). Thus, this finding may reflect that offspring whose parent’s cancer was short-lived had not needed to execute coping strategies; but alternatively may indicate that offspring had little time to enact coping strategies.

Offspring who lived with their ill parent also used fewer coping strategies than offspring who resided elsewhere. It is possible that the latter group had more adaptive coping as they were not exposed to the detriment of the cancer. Alternatively, offspring are found to mimic their parents coping (Kennedy & Lloyd-Williams, 2009). Therefore, offspring living at home may be adopting fewer coping strategies as parents with cancer are “constantly striving for normalcy on behalf of their children” (Helseth & Ulfsaet, 2003, p. 358) and are thereby not demonstrating coping strategies. Overall, it is unclear whether using fewer coping strategies reflected that offspring are less impacted by their parent’s cancer and therefore do not initiate coping strategies, or whether these offspring are acutely distressed. Indeed, disengaged coping (i.e. disengaging from the stressor) has been linked to more internalizing symptoms, such as mental health issues (Compas et al., 2001). Further, passive coping (e.g. withdrawal, avoidance) is also believed to impair offspring’s sense of self-efficacy in dealing with their parent’s cancer. More research to establish this relationship is warranted.

Strengths and Limitations.

A strength of this study was that recruitment and survey completion were conducted entirely online which minimised inconvenience regarding response times and participant burden. The method also ensured participant anonymity as names were not collected.

Limitations of this research were that it largely relied on retrospective self-report which introduces the possibility of recall bias. To minimise this occurring, a restriction was applied in which only offspring whose parents had cancer within the last 10 years could participate: a follow up time used in related research (e.g. Ashurst et al. 2009, Wong et al., 2009). Participants self-elected to the study and were recruited through social media or email correspondence, thus creating some selection bias. The sample was largely female (82%), meaning that findings in relation to male offspring should be treated with caution. Dispositional characteristics (e.g. optimism) relevant to coping, PTG, resilience, and emotion were not obtained. Furthermore, no data were collected from parents in regard to their functioning (e.g. parental depression). Therefore, we could not ascertain the degree to which other possibly relevant factors impacted upon the outcome variables. Given the cross-sectional study design, we were unable to discern how coping, resilience, PTG, and emotion changed as a function of parental cancer.

Implications for Psychosocial Oncology Practice

- Adaptive coping strategies were associated with more favourable outcomes among offspring affected by parental cancer.
- Offspring bereaved by parental cancer reported the highest degree of maladaptive coping.
- Offsprings’ adaption to their parent’s cancer may be improved through interventions aimed at increasing adaptive coping strategies and positive emotion, which in turn increase resilience and PTG. Such interventions may be particularly beneficial for offspring bereaved by parental cancer.

Conclusion

This study sought to understand a broader range of outcomes that may occur following parental cancer in terms of resilience, posttraumatic growth, and positive affect. Offspring who used more adaptive coping strategies in response to their parent's cancer reported higher resiliency, PTG, and positive emotion. Alternatively, offspring who used more maladaptive coping strategies had decreased resiliency and more negative emotion. Thus, offsprings' adaption to their parent's cancer may be improved through interventions aimed at increasing adaptive coping strategies. Our study demonstrated that sons and offspring bereaved by parental cancer utilised more maladaptive coping, which may have implications for their psychological wellbeing. Fewer coping strategies were used by offspring who lived with their ill parent, and among those whose parents' cancer was of shorter duration. It is unclear whether this demonstrated these offspring were managing well with their parent's cancer or struggling, and additional research to establish this is warranted.

Acknowledgements

We acknowledge the support of organisations; including the Prostate Cancer Foundation of Australia, Cancer Council, Freemasons, and Cancer Voices; for their assistance in recruitment. Participants in this research were recruited from Breast Cancer Network Australia's Review and Survey Group, a national online group of Australian women living with breast cancer who are interested in receiving invitations to participate in research. We acknowledge the contribution of the women involved in the Review and Survey Group who participated in this project. This research was supported by an Australian Government Research Training Program Scholarship.

CHAPTER 7. DISCUSSION AND CONCLUSION

7.1 Preamble

This thesis aims to improve understanding of how adolescents and young adults (12 – 24 years) are impacted by parental cancer. Three gaps in the extant research were considered: a limited body of evidence about offspring in their adolescence and young adulthood at the time of their parent's cancer diagnosis, rather than at the time of data collection; an absence of data quantifying and describing Australian families with adolescent and young adult offspring who are affected by parental cancer and their characteristics; and an overwhelming focus on offspring psychopathology arising from parental cancer. The three studies developed in response to these research gaps included Study 1: a systematic review; Study 2: a linked data investigation; and Study 3: a cross-sectional online survey. The following chapter synthesises the major findings across the three studies; and is followed by a summary of the strengths and limitations encountered. The significance of the research and its implications are then discussed, and some ideas for future research are proposed.

7.2 Synthesis of findings

7.2.1 The burden of parental cancer

Findings from the three studies indicate that parental cancer places a considerable burden on adolescent and young adult offspring, both at the individual and population-level. As demonstrated in the systematic literature review (Study 1), offspring may endure psychological and behavioural problems as a result of their parent's cancer. When considering such adverse outcomes alongside the considerable number of offspring identified in the linked data study (Study 2), it is probable that many Australian adolescents and young adults are contending with lasting negative impacts of their parent's cancer.

Of the offspring who responded to the online survey, 81% indicated they were *often* or *always* concerned about their parent's illness, indicating that it was a pervasive source of distress. Overall, there are direct and adverse consequences for adolescents and young adults who experience a parent's cancer. Given the sizable population of impacted offspring identified in this research, exposure to parental cancer is potentially an extensive public health problem in Australia.

7.2.2 Encountering parental cancer at age 18

In the linked data and online survey investigations (Studies 2 and 3), the mean age of offspring at their parent's cancer diagnosis was 18 years. As discussed elsewhere (see Study Two, page 100) encountering a parent's cancer at this age may have significant implications for their academic performance (Hoyt & Winn, 2004; Schmidt & Welsh, 2010; Sieh et al., 2013) and caregiving responsibilities (Patterson et al., 2017; Sieh et al., 2013). Separately, parental illness often creates financial pressures within a family as the ill parent's capacity to work is diminished (Berggren & Hanson, 2016; Lundquist, 2017). Results of a previous cross-sectional study indicated that older offspring obtained employment to help ease financial burden following their parent's cancer (Torp et al., 2013). Offspring aged 18 and older may be more inclined to assume financial responsibility in the wake of parental illness because this age generally corresponds to the end of formal schooling in Australia, thus allowing them more time to pursue employment compared to their younger peers. If parental cancer impacts upon offsprings' capacity to meet tasks that are necessary for healthy development, such as those relating to education (Patton et al., 2016), these young people are potentially vulnerable. Indeed, results of recent population-based data linkage research demonstrated parental cancer was linked to poorer outcomes among offspring in terms of lower educational and socioeconomic attainments in adulthood (Joergensen et al., 2018). Such findings highlight the detriment of parental cancer for offspring. Overall, these findings indicate that adolescents and young adults are generally facing a parent’s cancer diagnosis at an age in which they have more obligations- both as a result and independent of their parent’s illness. Consequently, these young people may experience parental cancer as highly disruptive.

7.2.3 Sex of offspring and parents

Results of this research were equivocal in regards to whether sons or daughters were more impacted by parental cancer. Respondents to the online survey (Study 3) were predominately female (82%). Whilst this likely reflects a sampling sex-bias (Patel, Doku, & Tennakoon, 2018), it could also be argued that daughters were more impacted by sons. In other words, research participation is often contingent upon perceived relevance and importance of the topic (Albaum & Smith, 2012), thus a study focused on the impact of parental cancer may attract more respondents who encountered a greater degree of impact in their experience of their parent’s illness. However, maladaptive coping was higher among sons participating in the online survey, and this was linked to decreased resilience and higher negative affect. Such results suggest that sons were more impacted by parental cancer, which too may be the reason for so few male respondents. Specifically, sons may be significantly impacted but emotionally withdraw due to cultural norms (Shields, 2002), thereby leading them to disengage from participating in this type of research. Regardless of these speculations, there were no clear findings as to whether sons or daughters were more impacted.

In considering the impact on sons and daughters, it is also important to acknowledge the sex of the ill parent. In the survey study (Study 3), no statistically significant association was detected between parent’s sex and offspring coping. However, in other research, offspring have been found to suffer more if their parent of the same-sex is diagnosed (Barkmann et al., 2007). Notably, in the linked data and online survey studies (Studies 2 and 3), the most common diagnoses were among mothers with breast cancer. Research has demonstrated that daughters suffer significant distress as a result of their mother’s cancer (Inbar et al., 2013). In the case of maternal breast cancer, daughters may encounter body image and sexual functioning issues (Adelson, 2012), as well as worry about their genetic susceptibility to the disease (Cappelli et al., 2005). Furthermore, a caregiving gap is created when a mother is ill (Ireland & Pakenham, 2010), which daughters are more likely to fill (Korneluk & Lee, 1998). Taken together, it is possible that the prevalence of maternal breast cancer identified in this research (and in particular the linked data results (Study 2)), indicates parental cancer was a potential problem for daughters within this cohort.

7.2.4 Sociodemographics, bereavement, and support

A major finding of this research was that Australian offspring most at risk of bereavement due to parental cancer are also the least likely to access psychosocial support because of their sociodemographic profile. Through population-based linked data, Study 2 demonstrated that offspring were bereaved by parental cancer at a faster rate if their family was socioeconomically disadvantaged or geographically isolated: factors that are consistently linked to under-utilisation of mental health services in Australia (Booth et al., 2004; Meadows et al., 2015). Furthermore, the online survey (Study 3) identified that bereaved offspring used higher levels of maladaptive coping, which was linked to reduced resilience and increased negative affect. Collectively, these results suggest that offspring whose parents die from cancer may suffer grief alongside decreased resilience and negative affect; but are also the least likely to receive support for their grief because of their socioeconomic disadvantage and geographic isolation.

7.2.5 Coping to minimise the detriment of parental cancer

Another major finding was that positive outcomes appear possible despite the threat of parental cancer, and may be more achievable among offspring who use more adaptive coping strategies. It is posited that coping processes are modifiable through intervention such as coping effectiveness training, which is group-based cognitive behavioural therapy training (Kennedy & Kilvert, 2017).

Given that higher adaptive coping was linked to greater posttraumatic growth, resilience, and positive affect within this research, it is possible that modifying offspring's coping through intervention may help them to achieve more favourable outcomes.

7.3 Strengths

The research undertaken in this dissertation had a number of strengths, one being the clear parameters established in regard to offspring age. Specifically, throughout the thesis, adolescent and young adult offspring were defined as those aged 12 – 24 years at the time of parental cancer. Although this strict inclusion criteria narrowed the scope of potential respondents, it also ensured that those who were included in the research adequately reflected the population of interest. As discussed earlier (see page 25), this was unlike other studies that claimed to focus on adolescent and young adult offspring, but suffered methodological flaws by either failing to define the age of offspring in their samples, or including participants in their adolescence and young adulthood at the time of the study rather than at the time of the parental cancer. By considering offspring age at parental diagnosis, age-related differences in functioning (Visser et al., 2004), coping and support needs (Ellis et al., 2016), distress (Compas et al., 1994) comfort (Mosher & Danoff-Burg, 2005), perceived stress (Lazarus, 1974), communication (Schrag et al., 2004) and psychosocial maladjustment (Barkmann et al., 2007) were potentially controlled for.

Another strength of the research was that it sought to expand understanding of parental cancer among non-biological offspring by including adoptive, surrogate and step-offspring, as well as offspring of same-sex parents. Doing so is important, in order to establish whether offspring within non-traditional family structures experience parental illness differently. Moreover, such inclusion challenges antiquated perspectives that lead to the exclusion or marginalisation of contemporary family structures in research Forster-Jones, 2007).

Despite best intentions, including non-biological offspring and offspring of same-sex parents was not entirely successful. Regarding non-biological offspring, the majority of participants (99%) in the online survey (Study 3) were biologically related to their ill parent, and there was no method of identifying non-biological offspring in the linked data study (Study 2), as current data linkage is limited to biological relationships as recorded on birth certificates. In addition, no studies included in the systematic literature review (Study 1) made mention to non-biological offspring or same-sex parents. In regards to the latter, this omission may be because a question about the sexual orientation of parents within this type of research may be perceived as unethical or even irrelevant by researchers. Certainly in the online survey (Study 3), offspring were not asked to specify their parent's sexual orientation as this sensitive question was not pertinent to the study. However, not asking this question may perpetuate a heteronormative perspective about parental cancer. Alternatively, parental cancer may be a less salient issue for non-biological offspring or those of same sex parents, thus minimising their desire to engage in such research. Interestingly, two same-sex parent families were identified in the linked data investigation (Study 2), despite data linkage having no capacity to link beyond biological relationships. However, because of linkage restrictions, there was no method to discern the nature of the relationship between these parents and their offspring (i.e. adoptive, step, surrogate), or establish whether these cases simply reflected a clerical coding error. Although the research in this dissertation was somewhat limited in its representation of contemporary family structures, it did help to identify the extent to which these offspring are underrepresented in the research and barriers that exist regarding their recruitment.

A final strength of this research was its methods of data collection. Study 1 involved a systematic literature review, in which pre-defined key search terms and the search protocol were developed in collaboration with a University of Adelaide School of Psychology Research Librarian. This approach to data collection ensured relevant literature was methodically identified and summarised (Moher et al., 2015), and based on a replicable and rigorous search protocol and inclusion and exclusion criteria (Khan et al., 2003; Stone, 2002). Study 2 relied on population-based administrative data captured over 33 years, thereby providing a detailed and longitudinal profile of parental cancer in Australia. This method was more time and cost-effective than relying on primary data collection (Kelman et al., 2002), and maximised privacy by utilising de-identified data rather than directly contacting research participants (Boyd et al., 2015). Also, as data were based on a nationally representative jurisdiction (Clark et al., 2010), findings could be extrapolated nationally. Separately, Study 3 was conducted entirely through an online survey. Similar to linked data analysis, this approach minimised participant burden and increased anonymity, as participant details were not recoded, and respondents could complete the survey at their discretion. This approach helped identify a considerable number of offspring because it relied on social media recruitment, thus facilitating rapid circulation that was largely inexpensive and easily executed (Kapp, Peters, & Oliver, 2013). This method was suitable for the target population of adolescents and young adults, given that social media usage and frequency of use is highest amongst younger cohorts (< 25 years of age) in Australia (Sensis, 2017). Finally, the three studies required little researcher involvement (or none, in the case of the linked data study) once in the data collection stage, making them much more time-efficient than traditional methods of data collection. Overall, these varied methods of data collection were robust and unique for this type of research, and resulted in relevant and representative data for each of the projects in the dissertation.

7.4 Limitations

Despite its strengths, this research experienced some limitations. One such limitation included changing what age constituted adolescence and young adulthood between Studies 1 and Studies 2 and 3. In the systematic literature review (Study 1), adolescents and young adults were defined as those aged 10 – 24 years. However, in the linked data and online survey studies (Studies 2 and 3), this age-definition changed to 12 – 24 years. Although this amendment perhaps minimised journal rejections for the Study 2 and 3 manuscripts (as the issue regarding 10 years being too young to represent adolescence was addressed), it also affected the continuity between studies. If the amended age definition (12 – 24 years) was utilised in the systematic review (Study 1), even fewer studies would have met inclusion criteria for review. If the original age definition (10 – 24 years) was retained following the systematic review, the number and sociodemographic profile of families identified through linked data (Study 2) would have differed. Furthermore, this wider age delineation may have increased the number of respondents in the online survey (Study 3), and consequently led to different results. Whilst changing the age definition does not drastically affect general interpretation of findings, it does somewhat undermine the cohesive narrative of the dissertation.

This research was also limited by the possibility of biased samples. Recruitment to the online survey (Study 3) relied upon paid and unpaid advertisements on social media, thereby targeting individuals engaged in online communities concerning cancer support and health. Although this method strengthened participant response, it may have also created a biased sample, as many respondents were already engaged with and thus at least somewhat proactive about their wellbeing. Similarly, in the systematic review (Study 1), all of the included manuscripts were based on studies in which participants self-selected to the research. It is unlikely that participants in these studies were acutely distressed in response to their parent’s cancer, as this likely would inhibit their capacity to engage in such research. This is much the same for other research focused on the impact of parental cancer, such as in a longitudinal study where offspring whose parent's cancer worsened or led to death withdrew their participation (Chen et al., 2017). In sum, these targeted and volunteer-dependent sampling techniques may have limited the array of experiences that actually exist in response to parental cancer, but that this may have been unavoidable given the nature of the research topic.

This research was limited by lack of consumer engagement with both parents and offspring. Given the nature of the studies selected and time constraints of the thesis, engaging with the target project was largely overlooked. This may have impacted the research regarding the planning and interpretation of results.

Another limitation in this research was the underrepresentation of sons, and offspring of single-parents. More females participated across the samples in the systematic literature review and online survey (Studies 1 and 3) limiting the extent to which conclusions can be made regarding offspring sex. Moreover, in these studies, offspring had parents in partnered relationships at their cancer; and in the linked data study (Study 2), there was no means of determining parental relationship status. This underrepresentation undermined understanding of what impact parental cancer has on sons and offspring of single-parents.

Lastly, this research was limited by its underrepresentation of Aboriginal and Torres Strait Islander parents with cancer and their offspring. In the linked data study (Study 2), reporting on the number and characteristics of Aboriginal and Torres Strait Islander families was prohibited by ethics restrictions. In the online survey (Study 3), a total of three participants identified as Aboriginal or Torres Strait Islander, eliminating the possibility of analysing the outcome variables in terms of Indigeneity. Currently, there is a dearth of literature that considers Aboriginal and Torres Strait Islander families affected by parental cancer. This is despite Aboriginal and Torres Strait Islander Australians experiencing higher cancer incidence and mortality, and lower survival rates when compared to non-Indigenous Australians (Australian Institute of Health and Welfare, 2018), and their having little access to culturally appropriate cancer care and support (Haigh M et al., 2018). Given that this research involved data limited in its representativeness of Aboriginal and Torres Strait Islander offspring, such issues that are unique to non-Indigenous Australian families impacted by parental cancer were not explored.

7.5 Significance of research

In spite of its limitations, the research contributes to a better understanding of how offspring, aged in their adolescence or young adulthood at the time of parental cancer, are impacted by their parent’s illness. Such research is important because this age represents a time of unique vulnerability. In particular, adolescence and young adulthood represents a major developmental transition (Institute of Medicine & National Research Council, 2015; Steinberg, 2005) at which point young people also have greater propensity to better understand their parent’s illness-related pain and potential loss (Christ et al., 1994). As has been previously argued, compared to younger children, these offspring adopt more caregiving and household responsibilities (Ireland & Pakenham, 2010; Sieh et al., 2013; Torp et al., 2013) and have more external pressures such as school (Sieh et al., 2013). As a result, these offspring may encounter more disruptions and distress as a result of parental cancer, but also must enact greater effectiveness in managing these challenges to minimise potential developmental ramifications. Where other research had overlooked offspring age at the time of this parent’s cancer, the research in this dissertation considered this as a key factor to capture the experiences of adolescents and young adults. Further, the evidence discussed in this thesis challenges the notion that older offspring simply adapt because of their advanced cognitive resources (e.g. Pederson & Revenson, 2005) by demonstrating that they are indeed impacted by parental cancer. Thus, through investigating the experiences of offspring in their adolescence and young adulthood at the time of parental cancer, it has contributed to better understanding how these young people experience their parent’s illness.

Based on the identifiable research, this dissertation contributes the first population-level profile of adolescents and young adults and their parents with cancer in Australia, thereby responding to a precedent set by international linked data research on the topic (Chen, Sjölander, et al., 2015; Inoue et al., 2015; Niemelä et al., 2012; Syse et al., 2012). The study identified 57,708 adolescents and young adults who encountered a parent’s incident cancer diagnosis between 1982 and 2015 in Western Australia. It demonstrated the most common diagnoses were among mothers with breast cancer, and that the majority of families resided in inner regional areas and were of low and middle socioeconomic status. Furthermore, it illustrated that offspring faced a parent’s death from cancer sooner if they were socioeconomically disadvantaged or geographically isolated; thus identifying which offspring were at greater risk. Since Western Australia has been found to be nationally representative in terms of sociodemographic and health indicators (Clark et al., 2010), these results may be generalisable to Australia.

Another contribution of this research was that it investigated a broader range of outcomes that can occur in terms of resilience, posttraumatic growth, and positive affect; and how coping impacts upon these outcomes. This evidence contributes to a larger body of research identifying growth outcomes in the wake of a parent’s physical or mental illness (e.g. Armistead et al., 1995; Banks et al., 2001; Johnston et al., 1992; Pakenham & Cox 2015; Umberger & Risko et al., 2016). Further, it helps to move away from the existing perspective focused only on negative outcomes that occur as a result of parental cancer.

7.6 Implications

7.6.1 Improving outcomes through adaptive coping

This research has significant implications for the provision of supportive care services for offspring and families impacted by parental cancer. As previously mentioned, the online survey (Study 3) identified that using more adaptive coping strategies was linked to greater posttraumatic growth, resilience, and positive affect. Furthermore, the relationship between adaptive coping and PTG occurred regardless of the level of concurrent maladaptive coping, indicating that adaptive coping may be a protective factor for PTG. These findings indicate that by utilising higher levels of adaptive coping in response to their parent's cancer, offspring may encounter more positive change.

Coping effectiveness training is based on the theory of stress and coping (Lazarus & Folkman, 1984), and aims to refine an individual's appraisal of a stressor, their choice of coping response to that stressor, as well as teach them standard cognitive behavioural coping technique (Kennedy & Kilvert, 2017). Clinical trials have demonstrated that coping effectiveness training lessened psychological distress and improved positive psychological states among men diagnosed with HIV (Chesney et al., 2003), and improved anxiety, depression, and psychological adjustment to spinal cord injury (Duchnick, Letsch, & Curtiss, 2009; Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011; Kennedy et al., 2003). Notably, among people with spinal cord injury, improvements in psychological wellbeing were made after fewer sessions of coping effectiveness training than supportive group therapy (Duchnick et al., 2009). Furthermore, interventions that aim to refine coping skills have had favourable results among people with cancer in terms of reduced distress (Kashani, Vaziri, Akbari, Jamshidifar, & Sanaei, 2014) and perceived benefits (Antoni et al., 2001); and have enhanced the quality of life among caregivers of cancer patients (Meyers et al., 2011).

The success of coping-focused interventions in other populations (Antoni et al., 2001; Chesney et al., 2003; Duchnick et al., 2009; Hoffman et al., 2011; Kashani et al., 2014; Kennedy et al., 2003; Meyers et al., 2011) suggest there is potential worth in applying such an approach to supportive care for offspring affected by parental cancer. This would not be unlike elements of pre-existing support interventions for families affected by parental cancer with dependent children (0 – 18 years), such as the United States Enhancing Connections (Lewis et al., 2015) and the European Child of Somatically Ill Parents (COSIP) programs (Romer et al., 2011). Both of these programs involve addressing offspring coping as a means of improving their adjustment to parental illness. However, these programs are also largely focused on parenting and delivered predominately to the parent with cancer (Lewis et al., 2015), or family-based therapy comprising a mixture of family and individual-child meetings (Romer et al., 2011). Although these are highly relevant to families with dependent children, they are perhaps less applicable to adolescents and young adults, whose age signifies individuation from their parents and thus more age-appropriate interventions.

Within this research, adaptive coping was linked to increased positive emotion, resilience, and PTG. Suggestively, interventions that aim to increase offspring's use of adaptive coping strategies may also result in benefits beyond those identified in this research and include those exhibited in other groups (e.g. reduced distress or improved quality of life). Interestingly, a common coping strategy that offspring reported using in the systematic literature review (Study 1) was peer-support. This strategy appears akin to the use of emotional support (i.e. *'I've been getting comfort and understanding from someone'*) and instrumental support (i.e. '*I've been trying to get advice or help from other people about what to do'*), both of which were items in adaptive coping. If offspring are already using adaptive coping strategies, it may simply be a matter of enhancing or refining the skills they already have. Overall, findings from this research indicated that adaptive coping was beneficial to offspring, and given that coping can be modified through intervention, this has implications for mobilising coping interventions among this population.

7.6.2 Accessible bereavement support

Results of this research has implications for bereavement support; especially that aimed at offspring who are geographically isolated or socioeconomically disadvantaged. Findings indicated that offspring bereaved by parental cancer used more maladaptive coping and that this was linked to less favourable outcomes in terms of higher negative affect and decreased resilience. Furthermore, offspring were bereaved sooner if their family was of low socioeconomic status, or resided remotely. As previously discussed (see Study Two, page 100), these findings suggests that offspring whose parents die from cancer may be struggling to cope and are also the least likely to access support for their grief (Booth et al., 2004; Meadows et al., 2015). Taken together, this indicates a potential need for bereavement support that targets these offspring and overcomes barriers related to sociodemographic factors.

In Australia, socioeconomic disadvantage and remoteness impose economic and mobility constraints that undermine access to health services, and fewer services are available in disadvantaged and remote areas (Australian Institute of Health and Welfare, 2018). There is an evident need for accessible and low-cost supportive services, however, this may be better addressed through products that reduce or augment face-to-face delivery. Although a relatively new area of supportive care in cancer, results of randomised control trials have indicated that online interventions for people with cancer have had favourable results. These results have included improvements in health related quality of life, reduced anxiety and depression, and reduced posttraumatic stress (Beatty, Koczwara, & Wade, 2016; Carpenter, Stoner, Schmitz, McGregor, & Doorenbos, 2014) (Duffecy et al., 2013). Further, web-based information for rural people with cancer have led to gains in knowledge and increased intention to access psychosocial support (Fennell et al., 2016).

Although internet use is higher among more advantaged and centrally located homes (Australian Bureau of Statistics, 2008), young Australians are the highest users of the internet (Sensis, 2017). Furthermore, online support may be particularly useful for adolescent and young adult offspring, who refrain from expressing disease-related concerns in order not to further burden their parent (Morris et al., 2016). Thus, web-based support may circumvent this avoidance by providing offspring with anonymity. Currently, the support service CanTeen Australia (CanTeen Australia, 2018) offer counselling support via web-chat and phone for young people aged 12 – 25 years whose parents have cancer. However, no evaluations on the outcomes of this support have yet been published.

7.6.3 Practical support

Lastly, the research findings have implications for the provision of practical support for offspring impacted by parental cancer. Across this dissertation, the highest number of diagnoses were among mothers with breast cancer, and offspring generally encountered a parent’s diagnosis at a mean age of 18 years. Both maternal cancer and older offspring age are factors related to increased caregiving and household responsibilities (Bartfai Jansson & Anderzen-Carlsson, 2017; Ireland & Pakenham, 2010; Pederson & Revenson, 2005; Sieh et al., 2013). Therefore, this indicates that offspring are burdened with a high degree of responsibilities, and may require practical support.

Adolescents and young adults report unmet needs in domestic responsibilities that arise from parental cancer (Patterson & Rangganadhan, 2010); and among offspring, unmet needs share a positive relationship with distress (McDonald et al., 2016). Additionally, caregiving tasks can disrupt a young person’s development trajectory by interrupting individuation and autonomous identify formation (Barkmann et al., 2007; Pakenham & Cox, 2015). Offspring have the same needs whether their parents are ill or healthy (Korneluk & Lee, 1998). Therefore, it may be important to provide offspring with practical assistance or even financial support to alleviate them of the extra responsibilities created from parental illness, such as the carrying out of household jobs. A recent review of support service websites for families impacted by parental cancer indicated only two services had a financial assistance program- neither of which were located in Australia (Morris, Ohan, & Martini, 2017). Across services, no mention was made of the provision of practical support. From this research, it is not possible to discern whether practical support is necessary or even desired among offspring affected by parental cancer. However, given that practical support has been identified as an unmet need among Australian adolescent and young adults (12 -24 years) facing a parent's cancer (McDonald et al., 2016), it is an area worthy of further attention.

7.7 Future research

Some of the aforementioned limitations propose areas for future research. First, investigations will be more robust if their sampling frameworks seek to combat sampling biases. Much of the research regarding parental cancer involves recruitment targeting cancer support and health organisations, thereby minimising representation of people who are disengaged from such support and potentially vulnerable or at-risk. Ideally, recruitment methods would also engage offspring who are acutely distressed, in order to understand a wider range of responses to parental cancer.

Social media research may have capacity to achieve this goal, whilst also advancing over traditional recruitment methods in terms of being largely inexpensive, simple to conduct, and resulting in wide and rapid circulation. For example, monetary reward for participation may incentivise the research and result in a higher number of respondents. Separately, longer running advertisements that target demographics (e.g. age or location) rather than listed interests (e.g. cancer support groups) may assist in recruiting a more diverse sample. This may also assist in addressing sampling biases present in this thesis, such as the overrepresentation of female offspring and parents in partnered relationships. Notably, these suggestions do not account for common barriers such as research costs or time-constraints and thus may have little realistic value. However, as research methods continue to develop and more platforms that facilitate recruitment emerge, it is possible that such proposals will become more relevant.

Another issue that emerged in this research that may warrant further investigation is addressing the underrepresentation of contemporary families (i.e. non-biological offspring and same-sex parents). Results of a national survey demonstrated people with cancer report adverse experiences in terms of care received and social support if they identified as lesbian, gay or bisexual (Hulbert-Williams et al., 2014). If this is consistent among non-heterosexual parents with cancer, it has implications for their offspring. Furthermore, non-biological offspring may be differentially impacted by their parent's cancer, especially if they are the children of same-sex parents.

Where targeting offspring of same-sex parents may be facilitated through sexual and gender identity-based community groups (e.g. Lesbian Gay Bisexual Transgender (LGBT) groups), methods for targeting non-biological offspring is less clear. As previously discussed, participants in Study 3 were mostly biological offspring, demonstrating the inadequacy of simply specifying an eligibility criteria with the intent of recruiting non-biological offspring. Respondent numbers may increase if participation is incentivised and recruitment strategies run for longer because these methods will likely attract greater attention. Alternatively, it is possible that non-biological offspring are already represented across parental cancer research, and that research need only define the nature of the parent-child relationship. Regardless of whether this is the case, future research should seek to better understand the experiences of non-traditional offspring by prioritising this as a factor of relevance within study designs.

Future research should continue to consider offspring age at the time of parental cancer as a means of targeting the population of interest. As discussed throughout this thesis, this is a key factor influencing how parental cancer is experienced, and has repercussions in terms of developmental ramifications. Defining offspring age will increase transparency and consequently the methodological strength of investigations.

Future research may consider expanding on findings from this dissertation by profiling health outcomes among Australian offspring using population-based linked data. The research presented in Study 2 provided a picture of who is affected by parental cancer in Australia, thereby identifying the extent of the problem, profiling sociodemographic characteristics, and indicating who was at risk in terms of parental bereavement. Whilst this is a useful starting point, future research of a similar nature may consider outcome data such as education data, or emergency department or ambulatory data. Such research could be guided by population based-studies done in other jurisdictions that have investigated offspring education and socioeconomic attainment (Joergensen et al., 2018) rates of offspring mortality (Chen, Sjölander, et al., 2015) and injury (Chen, Regodón, et al., 2015), and use of specialised psychiatric services (Niemelä et al., 2012). This evidence would establish longitudinal outcomes of parental cancer in Australia, thereby contributing a more thorough understanding of how offspring are impacted.

Relatedly, future research that enumerates parental cancer from nation-wide data rather than state-based data would be valuable. Although Study 2 data are based on a nationally representative jurisdiction (Clark et al., 2010) and can thus be projected Australia-wide, extrapolating these findings will provide an approximation at best. For example, Western Australia is not the most representative state in terms of rural or remote and Indigenous populations (Clark et al., 2010), thus making inferences regarding parental cancer within these populations at a national level is problematic. At present, no national data linkage system exists. However, with increasing recognition of the power in linked administrative datasets for research (Boyd et al., 2015; Tew, Dalziel, Petrie, & Clarke, 2016), a national dataset is not an unreasonable possibility for the future.

7.8 Conclusion

The research in this thesis found that adolescent and young adult offspring (12 – 24 years) are significantly impacted by their parent's cancer, and are at risk of psychological and behavioural problems. Retrospective population-based data demonstrated a considerable number of adolescents and young adults likely encounter parental cancer each year in Australia, and most often at an age of heightened vulnerability (~18 years). The most common diagnoses were among mothers with breast cancer, indicating that many offspring may be fulfilling a caregiving role created in the wake of maternal illness. Bereavement due to parental cancer was linked to less favourable outcomes in terms of decreased resilience and higher negative emotion. However, those at risk of bereavement were also the least likely to access psychosocial support because of their sociodemographic profile: a factor consistently linked to under-utilisation of health services in Australia. Adaption to parental cancer may be improved through interventions that aim to increase adaptive coping, as these were linked to higher positive emotion, resilience, and posttraumatic growth even in the presence of maladaptive coping behaviours. Such interventions may be particularly useful among bereaved offspring and sons, who had higher levels of maladaptive coping. Findings from this dissertation have considerable implications for promotion and planning of supportive care interventions for families affected by parental cancer.

APPENDIX A. TABLE A1

Table A1

Studies sampling offspring outside 12-24 years at parental cancer

Study	Offspring age at parent’s cancer	Sample specification (in title)
Barnes, J., Kroll, L., Burke, O., Lee, J., Jones, A., & Stein, A. (2000). Qualitative interview study of communication between parents and children about maternal breast cancer. Western Journal of Medicine, 173(6), 385-389. doi: 10.1136/bmj.321.7259.479	5-18 yrs[a]	-
Barnes, J., Kroll, L., Lee, J., Burke, O., Jones, A., & Stein, A. (2002). Factors predicting communication about the diagnosis of maternal breast cancer to children. Journal of Psychosomatic Research, 52(4), 209-214. doi: 10.1016/S0022-3999(02)00296-9	5-18 yrs[a]	-
Bugge, K. E., Helseth, S., & Darbyshire, P. (2008). Children's experiences of participation in a family support program when their parent has incurable cancer. Cancer nursing, 31(6), 426-434. doi: 10.1097/01.NCC.0000339250.83571.b0	5-18 yrs[a]	-
Bugge, K. E., Helseth, S., & Darbyshire, P. (2009). Parents’ experiences of a Family Support Program when a parent has incurable cancer. Journal of Clinical Nursing, 18(24), 3480-3488. doi: 10.1111/j.1365-2702.2009.02871	5-18 yrs[a]	-
Bekteshi, V., & Kayser, K. (2013). When a mother has cancer: pathways to relational growth for mothers and daughters coping with cancer. Psycho-Oncology, 22(10), 2379-2385. doi: 10.1002/pon.3299	9 months -18 yrs[a]	-

Benros, M. E., Laursen, T. M., Dalton, S. O., Nordentoft, M., & Mortensen, P. B. (2013). The Risk of Schizophrenia and Child Psychiatric Disorders in Offspring of Mothers with Lung Cancer and Other Types of Cancer: A Danish Nationwide Register Study. PLoS ONE, 8(11), e79031. doi: 10.1371/journal.pone.0079031	0-15 yrs[a]	-
Bultmann, J. C., Beierlein, V., Romer, G., Möller, B., Koch, U., & Bergelt, C. (2014). Parental cancer: Health-related quality of life and current psychosocial support needs of cancer survivors and their children. International Journal of Cancer, 135(11), 2668-2677. doi: 10.1002/ijc.28905	6-18 yrs[a]	-
Chen, R., Regodón, A., Sjölander, A., Valdimarsdóttir, U., Ye, W., Tiemeier, H., …Fang, F. (2015). Childhood injury after a parental cancer diagnosis. eLife, 4. doi: 10.7554/eLife.08500	1-18 yrs[a]	-
Chen, R., Sjölander, A., Valdimarsdóttir, U., Varnum, C., Almqvist, C., Ye, W., …Fang, F. (2015). Parental cancer diagnosis and child mortality--A population-based cohort study in Sweden. Cancer Epidemiology, 39(1), 79-85. doi: 10.1016/j.canep.2014.11.011	1-18 yrs[a]	-
Ashurst, K. L., Hans, J. D., & Smith, D. R. (2009). The resilience factor: What extension can learn from adolescents coping with parental cancer. Journal of Extension, 47(2).	11-20 yrs[a]	Adolescent
Chalmers, K. I., Kristjanson, L. J., Woodgate, R., Taylor-Brown, J., Nelson, F., Ramserran, S., & Dudgeon, D. (2000). Perceptions of the role of the school in providing information and support to adolescent children of women with breast cancer. Journal of Advanced Nursing, 31(6), 1430-1438. doi: 10.1046/j.1365-2648.2000.01449.x	≤12-17 yrs[a]	Adolescent
Beierlein, V., Bultmann, J. C., Moller, B., von Klitzing, K., Flechtner, H. H., Resch, F., …Bergelt, C. (2017). Measuring family functioning in families with parental cancer: Reliability and validity of the German adaptation of the Family Assessment Device (FAD). Journal of Psychosomatic Research, 93, 110-117. doi: 10.1016/j.jpsychores.2016.11.007	≤9-18 yrs[a]	-
Buchbinder, M., Longhofer, J., & McCue, K. (2009). Family routines and rituals when a parent has cancer. Family Systems & Health, 27(3), 213-227. doi: 10.1037/a0017005	0-9 yrs (approx.) [a]	-

Campbell-Enns, H. J., & Woodgate, R. L. (2013). Decision making for mothers with cancer: Maintaining the mother-child bond. European Journal of Oncology Nursing, 17(3), 261-268. doi: 10.1016/j.ejon.2012.07.006	0-10 yrs[a]	-
Davey, M. P., Tubbs, C. Y., Kissil, K., & Nino, A. (2011). 'We are survivors too': African-American youths' experiences of coping with parental breast cancer. Psycho-Oncology, 20(1), 77-87. doi: 10.1002/pon.1712	9-18 yrs (approx.) [a]	-
Azarbarzin, M., Malekian, A., & Taleghani, F. (2015). Effects of supportive-educative program on quality of life of adolescents living with a parent with cancer. Iranian journal of nursing and midwifery research, 20(5), 577. doi: 10.4103/1735-9066.164510	10-20 yrs[a]	Adolescent
Edwards, L., Watson, M., James-Roberts, I., Ashley, S., Tilney, C., Brougham, B., …Romer, G. (2008). Adolescent's stress responses and psychological functioning when a parent has early breast cancer. Psycho-Oncology, 17(10), 1039-1047. doi: 10.1002/pon.1323	6-17 yrs[a]	Adolescent
Elmberger, E., Bolund, C., Magnusson, A., Lutzen, K., & Andershed, B. (2008). Being a mother with cancer: achieving a sense of balance in the transition process. Cancer nursing, 31(1), 58-66. doi: 10.1097/01.ncc.0000305677.90963.67	1-24 yrs[a]	-
Flahault, C., Dolbeault, S., Sankey, C., & Fasse, L. (2017). Understanding grief in children who have lost a parent with cancer: How do they give meaning to this experience? Results of an interpretative phenomenological analysis. Death Stud. doi: 10.1080/07481187.2017.1383951	≤7-11 yrs[a]	-
Foran-Tuller, K., O'Hea, E. L., Moon, S., & Miller, S. J. (2012). Posttraumatic stress symptoms in children of mothers diagnosed with breast cancer. Journal of Psychosocial Oncology, 30(1), 41-56. doi: 10.1080/07347332.2011.633979	6-18 years[a]	-
Forrest, G., Plumb, C., Ziebland, S., & Stein, A. (2006). Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. BMJ, 332(7548), 998-1003. doi: 10.1136/bmj.38793.567801.AE	6-18 yrs[a]	-

Furlong, E. P. (2017). Protecting: A Grounded Theory Study of Younger Children's Experiences of Coping With Maternal Cancer. Cancer Nurs, 40(1), 13-21. doi: 10.1097/ncc.0000000000000345	7-11 yrs[a]	-
Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., Pras, E., Visser, A., Huizinga, G. A., & Hoekstra-Weebers, J. E. (2008). Quality of life of parents with children living at home: when one parent has cancer. Supportive Care in Cancer, 16(2), 133-141. doi: 10.1007/s00520-007-0299-7	4-18 yrs[a]	-
Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., van de Wiel, H. B., Visser, A., Huizinga, G. A., & Hoekstra-Weebers, J. E. (2007). Family functioning and adolescents' emotional and behavioural problems: when a parent has cancer. Annals of Oncology, 18(12), 1951-1956. doi: 10.1093/annonc/mdm373	4-18 yrs[a]	Adolescent
Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., van de Wiel, H. B., Visser, A., Huizinga, G. A., & Hoekstra-Weebers, J. E. (2009). Parent-child communication patterns during the first year after a parent's cancer diagnosis. Cancer, 115(18), 4227-4237. doi: 10.1002/cncr.24502	4-18 yrs[a]	-
Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., van de Wiel, H. B., Visser, A., Huizinga, G. A., & Hoekstra-Weebers, J. E. (2011). Adolescents' emotional reactions to parental cancer: effect on emotional and behavioral problems. Journal of Paediatric Psychology, 36(3), 346-359. doi: 10.1093/jpepsy/jsq090	4-18 yrs[a]	Adolescent
Gotze, H., Ernst, J., Brahler, E., Romer, G., & von Klitzing, K. (2015). Predictors of quality of life of cancer patients, their children, and partners. Psycho-Oncology, 24(7), 787-795. doi: 10.1002/pon.3725	≤11-18 yrs[a]	-
Gotze, H., Friedrich, M., Brahler, E., Romer, G., Mehnert, A., & Ernst, J. (2016). Psychological distress of cancer patients with children under 18 yrs and their partners-a longitudinal study of family relationships using dyadic data analysis. Supportive Care in Cancer, 25(1), 1-10. doi: 10.1007/s00520-016-3411-z	≤6-18 yrs[a]	-
Hailey, C., Rosenstein, D., Yopp, J., Grunfeld, G., Park, E., Deal, A., …Park, E. M. (2018). Communication with children about a parent's advanced cancer and measures of parental anxiety and	1-17 yrs[a]	-

depression: a cross-sectional mixed-methods study. Supportive Care in Cancer, 26(1), 287-295. doi: 10.1007/s00520-017-3847-9		
Hauken, M. A., Senneseth, M., Dyregrov, A., & Dyregrov, K. (2017). Anxiety and the Quality of Life of Children Living With Parental Cancer. Cancer nursing, 00(0). doi: 10.1097/ncc.0000000000000467	8-18 yrs[a]	-
Helseth, S., & Ulfsæt, N. (2005). Parenting experiences during cancer. Journal of Advanced Nursing, 52(1), 38-46. doi: 10.1111/j.1365-2648.2005.03562.x	0-18 yrs[a]	-
Helseth, S., & Ulfsaet, N. (2003). Having a parent with cancer: coping and quality of life of children during serious illness in the family. Cancer nursing, 26(5), 355-362. doi: 10.1097/00002820-200310000-00003	7-12 yrs[a]	-
Hemminki, K., & Mutanen, P. (2001). Parental cancer as a risk factor for nine common childhood malignancies. The British Journal of Cancer, 84(7), 990-993. doi: 10.1054/bjoc.2000.1629	0-18 yrs[a]	-
Hoke, L. A. (2001). Psychosocial adjustment in children of mothers with breast cancer. Psycho-Oncology, 10(5), 361-369. doi: 10.1002/pon.515	8-16 yrs[a]	-
Holland, C., Hocking, A., Joubert, L., McDermott, F., Niski, M. D., Thomson Salo, F., & Quinn, M. A. (2017). My Kite Will Fly: Improving Communication and Understanding in Young Children When a Mother Is Diagnosed with Life-Threatening Gynecological Cancer. J Palliat Med, 21(1), 78-84. doi: 10.1089/jpm.2017.0058	3-12 yrs[a]	-
Howell, K., Barrett-Becker, E., Burnside, A., Wamser-Nanney, R., Layne, C., & Kaplow, J. (2016). Children Facing Parental Cancer Versus Parental Death: The Buffering Effects of Positive Parenting and Emotional Expression. Journal of Child and Family Studies, 25(1), 152-164. doi: 10.1007/s10826-015-0198-3	3-12 yrs[a]	-
Huizinga, G. A., Van der Graaf, W. T. A., Visser, A., Dijkstra, J. S., & Hoekstra-Weebers, H. J. (2003). Psychosocial Consequences for Children of a Parent With Cancer: A Pilot Study. Cancer nursing, 26(3), 195-202. doi: 10.1097/00002820-200306000-00004	7-18 yrs[a]	-

Huizinga, G. A., Visser, A., van der Graaf, W. T., Hoekstra, H. J., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2010). Stress response symptoms in adolescents during the first year after a parent's cancer diagnosis. Supportive Care in Cancer, 18(11), 1421-1428. doi: 10.1007/s00520-009-0764-6	7-18 yrs[a]	Adolescent
Huizinga, G. A., Visser, A., van der Graaf, W. T., Hoekstra, H. J., & Hoekstra-Weebers, J. E. (2005). The quality of communication between parents and adolescent children in the case of parental cancer. Annals of Oncology, 16(12), 1956-1961. doi: 10.1093/annonc/mdi395	4-18 yrs[a]	Adolescent
Huizinga, G. A., Visser, A., Van der Graaf, W. T., Hoekstra, H. J., Stewart, R. E., & Hoekstra-Weebers, J. E. (2011). Family-oriented multilevel study on the psychological functioning of adolescent children having a mother with cancer. Psycho-Oncology, 20(7), 730-737. doi: 10.1002/pon.1779	11-18 yrs[a]	Adolescent
Inhestern, L., Bultmann, J. C., Beierlein, V., Möller, B., Romer, G., Koch, U., & Bergelt, C. (2016). Understanding parenting concerns in cancer survivors with minor and young-adult children. Journal of Psychosomatic Research, 87, 1-6. doi: 10.1016/j.jpsychores.2016.05.008	0-21 yrs[a]	Young adult
Inoue, I., Higashi, T., Iwamoto, M., Heiney, S. P., Tamaki, T., Osawa, K., . . . Matoba, M. (2015). A national profile of the impact of parental cancer on their children in Japan. Cancer Epidemiology, 39(6), 838. doi: 10.1016/j.canep.2015.10.005	0-18 yrs[a]	-
John, K., Becker, K., & Mattejat, F. (2013). Impact of family-oriented rehabilitation and prevention: an inpatient program for mothers with breast cancer and their children. Psycho-Oncology, 22(12), 2684-2692. doi: 10.1002/pon.3329	3-14 yrs[a]	-
Kennedy, V. L., & Lloyd-Williams, M. (2009). How children cope when a parent has advanced cancer. Psycho-Oncology, 18(8), 886-892. doi: 10.1002/pon.1455	8-18 yrs[a]	-
Kim, S., Ko, Y., & Jun, E. (2012). The impact of breast cancer on mother-child relationships in Korea. Psycho-Oncology, 21(6), 640-646. doi: 10.1002/pon.1941	5-18 yrs[a]	-

Kobayashi, M., Heiney, S. P., Osawa, K., Ozawa, M., & Matsushima, E. (2017). Effect of a group intervention for children and their parents who have cancer. Palliative and Supportive Care, 1-12. doi: 10.1017/s1478951516001115	6-12 yrs[a]	-
Krattenmacher, T., Kühne, F., Halverscheid, S., Wiegand-Grefe, S., Bergelt, C., Romer, G., & Möller, B. (2014). A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life. Journal of Psychosomatic Research, 76(3), 213-220. doi: 10.1016/j.jpsychores.2013.11.020	0-18 yrs[a]	-
Lewis, F. M., Brandt, P. A., Cochrane, B. B., Griffith, K. A., Grant, M., Haase, J. E.,…Shands, M. E. (2015). The Enhancing Connections Program: A Six-State Randomized Clinical Trial of a Cancer Parenting Program. Journal of Consulting & Clinical Psychology, 83(1), 12-23. doi: 10.1037/a0038219	8-12 yrs[a]	-
Lichtman, R. R., Taylor, S. E., Wood, J. V., Bluming, A. Z., Dosik, G. M., & Leibowitz, R. L. (1984). Relations with children after breast cancer: The mother-daughter relationship at risk. Journal of Psychosocial Oncology, 2(3-4), 1-19. 10.1300/J077v02n03_01	0-6 yrs[a]	-
Lindqvist, B., Schmitt, F., Santalahti, P., Romer, G., & Piha, J. (2007). Factors associated with the mental health of adolescents when a parent has cancer. Scandinavian Journal of Psychology, 48(4), 345-351. doi: 10.1111/j.1467-9450.2007.00573.x	11-17 yrs[a]	Adolescent
Möller, B., Barkmann, C., Krattenmacher, T., Kühne, F., Bergelt, C., Beierlein, V., …Romer, G. (2014). Children of cancer patients: Prevalence and predictors of emotional and behavioral problems. Cancer, 120(15), 2361-2370. doi: 10.1002/cncr.28644	6-21 yrs[a]	-
Nelson, E., Sloper, P., Charlton, A., & While, D. (1994). Children who have a parent with cancer: a pilot study. Journal of Cancer Education, 9(1), 30-36. doi: 10.1080/08858199409528262	6-16 yrs[a]	-
Nelson, E., & While, D. (2002). Children's adjustment during the first year of a parent's cancer diagnosis. Journal of Psychosocial Oncology, 20(1), 15-36. doi: 10.1300/J077v20n01_02	8-16 yrs[a]	-

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. doi: 10.1002/ijc.27466	0-21 yrs[a]	-
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, 25(12), 1477-1484.	0-21 yrs[a]	-
Phillips, F. (2015). The experience of adolescents who have a parent with advanced cancer: A phenomenological inquiry. Palliative & Supportive Care, 13(4), 1057-1069. doi: 10.1017/s1478951514001023	3-16 yrs[a]	Adolescent
Phillips, F., & Prezio, E. A. (2017). Wonders & Worries: evaluation of a child centered psychosocial intervention for families who have a parent/primary caregiver with cancer. Psycho-Oncology, 26(7), 1006-1012. doi: 10.1002/pon.4120	<2 - ≥19 yrs[a]	-
Rashi, C., Wittman, T., Tsimicalis, A., & Loiselle, C. G. (2015). Balancing Illness and Parental Demands: Coping With Cancer While Raising Minor Children. Oncology nursing forum, 42(4), 337-344. doi: 10.1188/15.0NF.337-344	0-22 yrs[a]	-
Schmitt, F., Manninen, H., Santalahti, P., Savonlahti, E., Pyrhonen, S., Romer, G., & Piha, J. (2007). Children of parents with cancer: a collaborative project between a child psychiatry clinic and an adult oncology clinic. Clinical Child Psychology and Psychiatry, 12(3), 421-436. doi: 10.1177/1359104507078475	4-17 yrs[a]	-
Schmitt, F., Piha, J., Helenius, H., Baldus, C., Kienbacher, C., Steck, B., …Romer, G. (2008). Multinational study of cancer patients and their children: factors associated with family functioning. Journal of Clinical Oncology, 26(36), 5877-5883. doi: 10.1200/jco.2007.12.8132	4-17 yrs[a]	-

Semple, C. J., & McCaughan, E. (2013). Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children. European Journal of Cancer Care, 22(2), 219-231. doi: 10.1111/ecc.12018	6-11 yrs[a]	-
Shallcross, A. J., Visvanathan, P. D., McCauley, R., Clay, A., & van Dernoot, P. R. (2016). The effects of the CLIMB(R) program on psychobehavioral functioning and emotion regulation in children with a parent or caregiver with cancer: A pilot study. J Psychosoc Oncol, 34(4), 259-273. doi: 10.1080/07347332.2016.1191577	6-11 yrs[a]	-
Siegel, K., Karus, D., & Raveis, V. H. (1996). Adjustment of children facing the death of a parent due to cancer. J Am Acad Child Adolesc Psychiatry, 35(4), 442-450. doi: 10.1097/00004583-199604000-00010	7-16 yrs[a]	-
Sigal, J. J., Perry, J. C., Robbins, J. M., Gagne, M. A., & Nassif, E. (2003). Maternal preoccupation and parenting as predictors of emotional and behavioral problems in children of women with breast cancer. J Clin Oncol, 21(6), 1155-1160. doi: 10.1200/jco.2003.03.031	6-18 yrs[a]	-
Stiffler, D., Haase, J., Hosei, B., & Barada, B. (2008). Parenting experiences with adolescent daughters when mothers have breast cancer. Oncology nursing forum, 35(1), 113. doi: 10.1188/08.ONF.113-120	10-15 yrs[a]	Adolescent
Stinesen Kollberg, K., Wilderäng, U., Möller, A., & Steineck, G. (2014). Worrying about one's children after breast cancer diagnosis: desired timing of psychosocial intervention. Supportive Care in Cancer, 22(11), 2987-2995. doi: 10.1007/s00520-014-2307-z	0-19+ yrs[a]	-
Strickland, J. T., Foley Wells, C., & Porr, C. (2015). Safeguarding the Children: The Cancer Journey of Young Mothers. Oncol Nurs Forum, 42(5), 534-541. doi: 10.1188/15.onf.534-541	0-17+ years[a]	-
Thastum, M., Johansen, M. B., Gubba, L., Olesen, L. B., & Romer, G. (2008). Coping, Social Relations, and Communication: A Qualitative Exploratory Study of Children of Parents with Cancer. Clinical Child Psychology and Psychiatry, 13(1), 123-138. doi: 10.1177/1359104507086345	8-15 yrs[a]	-

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. doi: 10.1177/1359104506067875	8-15 yrs[a]	-
Thastum, M., Watson, M., Kienbacher, C., Piha, J., Steck, B., Zachariae, R., …Romer, G. (2009). Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer. Cancer, 115(17), 4030-4039. doi: 10.1002/cncr.24449	4-17 yrs[a]	-
Vannatta, K., Grollman, J. A., Noll, R. B., & Gerhardt, C. A. (2008). Impact of maternal breast cancer on the peer interactions of children at school. Psycho-Oncology, 17(3), 252-259. doi: 10.1002/pon.1232	8-16 yrs[a]	-
Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2007). Emotional and behavioral problems in children of parents recently diagnosed with cancer: a longitudinal study, 46(1), 67-76. doi: 10.1080/02841860600949560	4-18 yrs[a]	-
Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., & Hoekstra-Weebers, J. E. (2006). Parental cancer: characteristics of parents as predictors for child functioning. Cancer, 106(5), 1178-1187.	4-18 yrs[a]	-
Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., & Hoekstra-Weebers, J. E. (2007). Temperament as a predictor of internalising and externalising problems in adolescent children of parents diagnosed with cancer. Support Care Cancer, 15(4), 395-403. doi: 10.1007/s00520-006-0117-7	4-18 yrs[a]	Adolescent
Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T. A., Klip, E. C., Pras, E., & Hoekstra-Weebers, J. E. H. M. (2005). Emotional and behavioural functioning of children of a parent diagnosed with cancer: a cross-informant perspective. Psycho-Oncology, 14(9), 746-758. doi: 10.1002/pon.902	4-18 yrs[a]	-
Watson, M., St. James-Roberts, I., Ashley, S., Tilney, C., Brougham, B., Edwards, L., …Romer, G. (2006). Factors associated with emotional and behavioural problems among school age children of breast cancer patients. British Journal of Cancer, 94(1), 43-50. doi: 10.1038/sj.bjc.6602887	6-17 yrs[a]	-
Weaver, K. E., Rowland, J. H., Alfano, C. M., & McNeel, T. S. (2010). Parental cancer and the family. Cancer, 116(18), 4395-4401. doi: 10.1002/cncr.25368	0-18 yrs[a]	-

Welch, A. S., Wadsworth, M. E., & Compas, B. E. (1996). Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. Cancer, 77(7), 1409-1418. doi: 10.1002/(sici)1097-0142(19960401)77:7<1409::aid-cncr28>3.0.co;2-4	6-18 yrs[a]	Adolescent
Wong, M., Looney, E., Michaels, J., Palesh, O., & Koopman, C. (2006). A preliminary study of peritraumatic dissociation, social support, and coping in relation to posttraumatic stress symptoms for a parent's cancer. Psycho-Oncology, 15(12), 1093-1098. doi: 10.1002/pon.1041	8-17 yrs[a]	-
Wong, M. L., Cavanaugh, C. E., Macleamy, J. B., Sojourner-Nelson, A., & Koopman, C. (2009). Posttraumatic growth and adverse long-term effects of parental cancer in children. Fam Syst Health, 27(1), 53-63. doi: 10.1037/a0014771	8-17 yrs[a]	-
Yoshida, S., Otani, H., Hirai, K., Ogata, A., Mera, A., Okada, S., …Oshima, A. (2010). A qualitative study of decision-making by breast cancer patients about telling their children about their illness. Supportive Care in Cancer, 18(4), 439-447. doi: 10.1007/s00520-009-0682-7	6-17 yrs[a]	-
Zahlis, E. H. (2001). The child's worries about the mother's breast cancer: sources of distress in school-age children. Oncology nursing forum, 28(6), 1019-1025.	8-12 yrs[a]	-
Zahlis, E. H., & Lewis, F. M. (1998). Mothers' stories of the school-age child's experience with the mother's breast cancer. Journal of Psychosocial Oncology, 16(2), 25-43 19p. doi: 10.1300/j077v16n02_02	8-12 yrs[a]	-
Huang, X., O'Connor, M., Hu, Y., Gao, H., & Lee, S. (2018). Children's understanding of maternal breast cancer: A qualitative study. European Journal of Oncology Nursing, 34, 8-14. doi: 10.1016/j.ejon.2018.02.006	7-18 yrs[a]	-
Corney, R., Puthussery, S., & Swinglehurst, J. (2016). Couple relationship in families with dependent children after a diagnosis of maternal breast cancer in the United Kingdom: Perspectives from mothers and fathers. Journal of Psychosocial Oncology, 34(5), 413-431. doi: 10.1080/07347332.2016.1199080	0-13 yrs[a]	-

Ernst, J., Götze, H., Krauel, K., Romer, G., Bergelt, C., Flechtner, H.-H., . . . von Klitzing, K. (2013). Psychological distress in cancer patients with underage children: gender-specific differences. Psycho-Oncology, 22(4), 823-828. doi: 10.1002/pon.3070	0-≥18 yrs[a]	-
Hauken, M. A., Pereira, M., & Senneseth, M. (2017). The Effects on Children's Anxiety and Quality of Life of a Psychoeducational Program for Families Living With Parental Cancer and Their Network: A Randomized Controlled Trial Study. Cancer Nurs. doi: 10.1097/ncc.0000000000000529	8-18 yrs[a]	-
Kristjanson, L. J., Chalmers, K. I., & Woodgate, R. (2004). Information and support needs of adolescent children of women with breast cancer. Oncology nursing forum, 31(1), 111-119. doi: 10.1188/04.onf.111-119	12-20 yrs[a]	Adolescent
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), 167-175. doi: 10.1037/0278-6133.15.3.167	6-32 yrs[b]	-
Giesbers, J., Verdonck-de Leeuw, I. M., van Zuuren F. J., Kleverlaan N., & H., v. d. L. M. (2010). Coping with parental cancer: web-based peer support in children. Psycho-Oncology, 19(8), 887-892. doi: 10.1002/pon.1636	8-46 yrs[b]	-
Leedham, B., & Meyerowitz, B. E. (1999). Responses to Parental Cancer: A Clinical Perspective. Journal of Clinical Psychology in Medical Settings, 6(4), 441-461. doi: 10.1023/A:1026228000254	4 - 32 yrs[b]	-
Syse, A., Aas, G. B., & Loge, J. H. (2012). Children and young adults with parents with cancer: a population-based study. Clinical Epidemiology, 4, 41-52. doi: 10.2147/CLEP.S28984	0-25 yrs[b]	Young adult
Teixeira, R. J., & Pereira, M. (2013). Factors contributing to posttraumatic growth and its buffering effect in adult children of cancer patients undergoing treatment. Journal of Psychosocial Oncology, 31(3), 235-265. doi: 10.1080/07347332.2013.778932	18-61 yrs[b]	-
Fisher, C. L., Wolf, B. M., Fowler, C., & Canzona, M. R. (2017). Experiences of "openness" between mothers and daughters during breast cancer: implications for coping and healthy outcomes. Psycho-Oncology, 26(11), 1872-1880. doi: 10.1002/pon.4253	18-51 yrs[c]	-

Kim, J. H., & Park, E. C. (2014). Influence of offspring on quality of life among cancer patients and survivors: results from the Korean longitudinal study of aging (KLoSA), 2008-2011. Asian Pac J Cancer Prev, 15(23), 10531-10537. doi: 10.7314/apjcp.2014.15.23.10531	≤31 - ≥45 yrs[c]	-
Levesque, J. V., & Maybery, D. J. (2014). The Parental Cancer Questionnaire: scale structure, reliability, and validity. Supportive Care in Cancer, 22(1), 23-32. doi: 10.1007/s00520-013-1935-z	18-50 yrs[c]	-
Levesque, J. V., & Maybery, D. J. (2014). Predictors of benefit finding in the adult children of patients with cancer. Journal of Psychosocial Oncology, 32(5), 535-554. doi: 10.1080/07347332.2014.936646	18 - ≥70 yrs[c]	-
Brooke, H. L., Ringback Weitoft, G., Talback, M., Feychting, M., & Ljung, R. (2017). Adult children's socioeconomic resources and mothers' survival after a breast cancer diagnosis: a Swedish population-based cohort study. BMJ Open, 7(3), e014968. doi: 10.1136/bmjopen-2016-014968	≥30 yrs[c]	-
Levesque, J. V., & Maybery, D. (2012). Parental Cancer: Catalyst for Positive Growth and Change. Qualitative Health Research, 22(3), 397-408. doi: 10.1177/1049732311421617	18-52 yrs[c]	-
Azarbarzin, M., Malekian, A., & Taleghani, F. (2016). Adolescents' Experiences When Living With a Parent With Cancer: A Qualitative Study. Iranian Red Crescent Medical Journal, 18(1), e26410. doi: 10.5812/ircmj.26410	ND	Adolescent
Bartfai Jansson, K., & Anderzen-Carlsson, A. (2017). Adolescents' Perspectives of Living With a Parent's Cancer: A Unique and Personal Experience. Cancer Nurs, 40(2), 94-101. doi: 10.1097/ncc.0000000000000358	ND	Adolescent
Bylund-Grenklo, T., Kreicbergs, U., Hauksdottir, A., Valdimarsdottir, U. A., Nyberg, T., Steineck, G., & Furst, C. J. (2013). Self-injury in teenagers who lost a parent to cancer: a nationwide, population-based, long-term follow-up. JAMA Pediatrics, 167(2), 133-140. doi: 10.1001/jamapediatrics.2013.430	ND	Teenage

Cappelli, M., Verma, S., Korneluk, Y., Hunter, A., Tomiak, E., Allanson, J., . . . Humphreys, L. (2005). Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer. Clinical Genetics, 67(6), 481-491. doi: 10.1111/j.1399-0004.2005.00456.x	ND	Adolescent
Chen, C. M., Du, B. F., Ho, C. L., Ou, W. J., Chang, Y. C., & Chen, W. C. (2017). Perceived Stress, Parent-Adolescent/Young Adult Communication, and Family Resilience Among Adolescents/Young Adults Who Have a Parent With Cancer in Taiwan: A Longitudinal Study. Cancer Nurs. doi: 10.1097/ncc.0000000000000488	ND	Adolescent, Young adult
Christ, G. H., Siegel, K., & Sperber, D. (1994). Impact of parental terminal cancer on adolescents. American Journal of Orthopsychiatry, 64(4), 604-613. doi: 10.1037/h0079569	ND	Adolescent
Bylund-Grenklo, T., Furst, C. J., Nyberg, T., Steineck, G., & Kreicbergs, U. (2016). Unresolved grief and its consequences. A nationwide follow-up of teenage loss of a parent to cancer 6-9 yrs earlier. Supportive Care in Cancer, 24(7), 3095-3103. doi: 10.1007/s00520-016-3118-1	ND	Teenage
Basinger, E. D., Wehrman, E. C., Delaney, A. L., & McAninch, K. G. (2015). A Grounded Theory of Students' Long-Distance Coping With a Family Member's Cancer. Qualitative Health Research, 25(8), 1085-1098. doi: 10.1177/1049732315576710	ND	-
Bylund-Grenklo, T., Kreicbergs, U., Valdimarsdottir, U. A., Nyberg, T., Steineck, G., & Furst, C. J. (2014). Self-injury in youths who lost a parent to cancer: Nationwide study of the impact of family-related and health-care-related factors. Psycho-Oncology, 23(9), 989-997. doi: 10.1002/pon.3515	ND	-
Bylund-Grenklo, T., Kreicbergs, U., Uggla, C., Valdimarsdóttir, U. A., Nyberg, T., Steineck, G., & Fürst, C. J. (2015). Teenagers want to be told when a parent's death is near: A nationwide study of cancer-bereaved youths' opinions and experiences. Acta Oncologica, 54(6), 944-950 947p. doi: 10.3109/0284186X.2014.978891	ND	Teenage
Bylund-Grenklo, T., Kreicbergs, U. C., Valdimarsdóttir, U. A., Nyberg, T., Steineck, G., & Fürst, C. J. (2013). Communication and trust in the care provided to a dying parent: a nationwide study of cancer-bereaved youths. Journal of Clinical Oncology, 31(23), 2886-2894. doi: 10.1200/JCO.2012.46.6102	ND	

Cho, O.-H., Yoo, Y.-S., & Hwang, K.-H. (2015). Comparison of parent–child communication patterns and parental role satisfaction among mothers with and without breast cancer. Applied Nursing Research, 28(2), 163-168. doi: 10.1016/j.apnr.2014.09.005	ND	-
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(6), 507-515. doi: 10.1037/10338-011	ND	-
Costas-Muniz, R. (2012). Hispanic adolescents coping with parental cancer. Supportive Care in Cancer, 20(2), 413-417. doi: 10.1007/s00520-011-1283-9	ND	Adolescent
Davey, M., Askew, J., & Godette, K. (2003). Parent and Adolescent Responses to Non-Terminal Parental Cancer: A Retrospective Multiple-Case Pilot Study. Families, Systems & Health: The Journal of Collaborative Family HealthCare, 21(3), 245. doi: 10.1037/1091-7527.21.3.245	ND	Adolescent
Davey, M. P., Nino, A., Kissil, K., & Ingram, M. (2012). African American parents' experiences navigating breast cancer while caring for their children. Qualitative Health Research, 22(9), 1260-1270. doi: 10.1177/1049732312449211	ND	-
Davey, M. P., Kissil, K., Lynch, L., Harmon, L.-R., & Hodgson, N. (2013). A culturally adapted family intervention for African American families coping with parental cancer: outcomes of a pilot study. Psycho-Oncology, 22(7), 1572-1580. doi: 10.1002/pon.3172	ND	-
Fitch, M. I., & Abramson, T. (2007). Information needs of adolescents when a mother is diagnosed with breast cancer. Canadian Oncology Nursing Journal, 17(1), 16-25. doi: 10.5737/1181912x1711620	ND	Adolescent
Harris, C. A., & Zakowski, S. G. (2003). Comparisons of distress in adolescents of cancer patients and controls. Psycho-Oncology, 12(2), 173-182. doi: 10.1002/pon.631	ND	Adolescent

Hirooka, K., Fukahori, H., Akita, Y., & Ozawa, M. (2016). Posttraumatic Growth Among Japanese Parentally Bereaved Adolescents: A Web-Based Survey. American Journal of Hospice and Palliative Medicine, 34(5), 1-7. doi: 10.1177/1049909115627776	ND	Adolescent
Jeppesen, E., Bjelland, I., Fosså, S. D., Loge, J. H., Sørebø, Ø., & Dahl, A. A. (2014). Does a parental history of cancer moderate the associations between impaired health status in parents and psychosocial problems in teenagers: a HUNT study. Cancer Medicine, 3(4), 919-926. doi: 10.1002/cam4.245	ND	Teenage
Kissil, K., Niño, A., Jacobs, S., Davey, M., & Tubbs, C. Y. (2010). 'It has been a good growing experience for me': growth experiences among African American youth coping with parental cancer. Families, Systems & Health, 28(3), 274-289. doi: 10.1037/a0020001	ND	-
Krattenmacher, T., Kühne, F., Führer, D., Beierlein, V., Brähler, E., Resch, F., …Möller, B. (2013). Coping skills and mental health status in adolescents when a parent has cancer: A multicenter and multi-perspective study. Journal of Psychosomatic Research, 74(3), 252-259. doi: 10.1016/j.jpsychores.2012.10.003	ND	-
Moore, C. W., Rauch, P. K., Baer, L., Pirl, W. F., & Muriel, A. C. (2015). Parenting changes in adults with cancer. Cancer, 121(19), 3551-3557. doi: 10.1002/cncr.29525	ND	-
Phillips, F., & Lewis, F. M. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. Palliative Medicine, 29(9), 851-858. doi: 10.1177/0269216315578989	ND	Adolescent
Rainville, F., Dumont, S., Simard, S., & Savard, M. H. (2012). Psychological distress among adolescents living with a parent with advanced cancer. Journal of Psychosocial Oncology, 30(5), 519-534. doi: 10.1080/07347332.2012.703765	ND	Adolescent
Rosenfeld, A., Caplan, G., Yaroslavsky, A., Jacobowitz, J., Yuval, Y., & Lebow, H. (1983). Adaptation of children of parents suffering from cancer: A preliminary study of a new field for primary prevention research. Journal of Primary Prevention, 3(4), 244-250. doi: 10.1007/bf01325407	ND	-
Spira, M., & Kenemore, E. (2000). Adolescent Daughters of Mothers with Breast Cancer: Impact and Implications. Clinical Social Work Journal, 28(2), 183-195. doi: 10.1023/A:1005106301713	ND	Adolescent

Sveen, J., Kreicbergs, U., Melcher, U., & Alvariza, A. (2015). Teenagers' reasoning about a parent's recent death in cancer. Palliat Support Care, 1-9. doi: 10.1017/s1478951515001054	ND	Teenage
Alvariza, A., Lovgren, M., Bylund-Grenklo, T., Hakola, P., Furst, C. J., & Kreicbergs, U. (2016). How to support teenagers who are losing a parent to cancer: Bereaved young adults' advice to healthcare professionals-A nationwide survey. Palliative and Supportive Care, 1-7. doi: 10.1017/s1478951516000730	ND	Teenage, Young adult
Huizinga, G. A., Visser, A., van der Graaf, W. T. A., Hoekstra, H. J., Klip, E. C., Pras, E., & Hoekstra-Weebers, J. E. H. M. (2005). Stress response symptoms in adolescent and young adult children of parents diagnosed with cancer. European Journal of Cancer, 41(2), 288-295. doi: 10.1016/j.ejca.2004.10.005	ND	Adolescent, Young adult
Inbar, C., Ety, B., Ayala, H., & Tamer, P. (2013). The mental health of breast cancer survivors and their adolescent daughters. Psycho-Oncology, 22(6), 1236-1241. doi: 10.1002/pon.3127	ND	Adolescent
Jantzer, V., Groß, J., Stute, F., Parzer, P., Brunner, R., Willig, K., …Resch, F. (2013). Risk behaviors and externalizing behaviors in adolescents dealing with parental cancer—a controlled longitudinal study. Psycho-Oncology, 22(11), 2611-2616. doi: 10.1002/pon.3327	ND	Adolescent
Jeppesen, E., Bjelland, I., Fossa, S. D., Loge, J. H., & Dahl, A. A. (2013). Psychosocial problems of teenagers who have a parent with cancer: a population-based case-control study (young-HUNT study). Journal of Clinical Oncology, 31(32), 4099-4104. doi: 10.1200/jco.2013.50.7061	ND	Teenage
Kissil, K., Nino, A., Ingram, M., & Davey, M. (2014). "I knew from day one that i'm either gonna fight this thing or be defeated": African American parents' experiences of coping with breast cancer. Journal of Family Nursing, 20(1), 98-119. doi: 10.1177/1074840713504035	ND	-
Kucukoglu, S., & Celebioglu, A. (2012). Effects of difficulties experienced by adolescents who have a parent with cancer on their psychological condition. Collegium Antropologicum, 36(3), 879-883.	ND	Adolescent

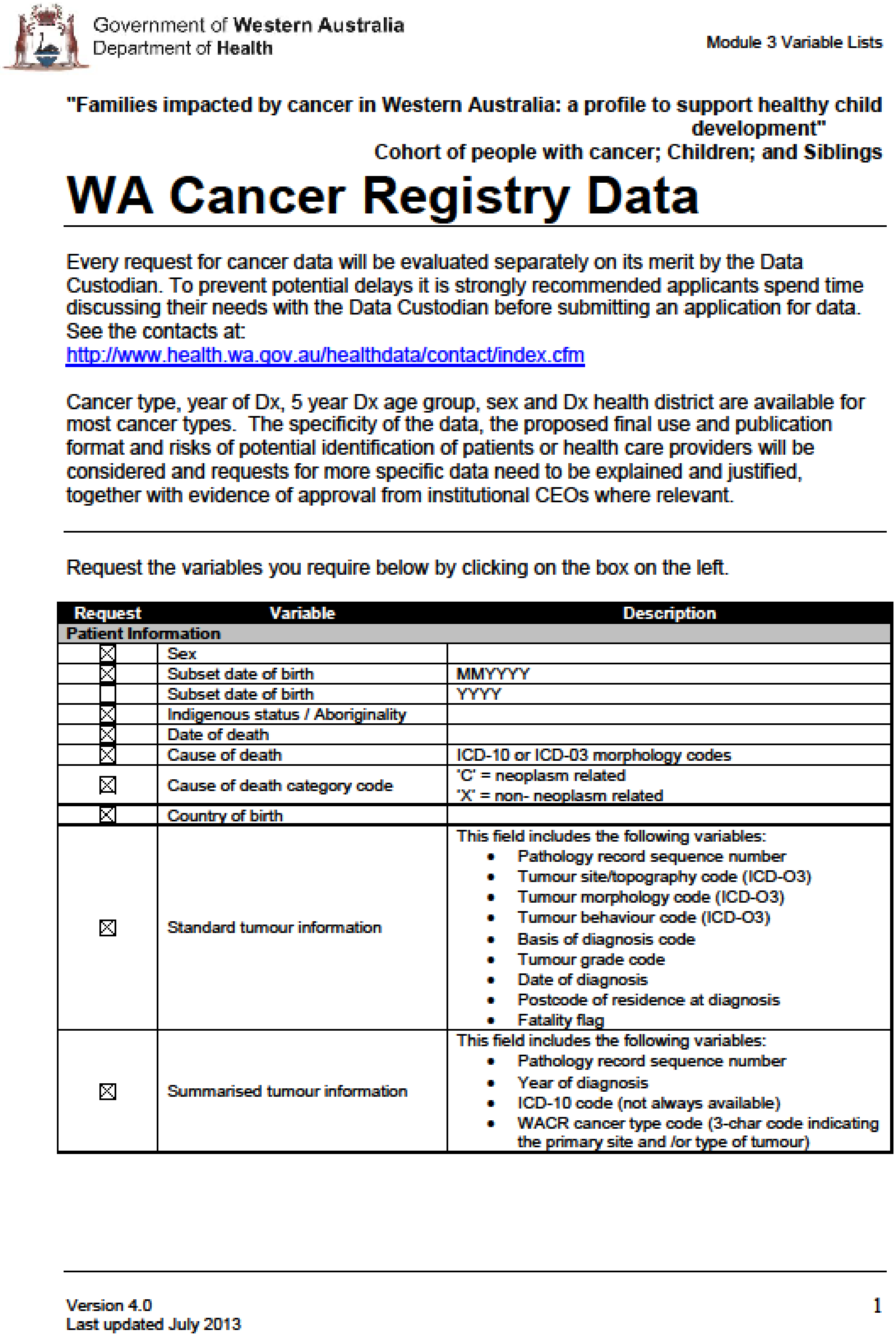
Küçükoğlu, S., & Çelebioğlu, A. (2013). Identification of psychological symptoms and associated factors in adolescents who have a parent with cancer in Turkey. European Journal of Oncology Nursing, 17(1), 75-80. doi: 10.1016/j.ejon.2011.10.008	ND	Adolescent
Kühne, F., Krattenmacher, T., Bergelt, C., Ernst, J. C., Flechtner, H.-H., Führer, D., . . . Möller, B. (2012). Parental palliative cancer: psychosocial adjustment and health-related quality of life in adolescents participating in a German family counselling service. BMC Palliative Care, 11, 21-21. doi: 10.1186/1472-684X-11-21	ND	Adolescent
Lewis, F. M., & Darby, E. L. (2003). Adolescent adjustment and maternal breast cancer: a test of the 'faucet hypothesis'. Journal of Psychosocial Oncology, 21(4), 81-104. doi: 10.1300/j077v21n04_05	ND	Adolescent
Lewis, F. M., & Hammond, M. A. (1996). The father's, mother's, and adolescent's functioning with breast cancer. Family Relations: An Interdisciplinary Journal of Applied Family Studies, 45(4), 456-465. doi: 10.2307/585176	ND	Adolescent
Maynard, A., Patterson, P., McDonald, F. E. J., & Stevens, G. (2013). What Is Helpful to Adolescents Who Have a Parent Diagnosed with Cancer? Journal of Psychosocial Oncology, 31(6), 675-697 623p. doi: 10.1080/07347332.2013.835021	ND	Adolescent
McDonald, F., 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. doi: 10.1002/pon.3942	ND	Adolescent; Young adult
Meriggi, F., Andreis, F., Liborio, N., Codignola, C., Rizzi, A., Prochilo, T., …Zaniboni, A. (2017). Parents with cancer: Searching for the right balance between telling the truth and protecting children. Palliative & Supportive Care, 15(1), 88-97. doi: 10.1017/S1478951516000444	ND	-
Metcalf, C. A., Arch, J. J., & Greer, J. A. (2017). Anxiety and its Correlates among Young Adults with a History of Parental Cancer. J Psychosoc Oncol, 35(5), 597-613. doi: 10.1080/07347332.2017.1307895	ND	Young adult

Olsson, M., Lundberg, T., Furst, C. J., Ohlen, J., & Forinder, U. (2017). Psychosocial Well-Being of Young People Who Participated in a Support Group Following the Loss of a Parent to Cancer. J Soc Work End Life Palliat Care, 1-17. doi: 10.1080/15524256.2016.1261755	ND	-
Patterson, P., McDonald, F. E., White, K. J., Walczak, A., & Butow, P. N. (2017). Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impacted by familial cancer. Psychooncology. doi: 10.1002/pon.4421	ND	Adolescent; Young adult
Patterson, P., McDonald, F. E. J., Butow, P., White, K. J., Costa, D. S. J., Pearce, A., & Bell, M. L. (2013). Psychometric evaluation of the Offspring Cancer Needs Instrument (OCNI): an instrument to assess the psychosocial unmet needs of young people who have a parent with cancer. Supportive Care in Cancer, 21(7), 1927-1938. doi: 10.1007/s00520-013-1749-z	ND	-
Patterson, P., McDonald, F. E. J., Ciarrochi, J., Hayes, L., Tracey, D., Wakefield, C. E., & White, K. (2015). A study protocol for Truce: a pragmatic controlled trial of a seven-week acceptance and commitment therapy program for young people who have a parent with cancer. BMC Psychology, 3(1). doi: 10.1186/s40359-015-0087-y	ND	-
Patterson, P., Pearce, A., & Slawitschka, E. (2011). The initial development of an instrument to assess the psychosocial needs and unmet needs of young people who have a parent with cancer: piloting the offspring cancer needs instrument (OCNI). Supportive Care in Cancer, 19(8), 1165-1174. doi: 10.1007/s00520-010-0933-7	ND	-
Schmitt, F., Santalahti, P., Saarelainen, S., Savonlahti, E., Romer, G., & Piha, J. (2008). Cancer families with children: factors associated with family functioning--a comparative study in Finland. Psycho-Oncology, 17(4), 363-372. doi: 10.1002/pon.1241	ND	-
Sears, H. A., & Sheppard, H. M. (2004). "I just wanted to be the kid": adolescent girls' experiences of having a parent with cancer. Can Oncol Nurs J, 14(1), 18-25.	ND	Adolescent

Tillquist, M., Backrud, F., & Rosengren, K. (2016). Dare to ask children as relatives! A qualitative study about female teenagers' experiences of losing a parent to cancer. Home Health Care Management & Practice, 28(2), 94-100. doi: 10.1177/1084822315610104	ND	Teenage
Torp, S., Thoresen, L., Grønningsæter, A., Grov, E., & Gustavsen, K. (2013). Financial and Social Effects on Children and Adolescents when a Parent is Diagnosed with Cancer. Child and Adolescent Social Work Journal, 30(4), 293-310. doi: 10.1007/s10560-012-0290-0	ND	Adolescent

Note: [a]Offspring <12 years; [b]Offspring <12 and >24 years; ND= offspring age not defined.

APPENDIX B. STUDY 2 DATASET VARIABLES



Government of **Western Australia**
Department of **Health**

Module 3 Variable Lists

"Families impacted by cancer in Western Australia: a profile to support healthy child development"
Cohort of people with cancer; Children; and Siblings

WA Cancer Registry Data

Every request for cancer data will be evaluated separately on its merit by the Data Custodian. To prevent potential delays it is strongly recommended applicants spend time discussing their needs with the Data Custodian before submitting an application for data. See the contacts at:
http://www.health.wa.gov.au/healthdata/contact/index.cfm

Cancer type, year of Dx, 5 year Dx age group, sex and Dx health district are available for most cancer types. The specificity of the data, the proposed final use and publication format and risks of potential identification of patients or health care providers will be considered and requests for more specific data need to be explained and justified, together with evidence of approval from institutional CEOs where relevant.

Request the variables you require below by clicking on the box on the left.

Request	Variable	Description
Patient Information		
☒	Sex	
☒	Subset date of birth	MMYYYY
☐	Subset date of birth	YYYY
☒	Indigenous status / Aboriginality	
☒	Date of death	
☒	Cause of death	ICD-10 or ICD-O3 morphology codes
☒	Cause of death category code	'C' = neoplasm related 'X' = non- neoplasm related
☒	Country of birth	
☒	Standard tumour information	This field includes the following variables: • Pathology record sequence number • Tumour site/topography code (ICD-O3) • Tumour morphology code (ICD-O3) • Tumour behaviour code (ICD-O3) • Basis of diagnosis code • Tumour grade code • Date of diagnosis • Postcode of residence at diagnosis • Fatality flag
☒	Summarised tumour information	This field includes the following variables: • Pathology record sequence number • Year of diagnosis • ICD-10 code (not always available) • WACR cancer type code (3-char code indicating the primary site and /or type of tumour)

Version 4.0
Last updated July 2013

1

Scope of the tumour records included
Within limits, you can specify some details of diagnosis date, age, and classes of tumours to include (these "classes" are based on tumour type and / or information quality issues).

As these restrictions are implemented by cutting-down a "complete" file, multiple versions are tedious to produce so please consider carefully.

The default file scope is: all ages, all diagnosis dates since 1/1/1982, diagnoses while resident both in and out of WA, all invasive, *in situ*, uncertain behaviour and benign tumours including the incidental SCC and BCC of skin, but EXCLUDING records based on HMDS data alone and records with a not-neoplastic or "suggestive of malignancy" quality-indicator code.

The following parameters can be specified if desired:

Request	Parameter	Specification
☒	Earliest diagnosis date (DD/MM/YYYY)	01/01/1982
☒	Latest diagnosis date	31/12/2015
☒	Minimum age at diagnosis (whole years)	0
☒	Maximum age at diagnosis	All ages
☒	Exclude non-WA resident diagnoses	
☒	Exclude SCC and BCC of skin (but retain benign, in situ, uncertain tumours)	
☐	"All cancers only" - limit to invasive malignancies, not including SCC/BCC of skin (Excludes non –cancers e.g. benign and in situ neoplasms)	
☐	All neoplasms including invasive malignancies, SCC & BCC skin, benign and in situ neoplasms	
Other specifications:		
Enter Details Here		

Sensitive Variables

All of the variables below have been determined as sensitive by the Data Custodian and therefore require written justification. Please provide this in the space in the table below. Items in **bold** require DOHWA HREC approval.

Request	Variable	Description
☐	**Full date of birth**	**DDMMYYYY** **Requires DOHWA HREC approval**
Enter justification here		
☐	**Cancer registration number**	**Requires DOHWA HREC approval**
Enter justification here		
☐	**UMRN (if supplied)**	**Requires DOHWA HREC approval**
Enter justification here		

Comments:

Enter any extra comments here

"Families impacted by cancer in Western Australia: a profile to support healthy child development"
Cohort of patients, Child and Sibling

Mortality Data

Every request for Mortality data will be evaluated separately on its merit by the Data Custodian. To prevent potential delays it is strongly recommended applicants spend time discussing their needs with the Mortality Data Custodian (DataServices@health.wa.gov.au) before submitting an application for data.

It is imperative applicants have referred to the online summary of Mortality data fields before requesting data. See this document online at: http://www.datalinkage-wa.org.au/downloads/data-collections

---

Request the variables you require below by clicking on the box on the left.

Request	Variable	Description
☒	Registration year	Year of the record
☒	Sex	
☐	Died in hospital flag	Flag derived by DLU
☒	Subset date of birth	MMYYYY
☐	Subset date of birth	YYYY
☐	Age of the person	When requesting Age of the person, also request Age text (below)
	Age text	Context in which the age can be quantified
☐	ATI status	Aboriginal or Torres Strait Islander descent
☐	ATSI status (doctor)	Aboriginal or Torres Strait Islander descent as indicated by doctor
☐	Post mortem	Whether a post mortem was/was not/is yet to be carried out
☐	Marital status	
☒	Date of death 1	YYYYMMDD When requesting Date of death 1, also request Date of death 2 and Date of death code (below)
	Date of death 2	1983 onwards
	Date of death code	
☐	Occupation	
	Occupation text	1984 onwards
	Main task	2002 onwards
☐	Occupation of the father of the deceased	
☐	Occupation of the mother of the deceased	
☐	Country of birth	2002 onwards
☐	Born overseas flag	2002 onwards
☐	Time resident in Australia (years and/or months)	2002 onwards
☐	Total time residency in Australian states	1984 - 2001
☐	Time of occupancy in Western Australia	1984 - 2001
☐	State unknown	State of residence unknown

☐	State of residence	Up to 8 fields
	Period of occupancy in state	1984 - 2001
☐	Deceased pregnant within 6 weeks of death	These variables can be unreliable.
☐	Deceased pregnant between 6 weeks and 12 months of death	
ABS Variables Unless otherwise stated, ABS coded variables are available from 1969 – 2013.		
☐	Aboriginal flag	When requesting Aboriginal flag, also request Registration year (top)
☐	Post mortem code	1999 - 2006
☐	Occupation code	1969 - 2007
☐	Country of Birth code	
☐	Cause of death code	
☐	Multiple cause of death codes	
	Entity Axis data	ICD codes as they appear on medical certificate 1997 to 2013.
	Record Axis data	ICD codes as they appear on medical certificate-cleaned data 1997 to 2013. When requesting these also required is Cause of Death code (ABS).
	Multi cause of death format type	Added by DLB. Indicates which format the multiple cases of death data is in.
☐	Place of occurrence code	1999-2002. Set for deaths due to or involving external causes W00-Y34.
☐	Activity code	1999-2002. Set for deaths due to external causes V01-Y34.
☐	Type of firearm used	1999-2002

Geocoding

Geocoding

Census year(s) requested:

☐ 1996 ☐ 2001 ☐ 2006 ☐ 2011

☐	Postcode	
☐	RA	Remoteness Area
☐	SEIFA	Socioeconomic status. If selecting also select Radius.
☐	Radius	
☐	Local Government Area (ABS)	1996, 2001, 2006, 2011 census
☐	Statistical Local Area (ABS)	1996, 2001, 2006 census
☐	SA2 (ABS)	2011 census

Geocoding Information:

The Data Linkage Branch routinely processes address data from the Mortality Register, to match each record's address to a longitude and latitude. DLB also provides a radius, a numeric field which is inversely proportionate to the accuracy of the match. The process is dependent upon the quality of the address data, and in some cases an address may be difficult or impossible to geocode accurately, or at all.

While the latitude and longitude cannot be provided to researchers for reasons of confidentiality, corresponding geocodes are available, including Statistical Area (SA1 and SA2), Collection District (CD), Statistical Local Area (SLA) and Local Government Area (LGA). Some of these are realigned from one census to the next. The geocodes available are CD, SLA and LGA for the 1996, 2001 and 2006 censes, while SA1, SA2 and LGA are available for 2011. Additionally, for each geocode/census combination, the Data Linkage Branch can assign Socio-Economic Indexes for Area (SEIFA) and/or Remoteness Areas (RA). Please note that records with a large radius may not fall unambiguously into a single geographical area (such as a specific CD), in which case the geocode and derived SEIFA and RA cannot be provided.

The boundaries, SEIFAs and RAs are developed by the Australian Bureau of Statistics (ABS), and the Data Linkage Branch uses mapping files available through the ABS website to attach them to the data. Queries about their interpretation and use should be directed to the ABS. For further information, please visit the ABS website at www.abs.gov.au.

Please note that, due to their small coverage, CD and SA1 are not usually included. Should you require these on your extract please provide written justification in the Sensitive Variables section of this document.

Sensitive Variables

All of the variables below have been determined as sensitive by the Data Custodian and therefore require written justification. Please provide this in the space in the table below. All Items require DOHWA HREC approval.

Request	Variable	Description
☐	**Full date of birth**	**DDMMYYYY**
Enter justification here		
☐	**Cause of Death text**	May be provided where coded COD is not available. Contains multiple fields- see data dictionary for details.
Enter justification here		
☐	**Place of death suburb**	1984 on Not necessarily a residential address - may be the suburb of a hospital.
Enter justification here		
☐	**Place of death postcode**	Not necessarily a residential address - may be the postcode of a hospital.
Enter justification here		
☐	**Place of death hospital**	This variable can be unreliable and will require approvals from the CEOs of the Area Health Services.
Enter justification here		
☐	**Collection District (ABS)**	Refer to geocoding information above (1996, 2001 and 2006 census)
Enter justification here		
☐	**SA1 (ABS)**	Refer to geocoding information above (2011 census)
Enter justification here		
☐	**Place of birth text**	This variable can be unreliable and will require approvals from the CEOs of the Area Health Services.
Enter justification here		

Comments:

Enter any extra comments here

Birth Data

Every request for Birth data will be evaluated separately on its merit by the Data Custodian. To prevent potential delays it is strongly recommended applicants spend time discussing their needs with the Data Custodian, Janine Alan (janine.alan@health.wa.gov.au) before submitting an application for data.

Request the variables you require below by clicking on the box on the left.

Request	Variable	Description
Child's details		
☒	Birth registration year	Year event registered not necessarily same as year of birth
☒	Sex	
☒	Subset date of birth	MMYYYY
☐	Subset date of birth	YYYY
☒	ATI status	2007 onwards
☐	Birth weight	1984 onwards
☐	Born alive	
☒	Plurality	
☐	Gestation period	1984 onwards—only available for stillbirths
☐	Born in hospital	Flag derived by DLU which indicates if the child was born in hospital
☒	Place of birth state	
☒	Place of birth country	
Mother's details		
☐	Occupation	
☒	ATI status	Not available on records prior to 1992
☒	Place of birth	
☒	Age	
☒	Year mother arrived in Australia	2002 onwards
Father's details		
☐	Occupation	
☒	ATI status	Not available on records prior to 1992
☒	Place of birth	
☒	Age	
☒	Year father arrived in Australia	2002 onwards
Other		
☐	Date of marriage	Year only

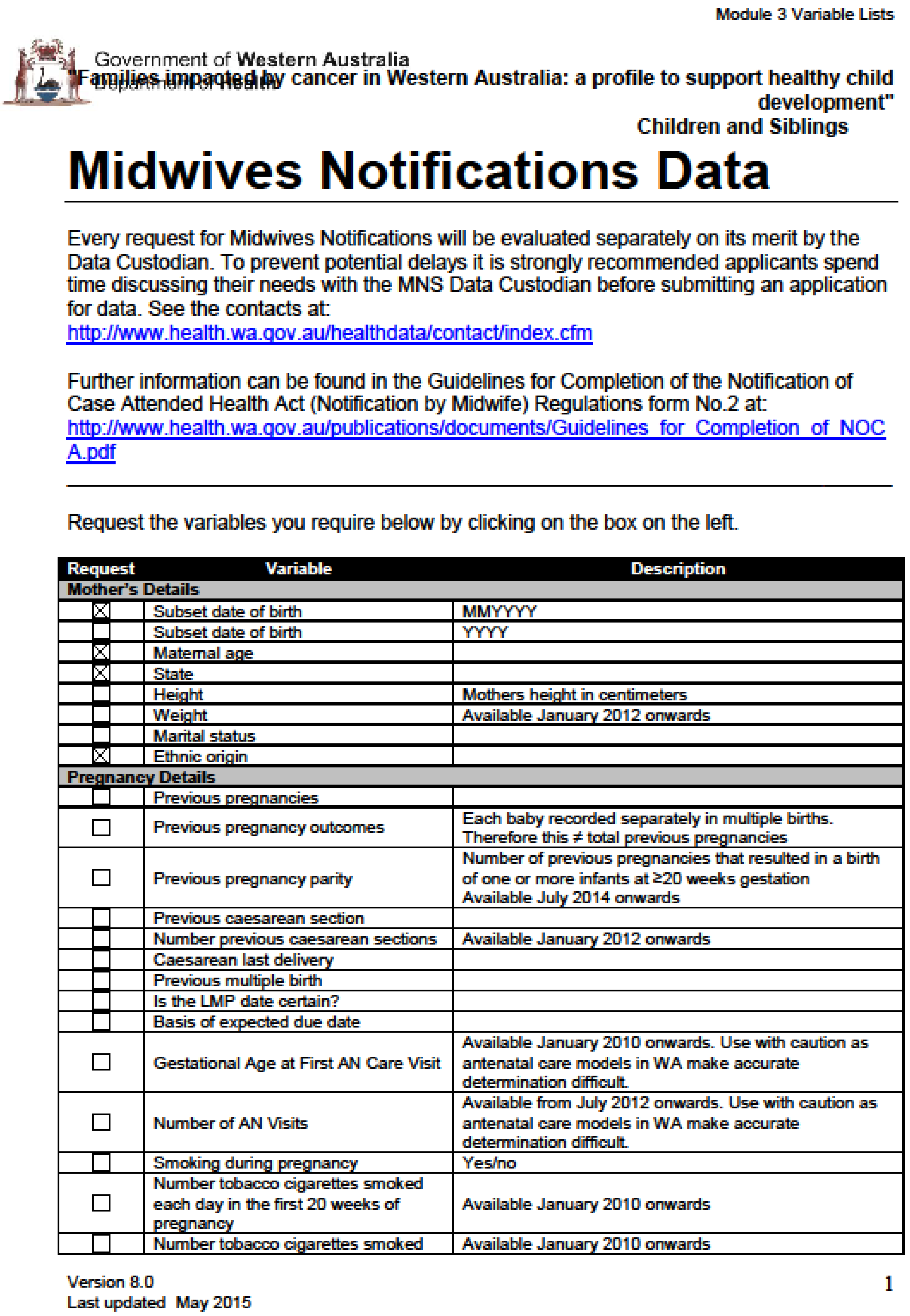
Sensitive Variables

All of the variables below have been determined as sensitive by the Data Custodian and therefore require written justification. Please provide this in the space in the table below. Items in **bold** require DOHWA HREC approval.

Request	Variable	Description
☐	**Baby's Full date of birth**	**DDMMYYYY** **Requires DOHWA HREC approval**
Enter justification here		
☐	**Place of birth postcode**	**Requires DOHWA HREC approval** **May require approvals from Area Health Services.** Please note that this is most often the postcode of a hospital, not the residential postcode.
Enter justification here		
☐	**Place of birth hospital**	**Requires DOHWA HREC approval** **May require approvals from Area Health Services.** Numeric field
Enter justification here		
☐	**Informant's postcode**	**Requires DOHWA HREC approval** Please note that the parent is not always the informant.
Enter justification here		

Comments:

Enter any extra comments here



Government of Western Australia
Department of Health

"Families impacted by cancer in Western Australia: a profile to support healthy child development"
Children and Siblings

Midwives Notifications Data

Every request for Midwives Notifications will be evaluated separately on its merit by the Data Custodian. To prevent potential delays it is strongly recommended applicants spend time discussing their needs with the MNS Data Custodian before submitting an application for data. See the contacts at:
http://www.health.wa.gov.au/healthdata/contact/index.cfm

Further information can be found in the Guidelines for Completion of the Notification of Case Attended Health Act (Notification by Midwife) Regulations form No.2 at:
http://www.health.wa.gov.au/publications/documents/Guidelines_for_Completion_of_NOCA.pdf

---

Request the variables you require below by clicking on the box on the left.

Request	Variable	Description
Mother's Details		
☒	Subset date of birth	MMYYYY
☐	Subset date of birth	YYYY
☒	Maternal age	
☒	State	
☐	Height	Mothers height in centimeters
☐	Weight	Available January 2012 onwards
☐	Marital status	
☒	Ethnic origin	
Pregnancy Details		
☐	Previous pregnancies	
☐	Previous pregnancy outcomes	Each baby recorded separately in multiple births. Therefore this ≠ total previous pregnancies
☐	Previous pregnancy parity	Number of previous pregnancies that resulted in a birth of one or more infants at ≥20 weeks gestation Available July 2014 onwards
☐	Previous caesarean section	
☐	Number previous caesarean sections	Available January 2012 onwards
☐	Caesarean last delivery	
☐	Previous multiple birth	
☐	Is the LMP date certain?	
☐	Basis of expected due date	
☐	Gestational Age at First AN Care Visit	Available January 2010 onwards. Use with caution as antenatal care models in WA make accurate determination difficult.
☐	Number of AN Visits	Available from July 2012 onwards. Use with caution as antenatal care models in WA make accurate determination difficult.
☐	Smoking during pregnancy	Yes/no
☐	Number tobacco cigarettes smoked each day in the first 20 weeks of pregnancy	Available January 2010 onwards
☐	Number tobacco cigarettes smoked	Available January 2010 onwards

	each day after the first 20 weeks of pregnancy	
☐	Complications of pregnancy	Tick box value supplied, not ICD code
☐	Medical conditions	Tick box value supplied, not ICD code
☐	Procedures/treatments	
☐	Intended place of birth at onset of labour	
Labour Details		
☐	Onset of labour	Method (e.g. induced)
☐	Augmentation	
☐	Induction	
☐	Analgesia (during labour)	
Delivery Details		
☐	Duration of labour 1st stage	
☐	Duration of labour 2nd stage	
☐	Anaesthesia (during delivery)	
☐	Complications of labour and delivery	Tick box value supplied, not ICD code
☐	Estimated blood loss at delivery	Measured in mL. Available July 2014 onwards
☐	Perineal status	
☐	Reason for caesarean section	Available July 2014 onwards
Baby Details		
☐	Indigenous Status	Available January 2012 onwards
☐	Born before arrival	Yes/No
☒	Subset date of birth	MMYYYY
☐	Subset date of birth	YYYY
☒	Plurality	Number of babies in this birth
☒	Baby number	Order in delivery
☐	Presentation	Position (e.g. breech)
☐	Method of birth	
☐	Reason for caesarean section	If requesting this field, also request 'Method of Birth' above Available July 2014 onwards
☐	Accoucheur(s)	Profession of the person who delivered the baby
☒	Gender	
☐	Status of baby at birth	Alive/stillborn
☐	Infant weight	
☐	Length of baby (cms)	
☐	Head circumference	
☐	Time to establish unassisted regular breathing	Recorded in minutes
☐	Resuscitation	Method used
☐	Apgar score at 1 minute	
☐	Apgar score at 5 minutes	
☐	Estimated gestation	Clinical estimation in weeks, available 1986 onwards
☐	Baby separation date	MMYYYY only
☐	Baby length of stay in days	Derived variable
☐	Mode of separation	E.g. transferred, went home
☐	Number of Days in Special Care Nursery at birth site	
Other variables		

The following variables are derived using the algorithms developed by Dr Eve Blair et al.

References:

(1) Blair, E.M., Liu, Y., de Klerk, N.H. & Lawrence, D.M. (2005) Optimal fetal growth for the Caucasian singleton and assessment of appropriateness of fetal growth: an analysis of a total population perinatal database. *BMC Pediatrics*, 5, 13-25.

(2) Blair, E.M., Liu, Y. & Cosgrove, P. (2004) Choosing the best estimate of gestational age from routinely collected population-based perinatal data. *Paediatric and Perinatal Epidemiology*, 18, 270-276.

☐	POBW	Percentage Optimal Birth Weight
☐	POHC	Percentage Optimal Head Circumference
☐	POL	Percentage Optimal Length
☐	Estimate of Gestational Age	Algorithmic Estimate of Gestational Age Based on LMP, EDD, baby date of birth

Geocoding

Geocoding		
Census year(s) requested: ☒ 1996 ☒ 2001 ☒ 2006 ☒ 2011		
☒	Postcode	
☒	RA	Remoteness Area
☒	SEIFA	Socioeconomic status. If selecting also select Radius.
☒	Radius	
☐	Local Government Area (ABS)	1996, 2001, 2006, 2011 census
☒	Statistical Local Area (ABS)	1996, 2001, 2006 census
☒	SA2 (ABS)	2011 census

Geocoding Information:
The Data Linkage Branch routinely processes address data from the MNS, to match each record's address to a longitude and latitude. DLB also provides a radius, a numeric field which is inversely proportionate to the accuracy of the match. The process is dependent upon the quality of the address data, and in some cases an address may be difficult or impossible to geocode accurately, or at all.

While the latitude and longitude cannot be provided to researchers for reasons of confidentiality, corresponding geocodes are available, including Statistical Area (SA1 and SA2), Collection District (CD), Statistical Local Area (SLA) and Local Government Area (LGA). Some of these are realigned from one census to the next. The geocodes available are CD, SLA and LGA for the 1996, 2001 and 2006 censes, while SA1, SA2 and LGA are available for 2011. Additionally, for each geocode/census combination, the Data Linkage Branch can assign Socio-Economic Indexes for Area (SEIFA) and/or Remoteness Areas (RA). Please note that records with a large radius may not fall unambiguously into a single geographical area (such as a specific CD), in which case the geocode and derived SEIFA and RA cannot be provided.

The boundaries, SEIFAs and RAs are developed by the Australian Bureau of Statistics (ABS), and the Data Linkage Branch uses mapping files available through the ABS website to attach them to the data. Queries about their interpretation and use should be directed to the ABS. For further information, please visit the ABS website at www.abs.gov.au.

Please note that, due to their small coverage, CD and SA1 are not usually included. Should you require these on your extract please provide written justification in the Sensitive Variables section of this document.

Sensitive Variables

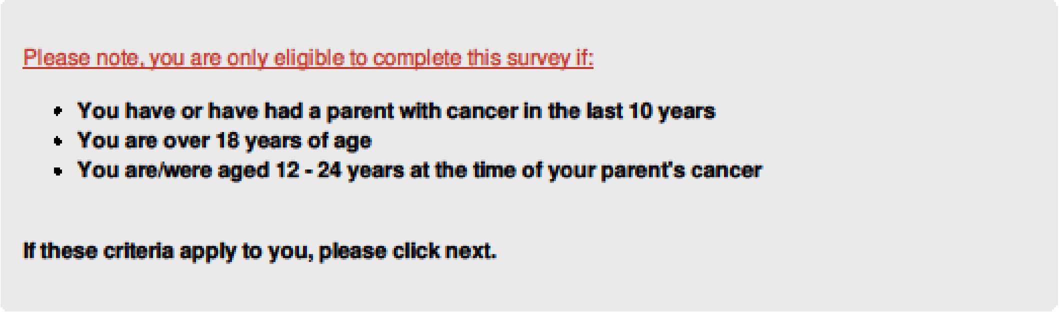
All of the variables below have been determined as sensitive by the MNS Data Custodian and therefore require written justification. Please provide this in the space in the table below. Items in **bold** require DOHWA HREC approval.

Request	Variable	Description
☐	**Full date of birth of mother**	**DDMMYYYY** **Requires DOHWA HREC approval**
Enter justification here		
☐	**Full date of birth of baby**	**DDMMYYYY** **Requires DOHWA HREC approval**
Enter justification here		
☐	Expected due date	MMYYYY only
Enter justification here		
☐	Collection District (ABS)	Refer to geocoding information above (1996, 2001 and 2006 census)
Enter justification here		
☐	SA1 (ABS)	Refer to geocoding information above (2011 census)
Enter justification here		
☐	Date of last menstrual period	DDMMYYYY Be careful with the reliability of this variable
Enter justification here		
☐	**Reporting establishment**	The establishment reporting the birth, which may be the first maternity establishment to care for the woman after the birth (i.e. may not be place of birth and therefore may not match hospital code from linked HMDS records). May require approvals from the Chief Executives of the Area Health Services and/or private hospitals. **Requires DOHWA HREC approval**
Enter justification here		
☐	Home birth type	Derived field that indicates if birth at home was public, private or uncontracted home birth.
Enter justification here		
☐	**Baby transferred to**	May require approvals from the Chief Executives of the Area Health Services and/or private hospitals. If requesting this variable, also request 'mode of separation'. **Requires DOHWA HREC approval**
Enter justification here		

Comments:

Enter any extra comments here

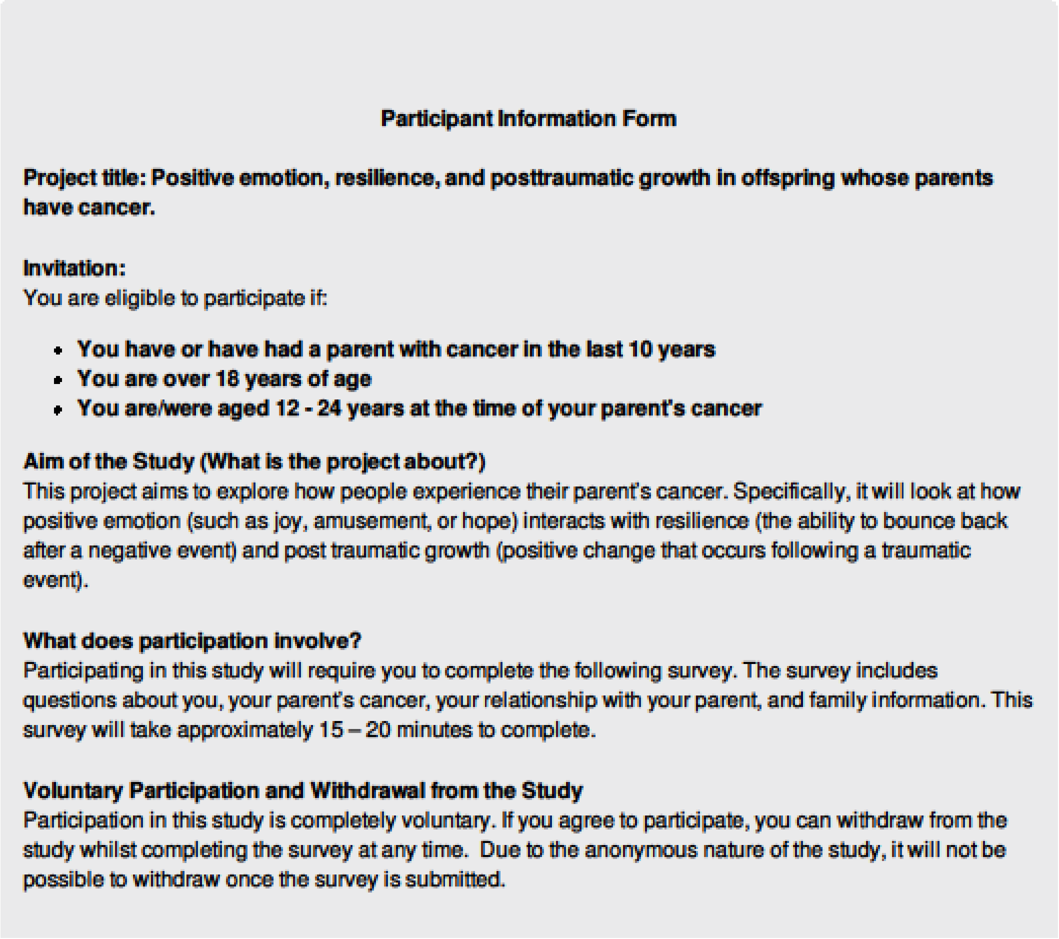
APPENDIX C. STUDY 3 SURVEY



Please note, you are only eligible to complete this survey if:

- **You have or have had a parent with cancer in the last 10 years**
- **You are over 18 years of age**
- **You are/were aged 12 - 24 years at the time of your parent's cancer**

If these criteria apply to you, please click next.



Participant Information Form

Project title: Positive emotion, resilience, and posttraumatic growth in offspring whose parents have cancer.

Invitation:
You are eligible to participate if:

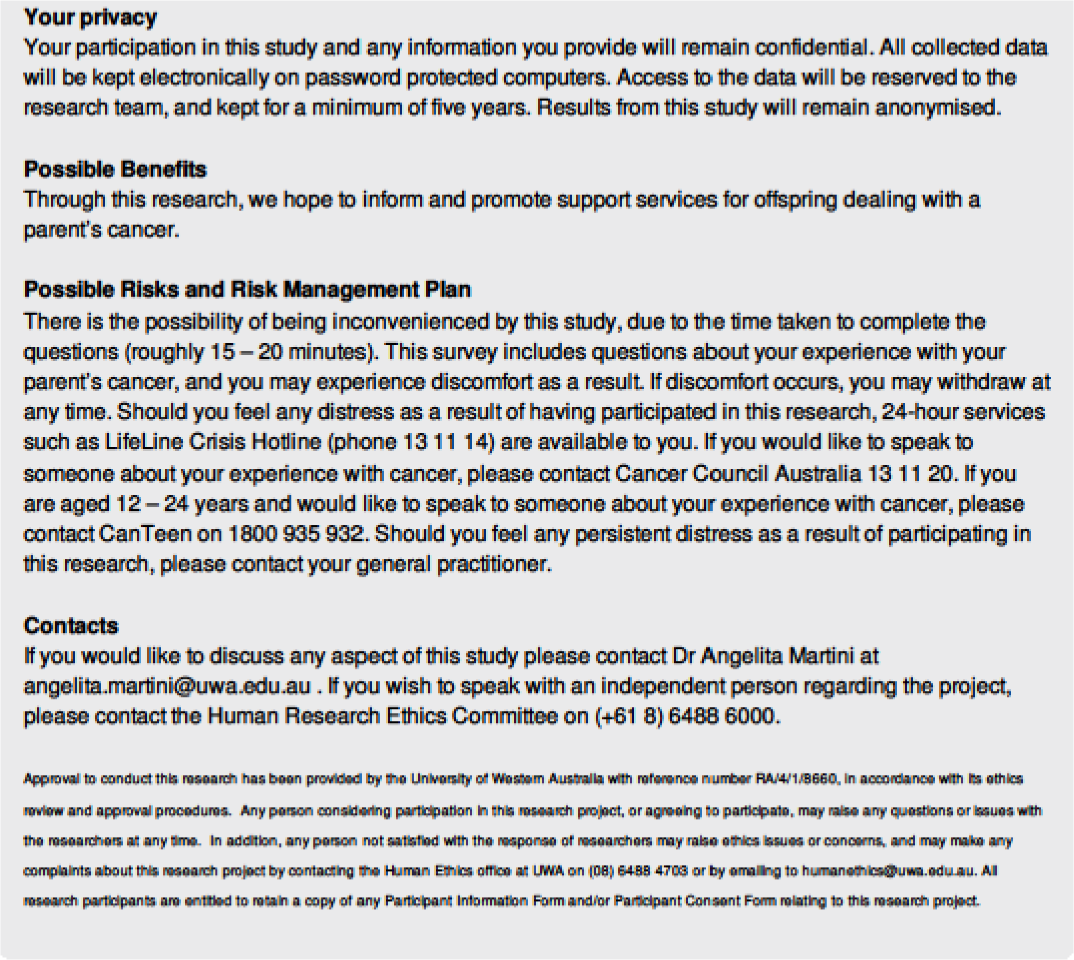
- **You have or have had a parent with cancer in the last 10 years**
- **You are over 18 years of age**
- **You are/were aged 12 - 24 years at the time of your parent's cancer**

Aim of the Study (What is the project about?)
This project aims to explore how people experience their parent's cancer. Specifically, it will look at how positive emotion (such as joy, amusement, or hope) interacts with resilience (the ability to bounce back after a negative event) and post traumatic growth (positive change that occurs following a traumatic event).

What does participation involve?
Participating in this study will require you to complete the following survey. The survey includes questions about you, your parent's cancer, your relationship with your parent, and family information. This survey will take approximately 15 – 20 minutes to complete.

Voluntary Participation and Withdrawal from the Study
Participation in this study is completely voluntary. If you agree to participate, you can withdraw from the study whilst completing the survey at any time. Due to the anonymous nature of the study, it will not be possible to withdraw once the survey is submitted.

Note: Items reflecting the same question but phrased in either past or present tense were not repeated in the survey, but appeared depending on participants' response to Question 3 (i.e. does your parent currently have cancer or did they have cancer in the last 10 years?). See Appendix D for questionnaire logic.



Your privacy

Your participation in this study and any information you provide will remain confidential. All collected data will be kept electronically on password protected computers. Access to the data will be reserved to the research team, and kept for a minimum of five years. Results from this study will remain anonymised.

Possible Benefits

Through this research, we hope to inform and promote support services for offspring dealing with a parent's cancer.

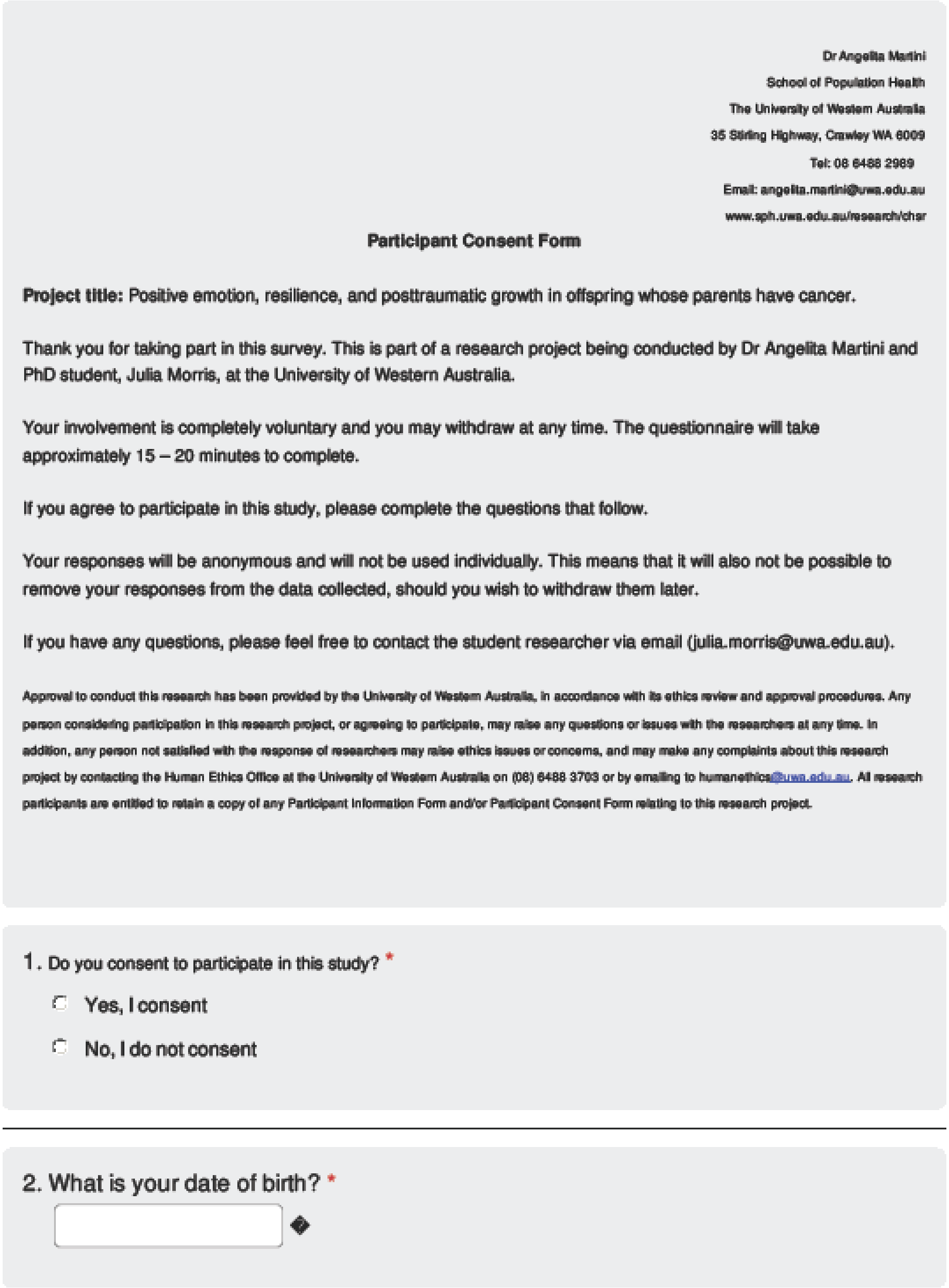
Possible Risks and Risk Management Plan

There is the possibility of being inconvenienced by this study, due to the time taken to complete the questions (roughly 15 – 20 minutes). This survey includes questions about your experience with your parent's cancer, and you may experience discomfort as a result. If discomfort occurs, you may withdraw at any time. Should you feel any distress as a result of having participated in this research, 24-hour services such as LifeLine Crisis Hotline (phone 13 11 14) are available to you. If you would like to speak to someone about your experience with cancer, please contact Cancer Council Australia 13 11 20. If you are aged 12 – 24 years and would like to speak to someone about your experience with cancer, please contact CanTeen on 1800 935 932. Should you feel any persistent distress as a result of participating in this research, please contact your general practitioner.

Contacts

If you would like to discuss any aspect of this study please contact Dr Angelita Martini at angelita.martini@uwa.edu.au . If you wish to speak with an independent person regarding the project, please contact the Human Research Ethics Committee on (+61 8) 6488 6000.

Approval to conduct this research has been provided by the University of Western Australia with reference number RA/4/1/8660, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 4703 or by emailing to humanethics@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.



Dr Angelita Martini
School of Population Health
The University of Western Australia
35 Stirling Highway, Crawley WA 6009
Tel: 08 6488 2989
Email: angelita.martini@uwa.edu.au
www.sph.uwa.edu.au/research/chsr

Participant Consent Form

Project title: Positive emotion, resilience, and posttraumatic growth in offspring whose parents have cancer.

Thank you for taking part in this survey. This is part of a research project being conducted by Dr Angelita Martini and PhD student, Julia Morris, at the University of Western Australia.

Your involvement is completely voluntary and you may withdraw at any time. The questionnaire will take approximately 15 – 20 minutes to complete.

If you agree to participate in this study, please complete the questions that follow.

Your responses will be anonymous and will not be used individually. This means that it will also not be possible to remove your responses from the data collected, should you wish to withdraw them later.

If you have any questions, please feel free to contact the student researcher via email (julia.morris@uwa.edu.au).

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics Office at the University of Western Australia on (08) 6488 3703 or by emailing to humanethics@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

1. Do you consent to participate in this study? *

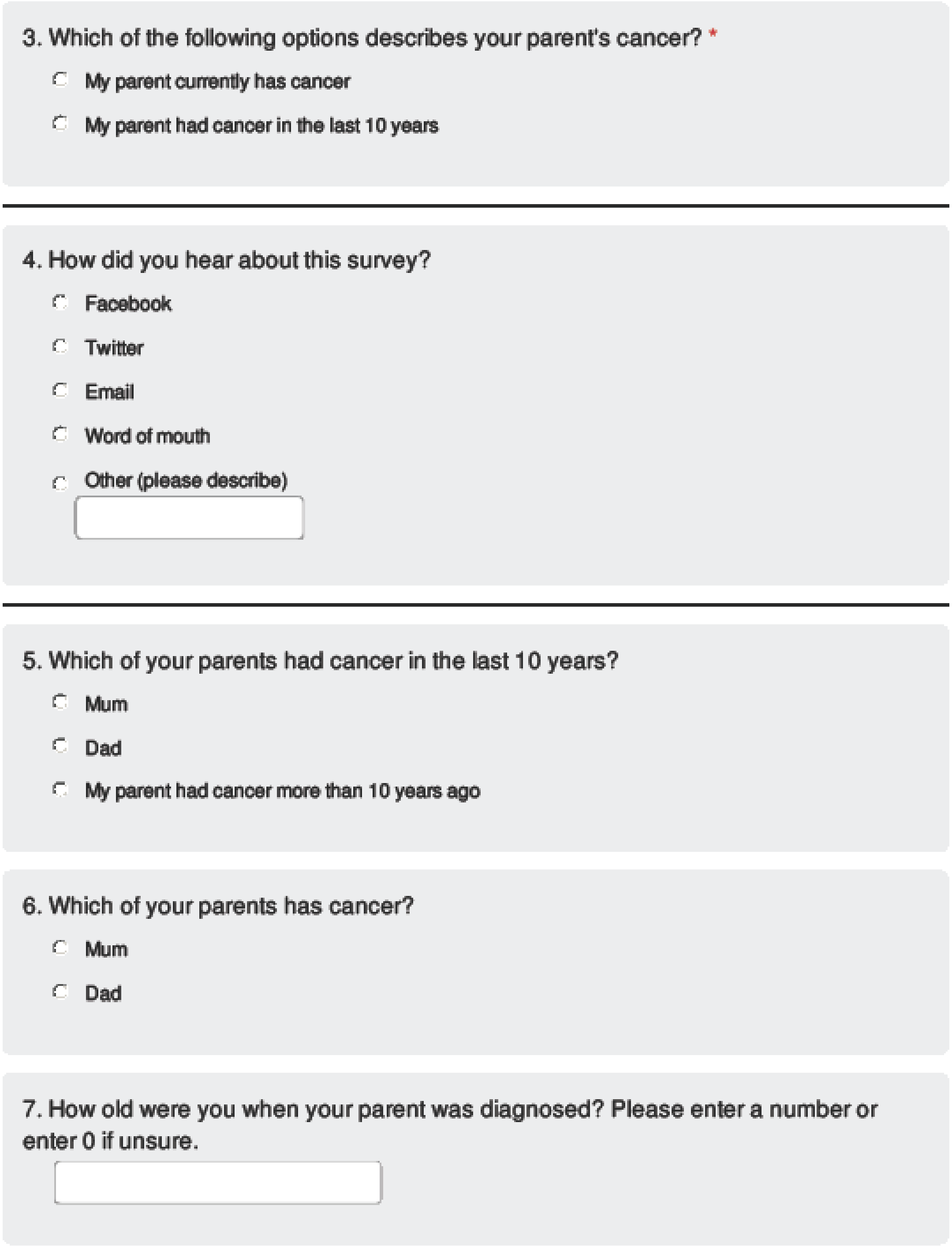
○ Yes, I consent

○ No, I do not consent

---

2. What is your date of birth? *

☐ �



3. Which of the following options describes your parent's cancer? *

○ My parent currently has cancer

○ My parent had cancer in the last 10 years

4. How did you hear about this survey?

○ Facebook

○ Twitter

○ Email

○ Word of mouth

○ Other (please describe)

5. Which of your parents had cancer in the last 10 years?

○ Mum

○ Dad

○ My parent had cancer more than 10 years ago

6. Which of your parents has cancer?

○ Mum

○ Dad

7. How old were you when your parent was diagnosed? Please enter a number or enter 0 if unsure.

11. What is their main or primary cancer?

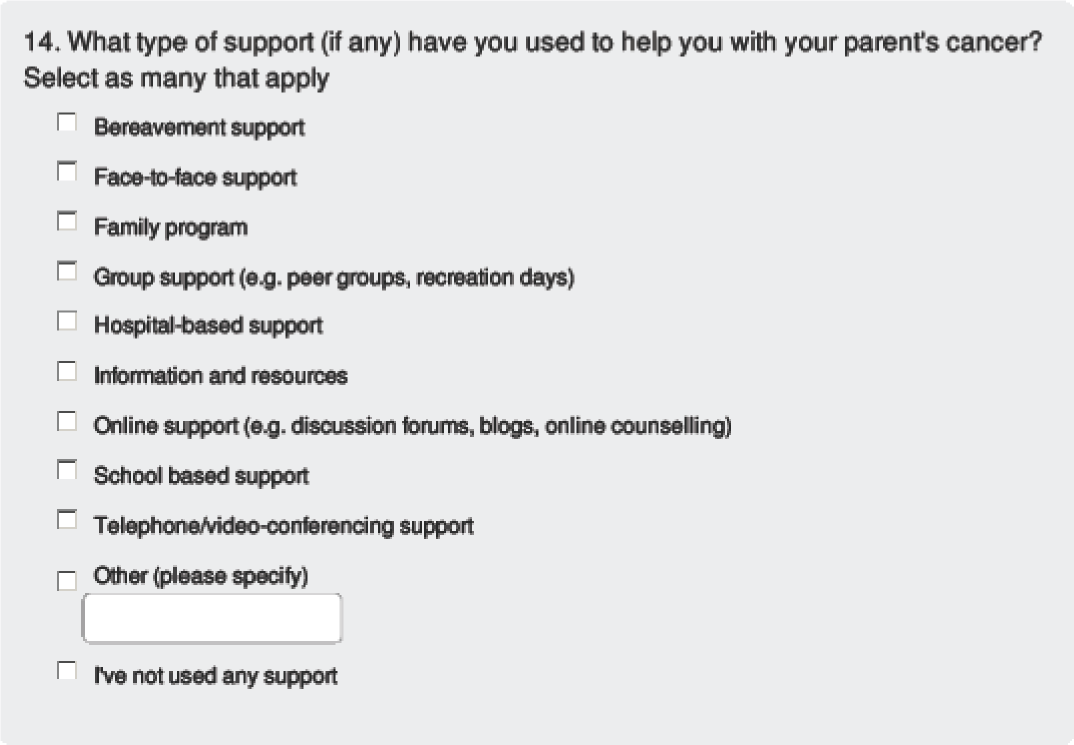
○ Anal
○ Bladder
○ Bone
○ Bowel
○ Brain
○ Breast
○ Cervical
○ Colon
○ Colorectal
○ Gallbladder
○ Head and neck
○ Hodkin lymphoma
○ Kidney
○ Laryngeal
○ Lip
○ Liver
○ Leukaemia
○ Lung
○ Skin (melanoma)
○ Mouth
○ Multiple Myeloma
○ Multiple primary
○ Non-Hodgkin lymphoma
○ Skin (non-melanoma)
○ Oesophageal
○ Other soft tissue
○ Ovarian
○ Pancreatic
○ Prostate
○ Rectal
○ Stomach
○ Testicular
○ Thyroid
○ Tongue
○ Unknown primary
○ Uterine
○ Unsure
○ Other (please specify)

12. How often did you worry about their disease?

Never	Rarely	Sometimes	Often	All of the time
○	○	○	○	○

13. How often do you worry about their disease?

Never	Rarely	Sometimes	Often	All of the time
○	○	○	○	○



14. What type of support (if any) have you used to help you with your parent's cancer? Select as many that apply

☐ Bereavement support

☐ Face-to-face support

☐ Family program

☐ Group support (e.g. peer groups, recreation days)

☐ Hospital-based support

☐ Information and resources

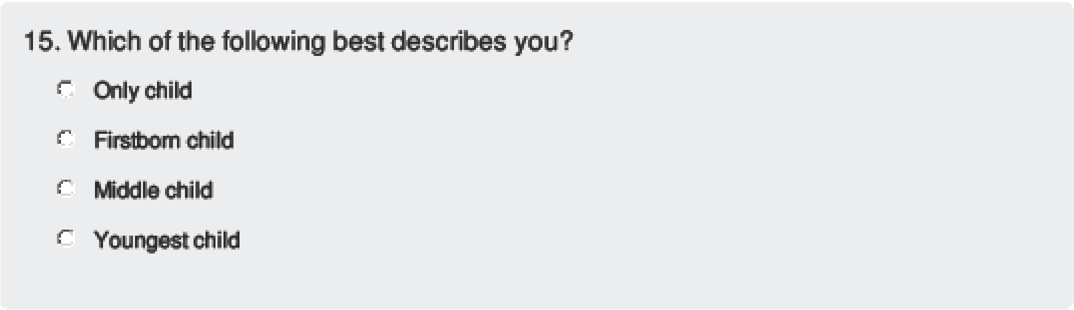
☐ Online support (e.g. discussion forums, blogs, online counselling)

☐ School based support

☐ Telephone/video-conferencing support

☐ Other (please specify)

☐ I've not used any support



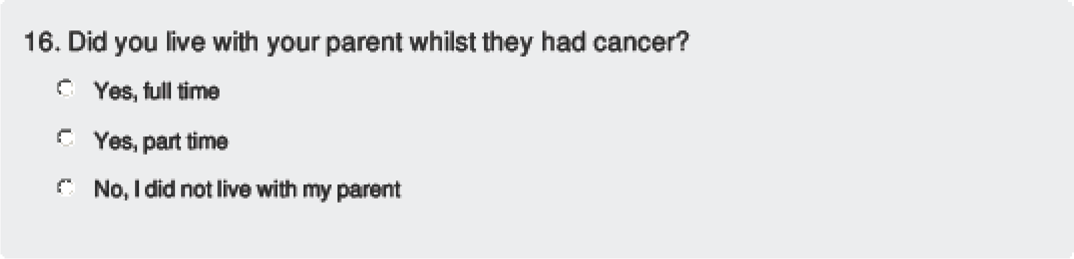
15. Which of the following best describes you?

○ Only child

○ Firstborn child

○ Middle child

○ Youngest child

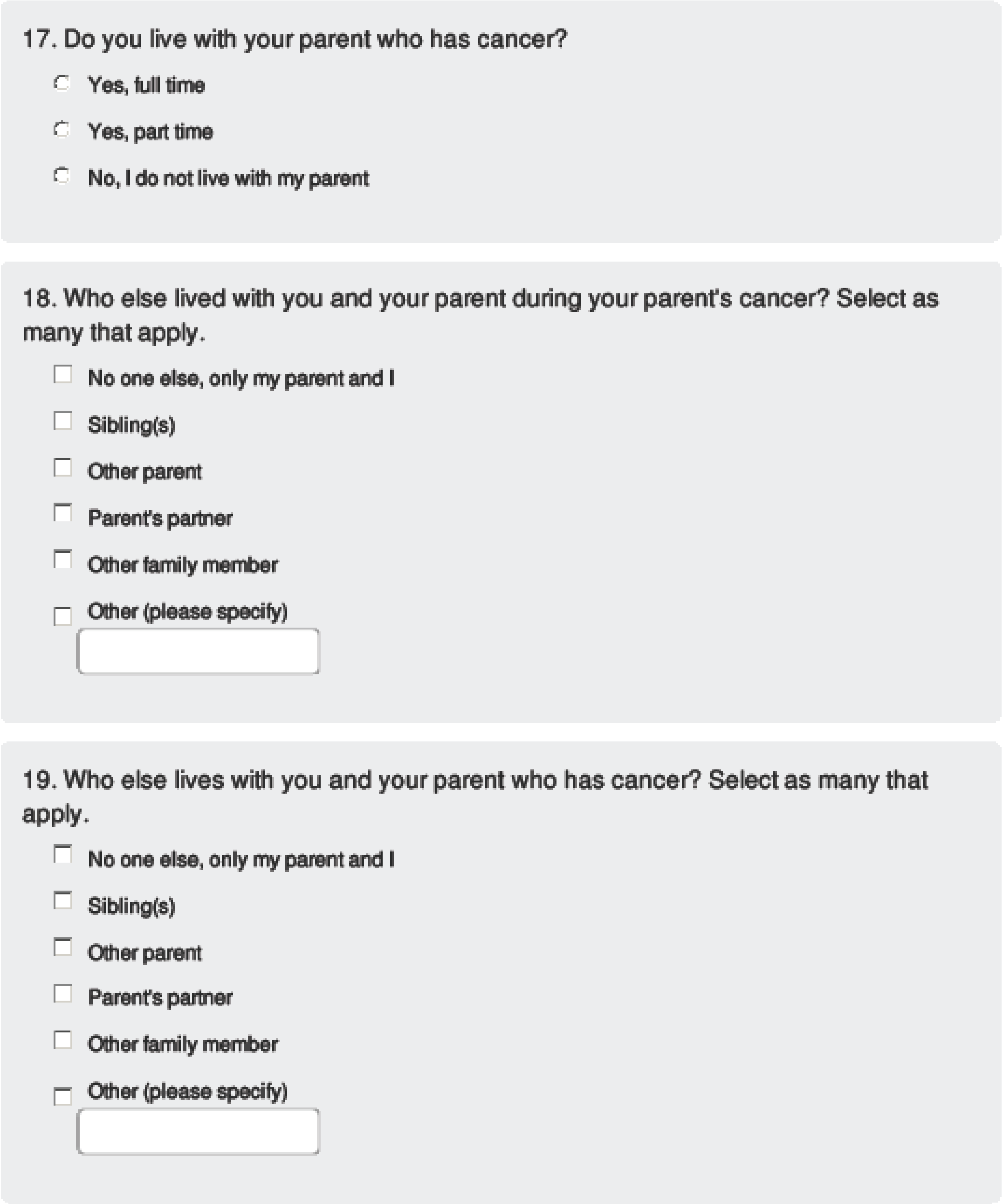


16. Did you live with your parent whilst they had cancer?

○ Yes, full time

○ Yes, part time

○ No, I did not live with my parent



17. Do you live with your parent who has cancer?

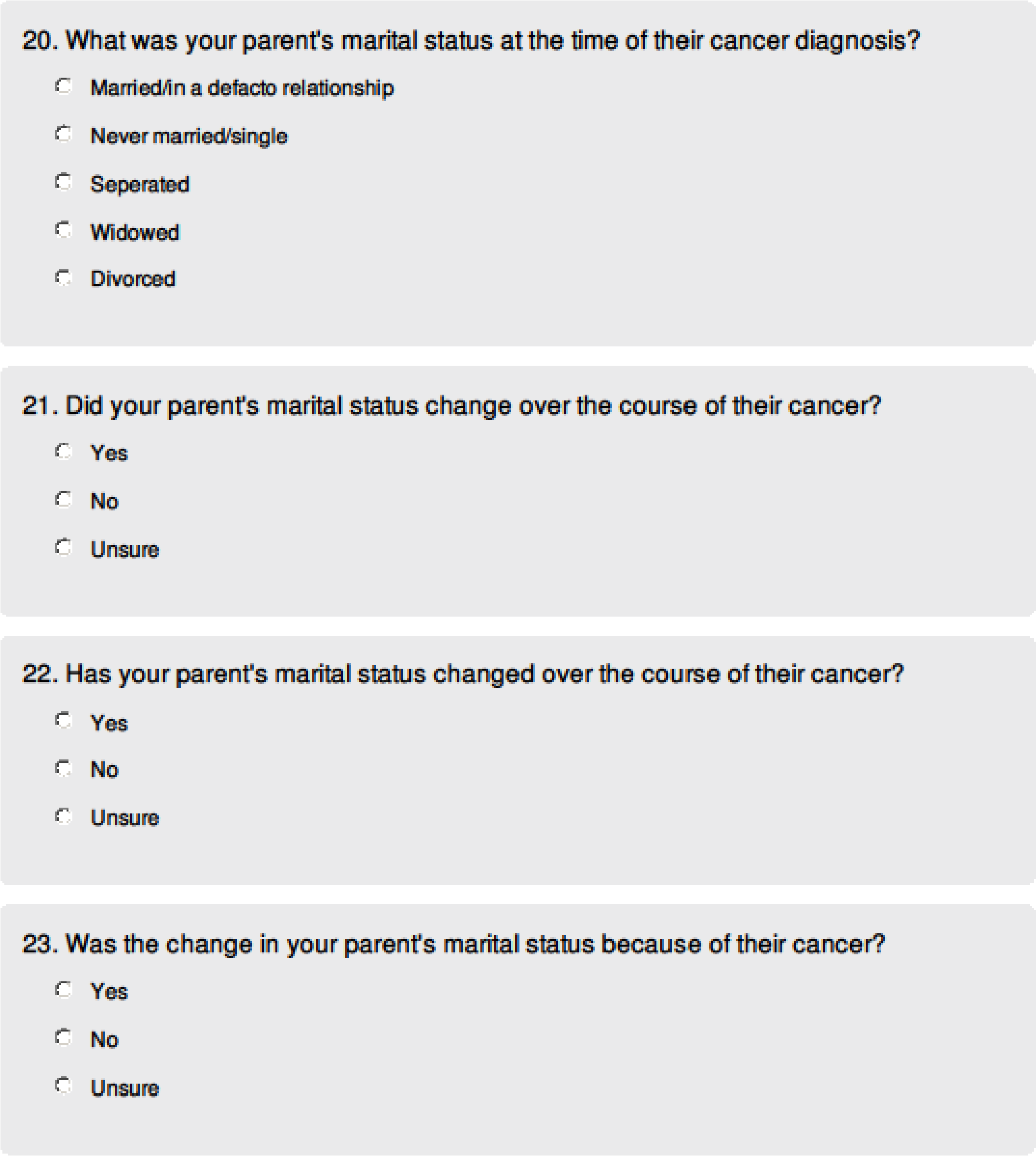
- ○ Yes, full time
- ○ Yes, part time
- ○ No, I do not live with my parent

18. Who else lived with you and your parent during your parent's cancer? Select as many that apply.

- ☐ No one else, only my parent and I
- ☐ Sibling(s)
- ☐ Other parent
- ☐ Parent's partner
- ☐ Other family member
- ☐ Other (please specify)

19. Who else lives with you and your parent who has cancer? Select as many that apply.

- ☐ No one else, only my parent and I
- ☐ Sibling(s)
- ☐ Other parent
- ☐ Parent's partner
- ☐ Other family member
- ☐ Other (please specify)



20. What was your parent's marital status at the time of their cancer diagnosis?

○ Married/in a defacto relationship
○ Never married/single
○ Seperated
○ Widowed
○ Divorced

21. Did your parent's marital status change over the course of their cancer?

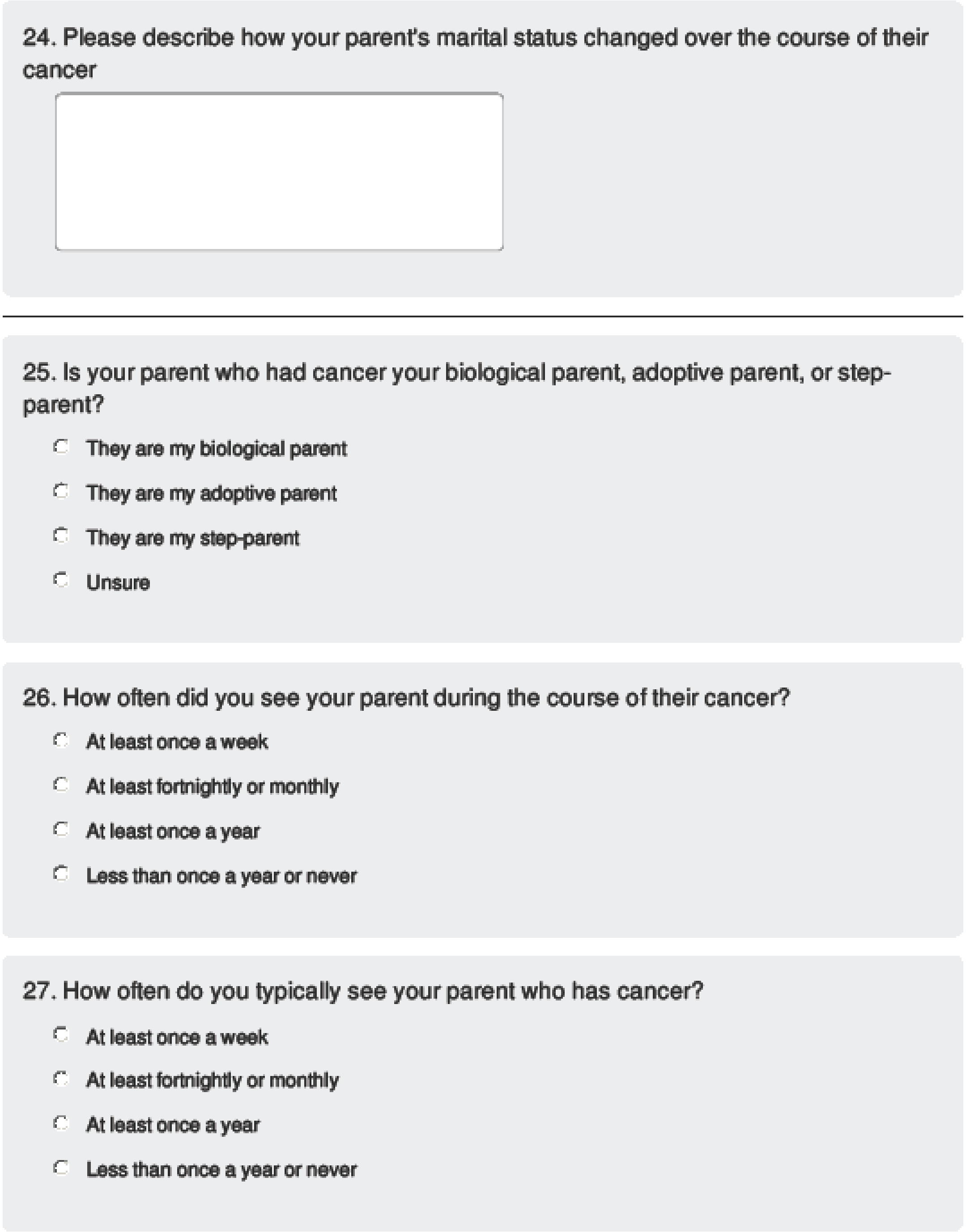
○ Yes
○ No
○ Unsure

22. Has your parent's marital status changed over the course of their cancer?

○ Yes
○ No
○ Unsure

23. Was the change in your parent's marital status because of their cancer?

○ Yes
○ No
○ Unsure



24. Please describe how your parent's marital status changed over the course of their cancer

---

25. Is your parent who had cancer your biological parent, adoptive parent, or step-parent?

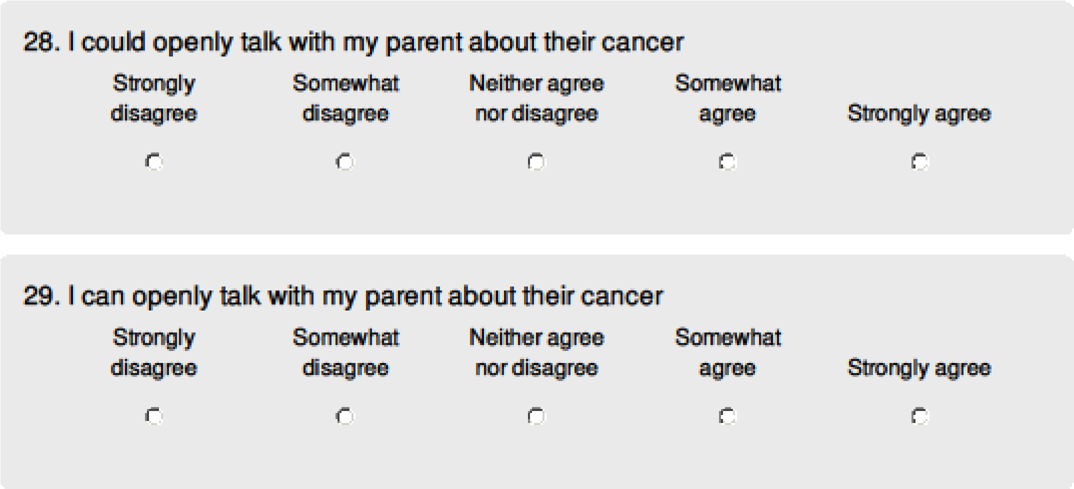
○ They are my biological parent
○ They are my adoptive parent
○ They are my step-parent
○ Unsure

26. How often did you see your parent during the course of their cancer?

○ At least once a week
○ At least fortnightly or monthly
○ At least once a year
○ Less than once a year or never

27. How often do you typically see your parent who has cancer?

○ At least once a week
○ At least fortnightly or monthly
○ At least once a year
○ Less than once a year or never

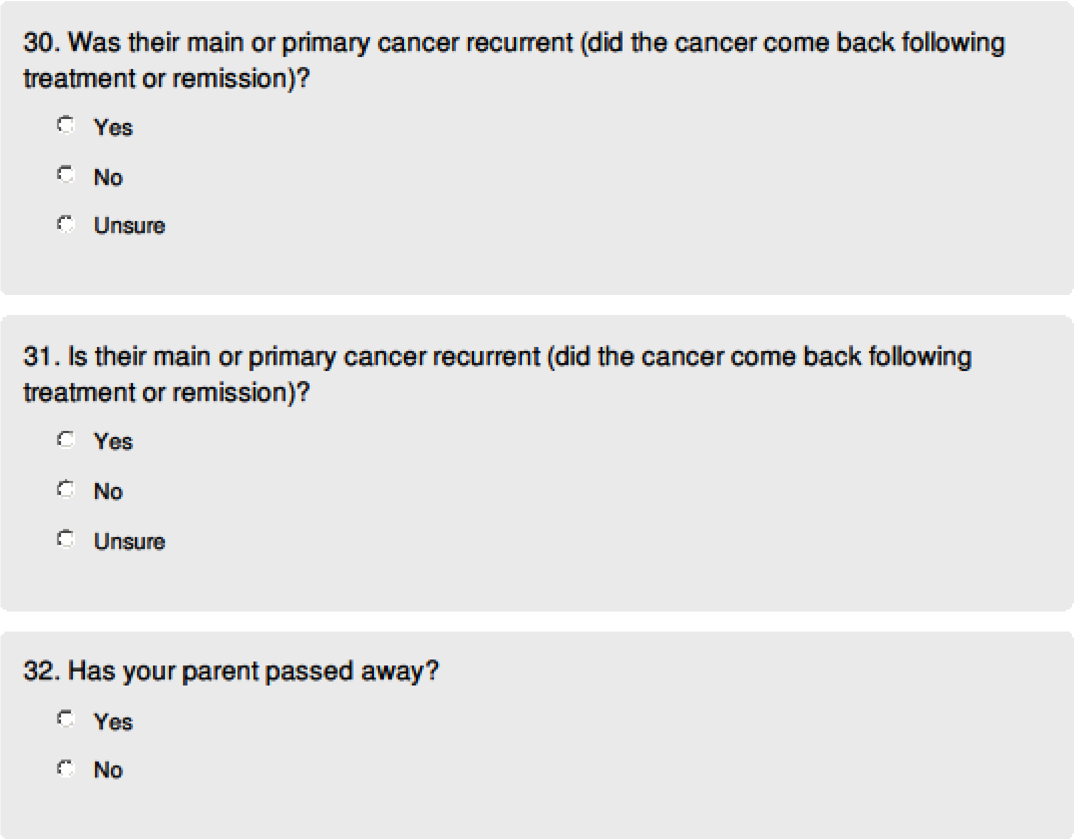


28. I could openly talk with my parent about their cancer

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
○	○	○	○	○

29. I can openly talk with my parent about their cancer

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
○	○	○	○	○



30. Was their main or primary cancer recurrent (did the cancer come back following treatment or remission)?

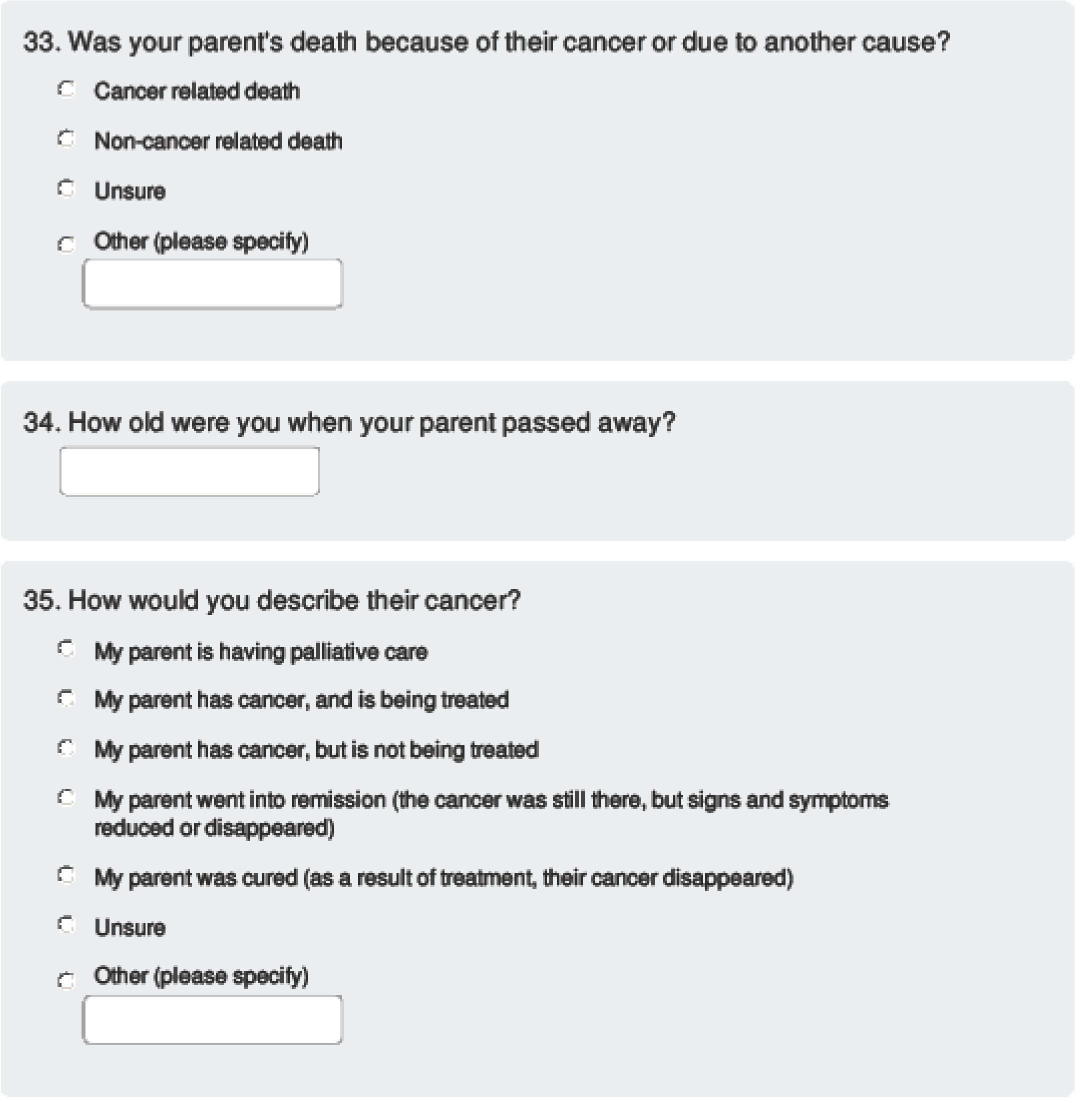
○ Yes
○ No
○ Unsure

31. Is their main or primary cancer recurrent (did the cancer come back following treatment or remission)?

○ Yes
○ No
○ Unsure

32. Has your parent passed away?

○ Yes
○ No



33. Was your parent's death because of their cancer or due to another cause?

○ Cancer related death

○ Non-cancer related death

○ Unsure

○ Other (please specify)

34. How old were you when your parent passed away?

35. How would you describe their cancer?

○ My parent is having palliative care

○ My parent has cancer, and is being treated

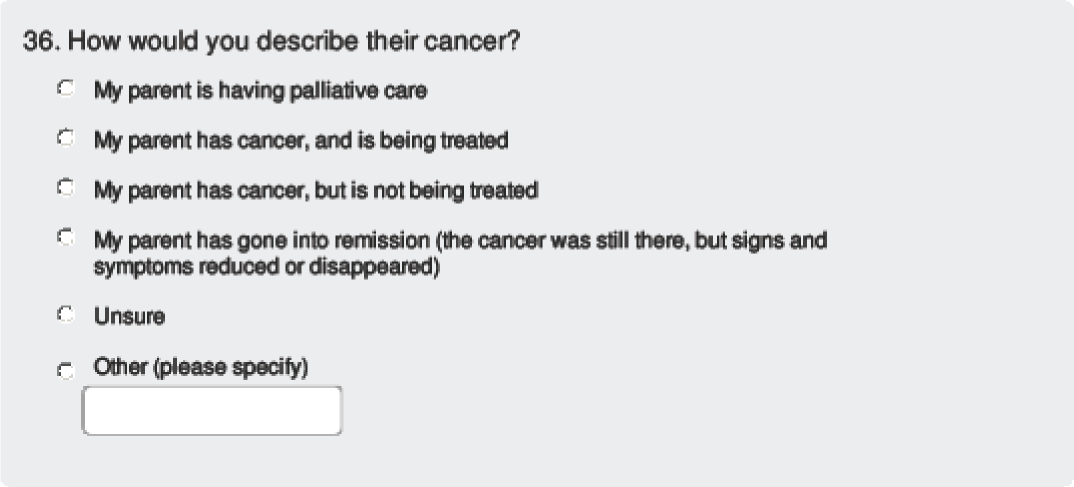
○ My parent has cancer, but is not being treated

○ My parent went into remission (the cancer was still there, but signs and symptoms reduced or disappeared)

○ My parent was cured (as a result of treatment, their cancer disappeared)

○ Unsure

○ Other (please specify)



36. How would you describe their cancer?

○ My parent is having palliative care

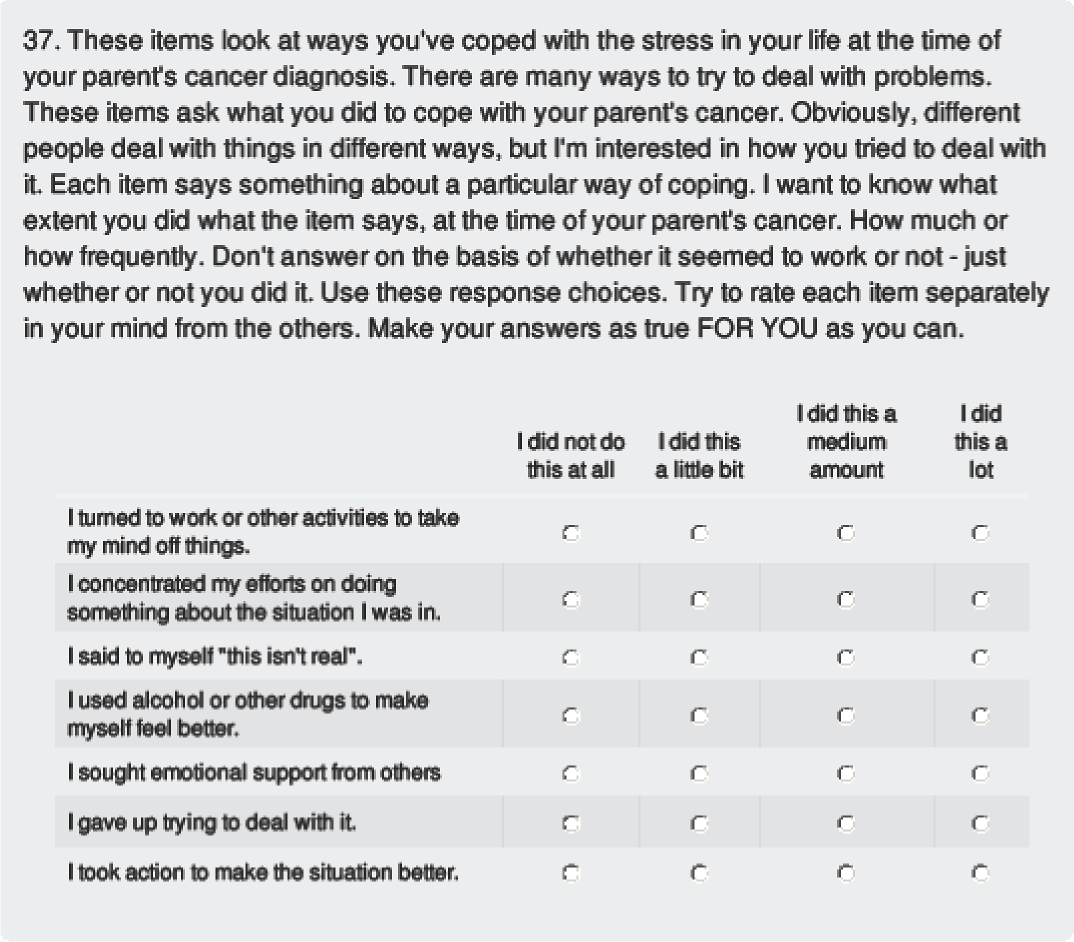
○ My parent has cancer, and is being treated

○ My parent has cancer, but is not being treated

○ My parent has gone into remission (the cancer was still there, but signs and symptoms reduced or disappeared)

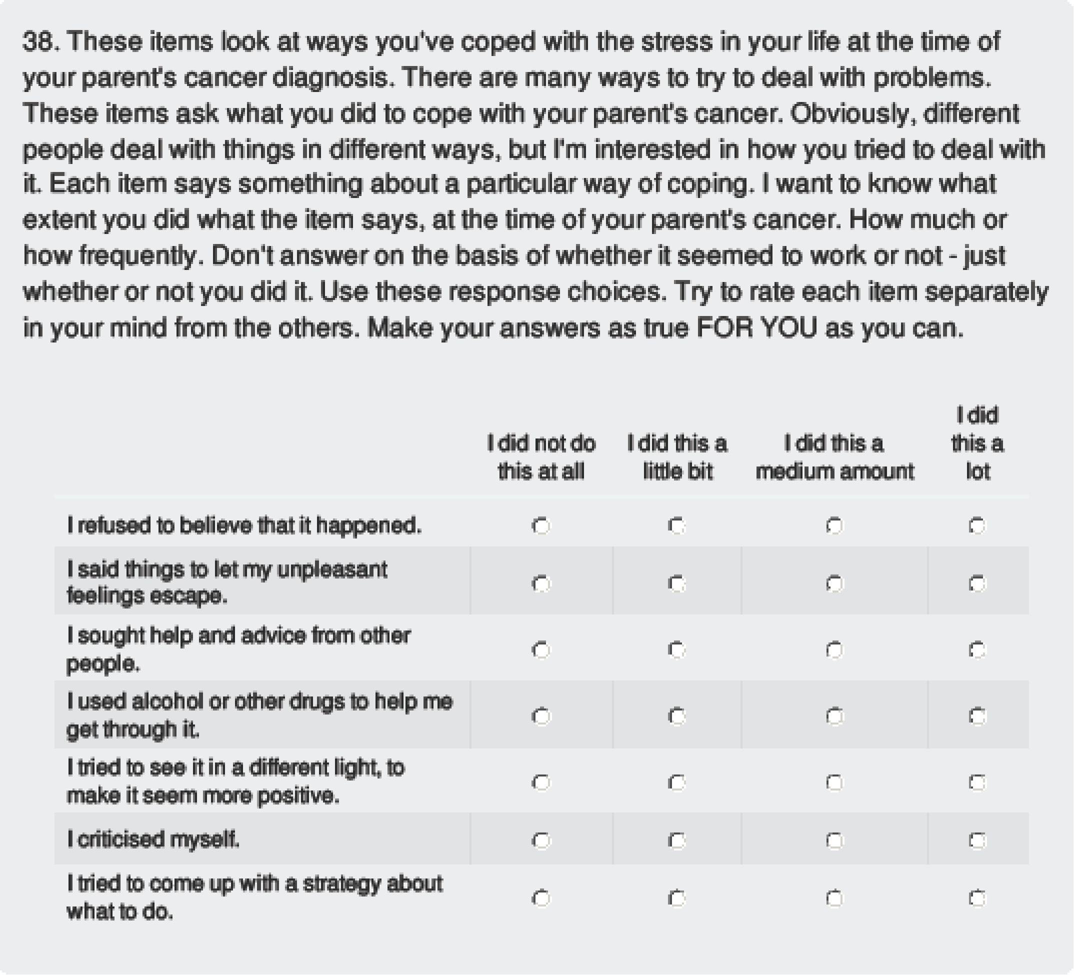
○ Unsure

○ Other (please specify)



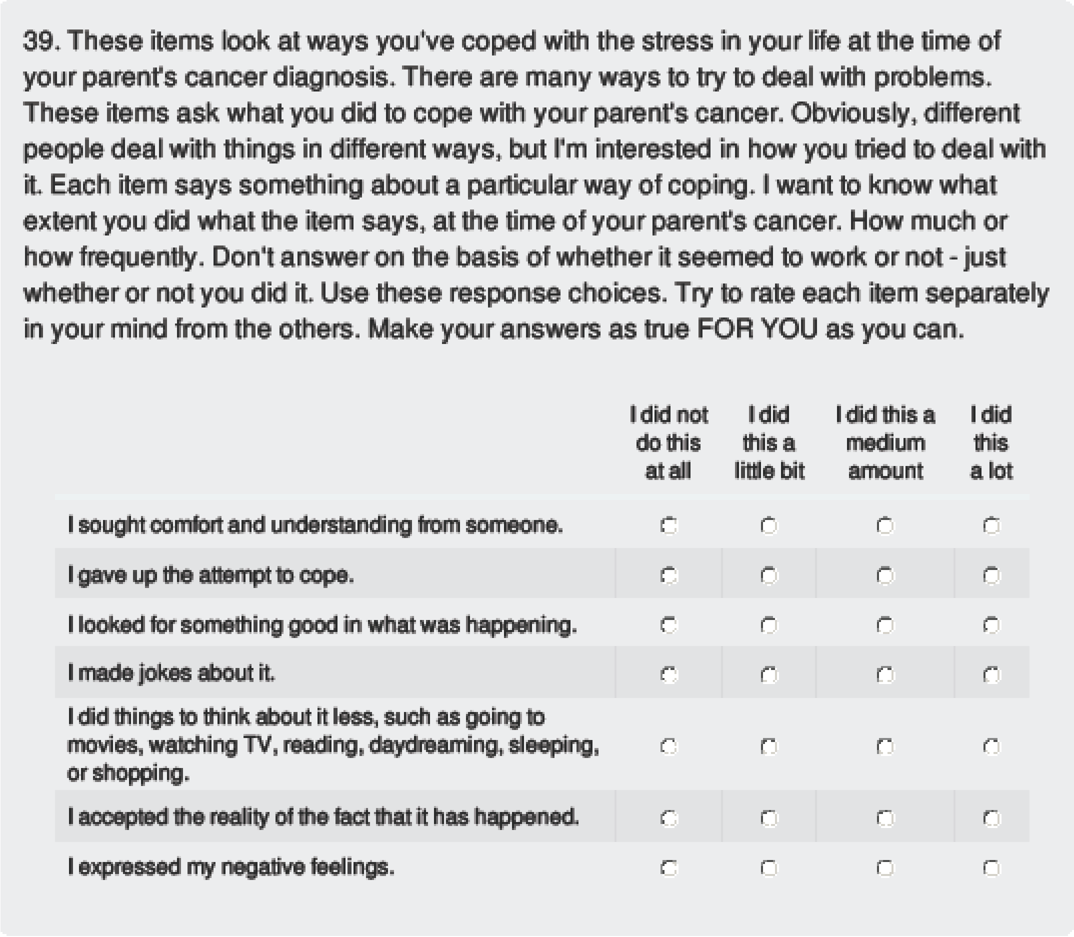
37. These items look at ways you've coped with the stress in your life at the time of your parent's cancer diagnosis. There are many ways to try to deal with problems. These items ask what you did to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you tried to deal with it. Each item says something about a particular way of coping. I want to know what extent you did what the item says, at the time of your parent's cancer. How much or how frequently. Don't answer on the basis of whether it seemed to work or not - just whether or not you did it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I did not do this at all	I did this a little bit	I did this a medium amount	I did this a lot
I turned to work or other activities to take my mind off things.	○	○	○	○
I concentrated my efforts on doing something about the situation I was in.	○	○	○	○
I said to myself "this isn't real".	○	○	○	○
I used alcohol or other drugs to make myself feel better.	○	○	○	○
I sought emotional support from others	○	○	○	○
I gave up trying to deal with it.	○	○	○	○
I took action to make the situation better.	○	○	○	○



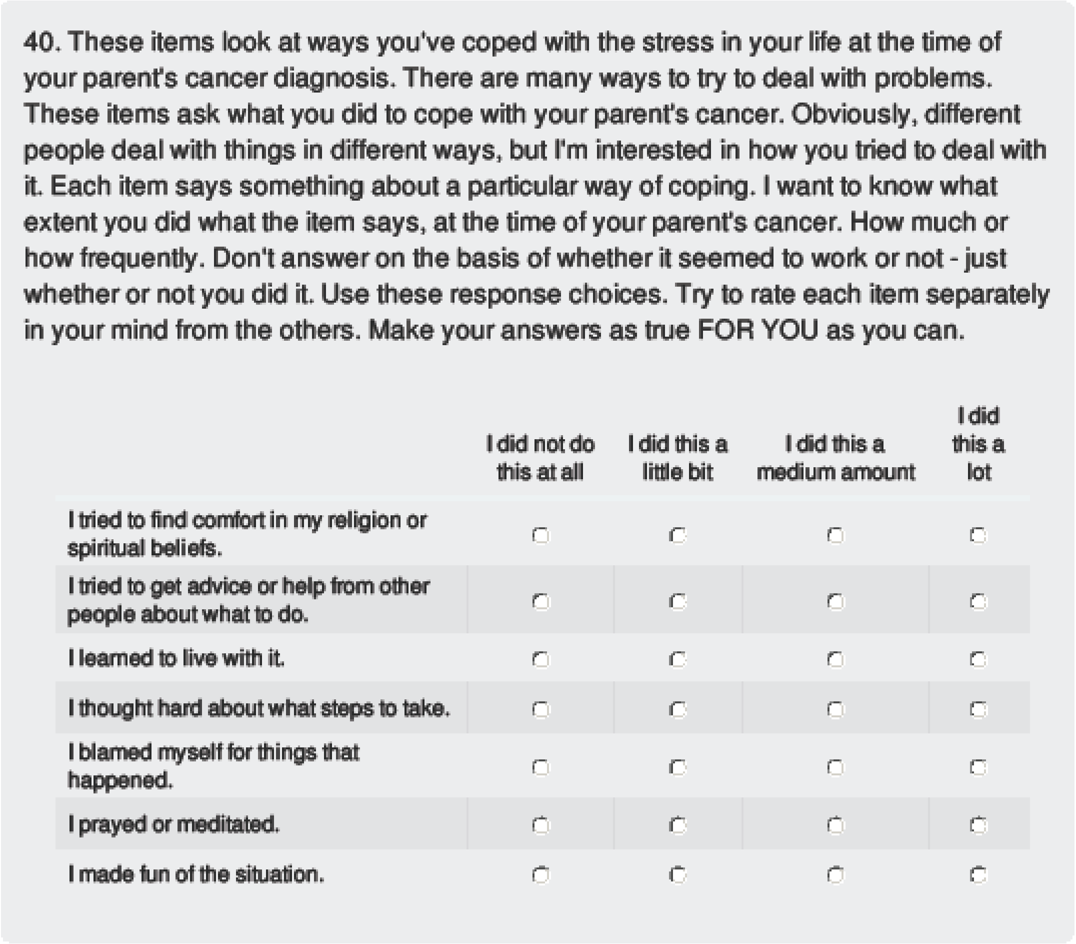
38. These items look at ways you've coped with the stress in your life at the time of your parent's cancer diagnosis. There are many ways to try to deal with problems. These items ask what you did to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you tried to deal with it. Each item says something about a particular way of coping. I want to know what extent you did what the item says, at the time of your parent's cancer. How much or how frequently. Don't answer on the basis of whether it seemed to work or not - just whether or not you did it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I did not do this at all	I did this a little bit	I did this a medium amount	I did this a lot
I refused to believe that it happened.	○	○	○	○
I said things to let my unpleasant feelings escape.	○	○	○	○
I sought help and advice from other people.	○	○	○	○
I used alcohol or other drugs to help me get through it.	○	○	○	○
I tried to see it in a different light, to make it seem more positive.	○	○	○	○
I criticised myself.	○	○	○	○
I tried to come up with a strategy about what to do.	○	○	○	○



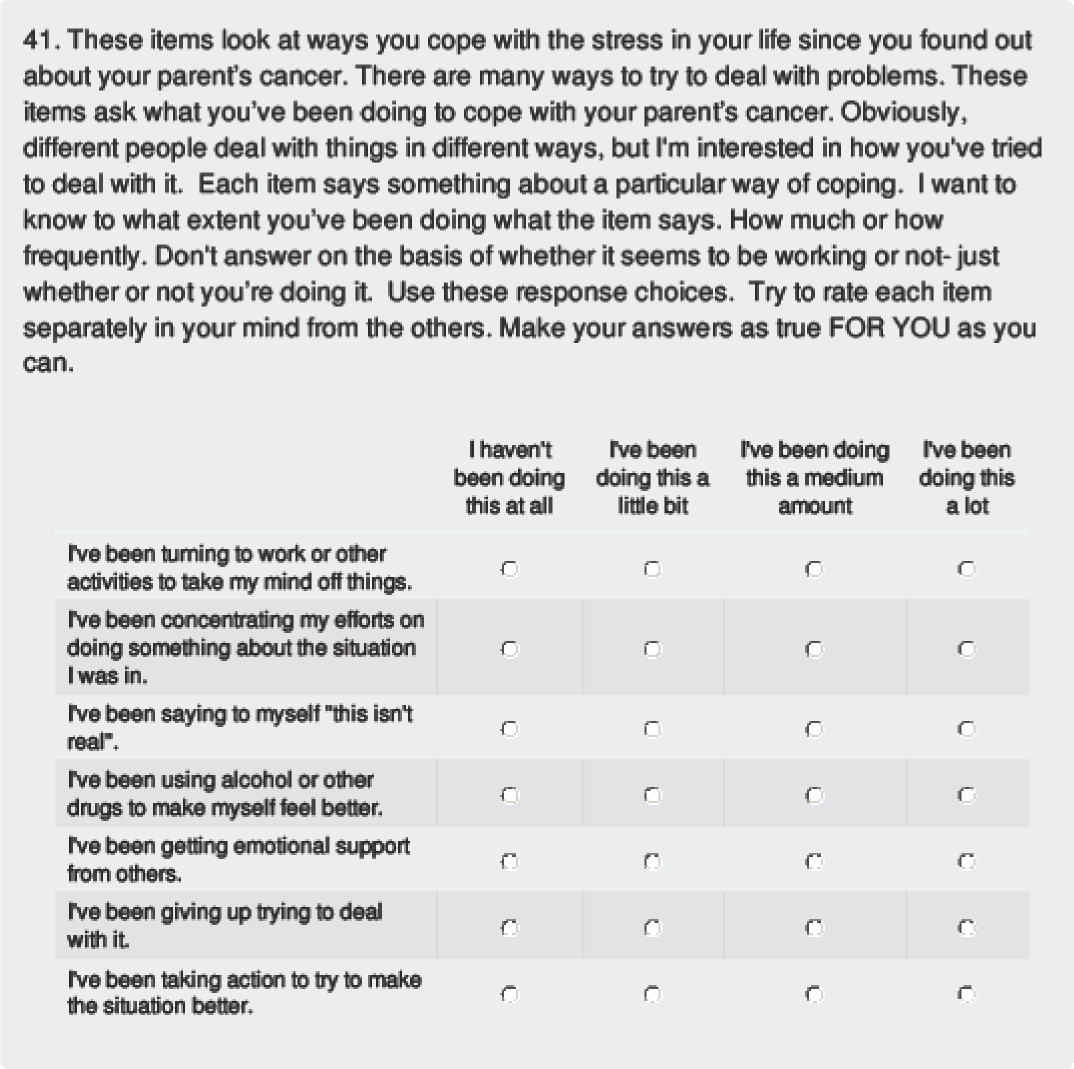
39. These items look at ways you've coped with the stress in your life at the time of your parent's cancer diagnosis. There are many ways to try to deal with problems. These items ask what you did to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you tried to deal with it. Each item says something about a particular way of coping. I want to know what extent you did what the item says, at the time of your parent's cancer. How much or how frequently. Don't answer on the basis of whether it seemed to work or not - just whether or not you did it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I did not do this at all	I did this a little bit	I did this a medium amount	I did this a lot
I sought comfort and understanding from someone.	○	○	○	○
I gave up the attempt to cope.	○	○	○	○
I looked for something good in what was happening.	○	○	○	○
I made jokes about it.	○	○	○	○
I did things to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	○	○	○	○
I accepted the reality of the fact that it has happened.	○	○	○	○
I expressed my negative feelings.	○	○	○	○



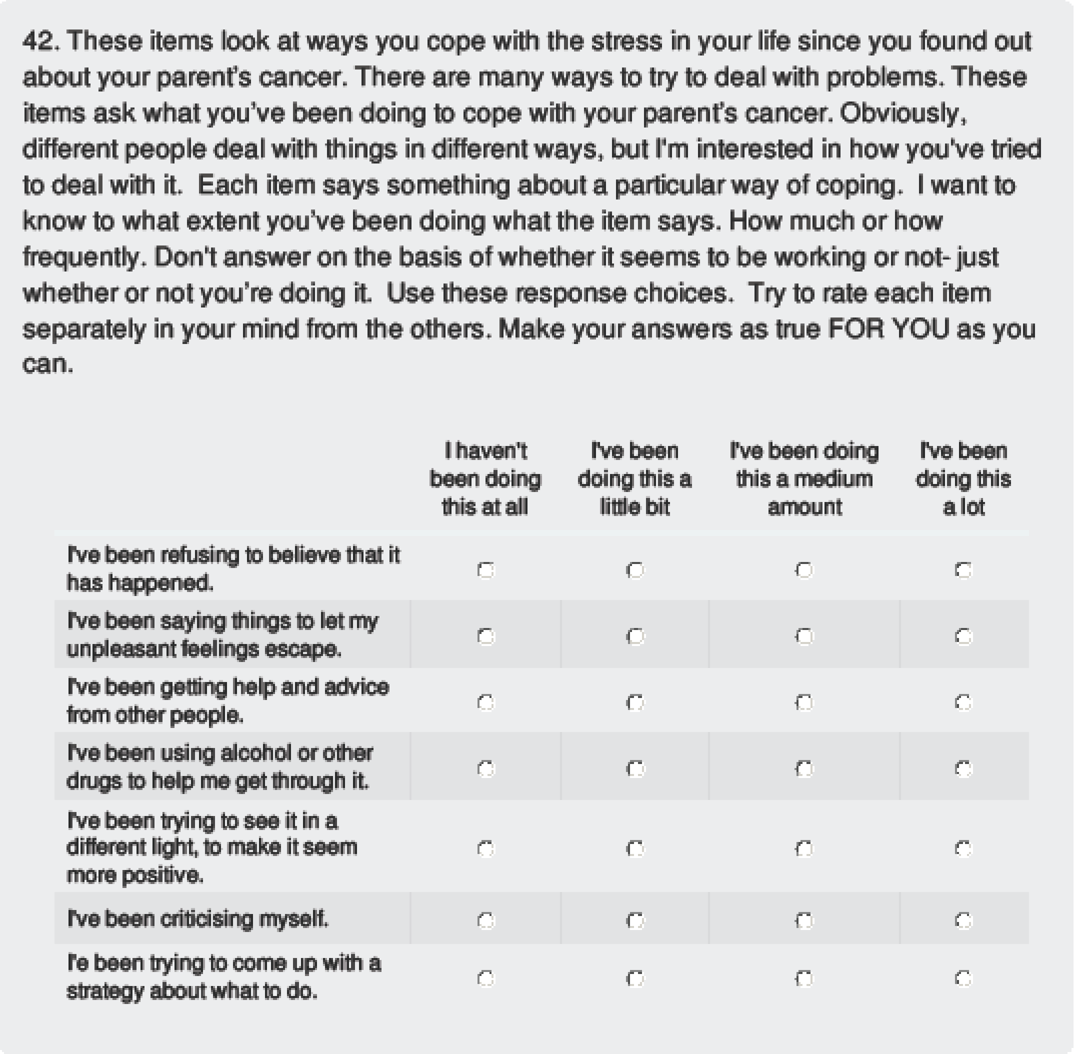
40. These items look at ways you've coped with the stress in your life at the time of your parent's cancer diagnosis. There are many ways to try to deal with problems. These items ask what you did to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you tried to deal with it. Each item says something about a particular way of coping. I want to know what extent you did what the item says, at the time of your parent's cancer. How much or how frequently. Don't answer on the basis of whether it seemed to work or not - just whether or not you did it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I did not do this at all	I did this a little bit	I did this a medium amount	I did this a lot
I tried to find comfort in my religion or spiritual beliefs.	○	○	○	○
I tried to get advice or help from other people about what to do.	○	○	○	○
I learned to live with it.	○	○	○	○
I thought hard about what steps to take.	○	○	○	○
I blamed myself for things that happened.	○	○	○	○
I prayed or meditated.	○	○	○	○
I made fun of the situation.	○	○	○	○



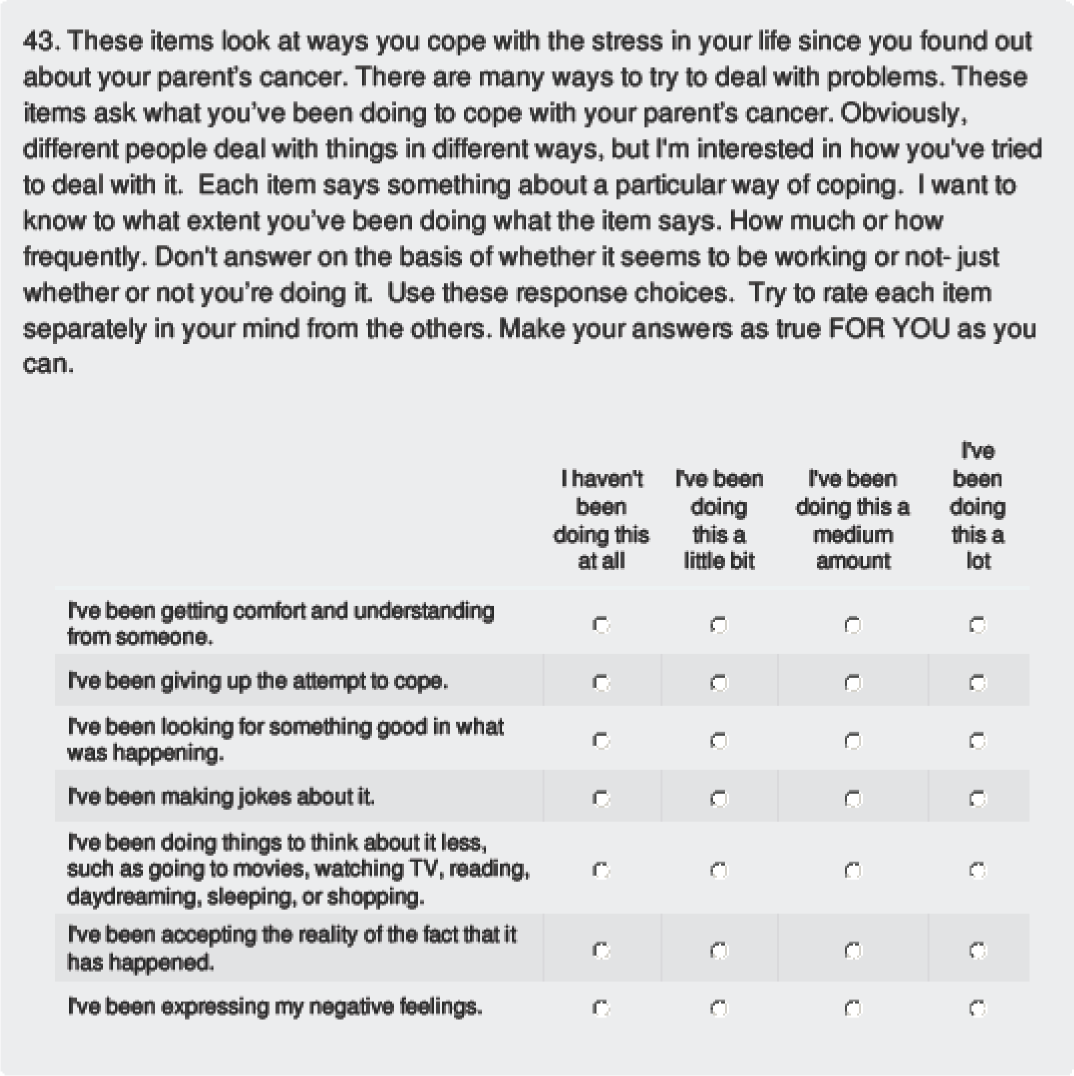
41. These items look at ways you cope with the stress in your life since you found out about your parent's cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.	○	○	○	○
I've been concentrating my efforts on doing something about the situation I was in.	○	○	○	○
I've been saying to myself "this isn't real".	○	○	○	○
I've been using alcohol or other drugs to make myself feel better.	○	○	○	○
I've been getting emotional support from others.	○	○	○	○
I've been giving up trying to deal with it.	○	○	○	○
I've been taking action to try to make the situation better.	○	○	○	○



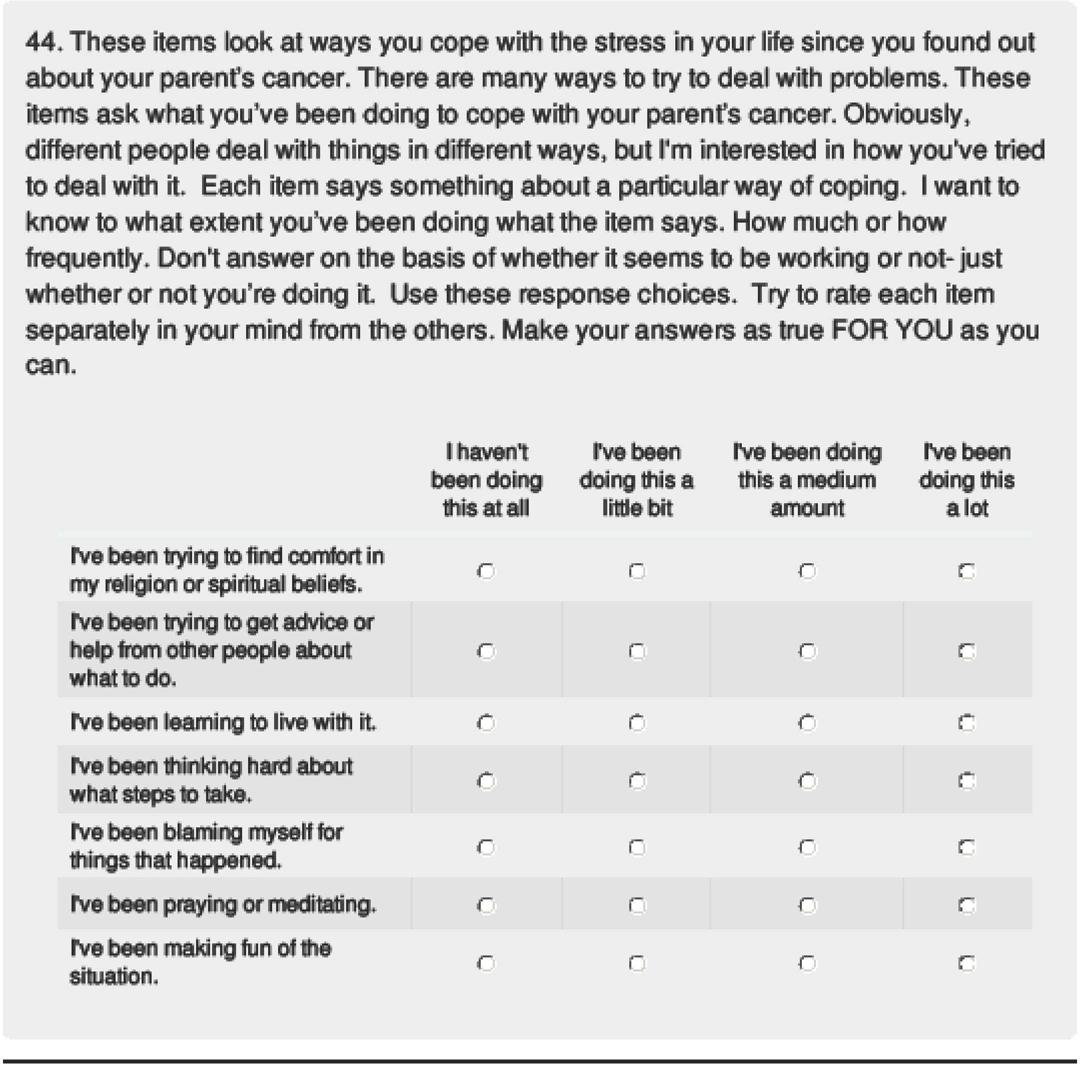
42. These items look at ways you cope with the stress in your life since you found out about your parent's cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been refusing to believe that it has happened.	○	○	○	○
I've been saying things to let my unpleasant feelings escape.	○	○	○	○
I've been getting help and advice from other people.	○	○	○	○
I've been using alcohol or other drugs to help me get through it.	○	○	○	○
I've been trying to see it in a different light, to make it seem more positive.	○	○	○	○
I've been criticising myself.	○	○	○	○
I'e been trying to come up with a strategy about what to do.	○	○	○	○



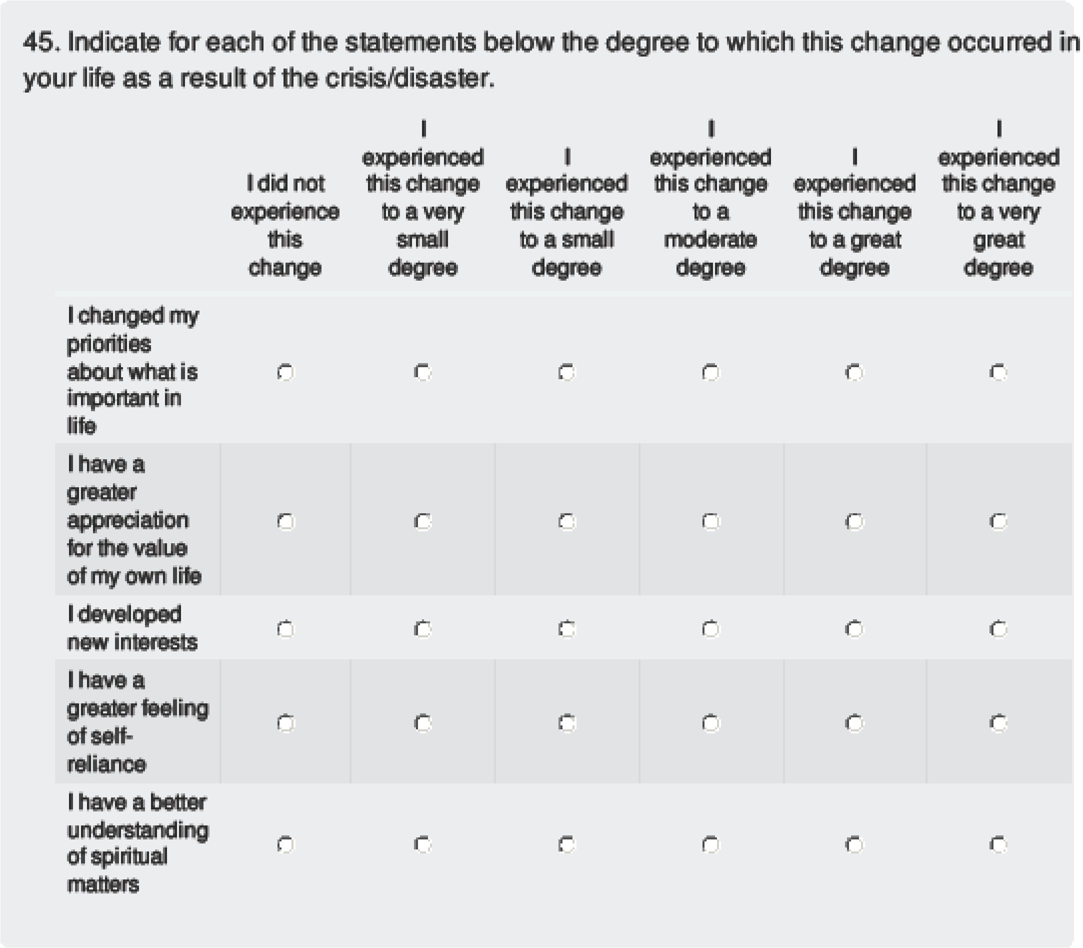
43. These items look at ways you cope with the stress in your life since you found out about your parent's cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been getting comfort and understanding from someone.	○	○	○	○
I've been giving up the attempt to cope.	○	○	○	○
I've been looking for something good in what was happening.	○	○	○	○
I've been making jokes about it.	○	○	○	○
I've been doing things to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	○	○	○	○
I've been accepting the reality of the fact that it has happened.	○	○	○	○
I've been expressing my negative feelings.	○	○	○	○



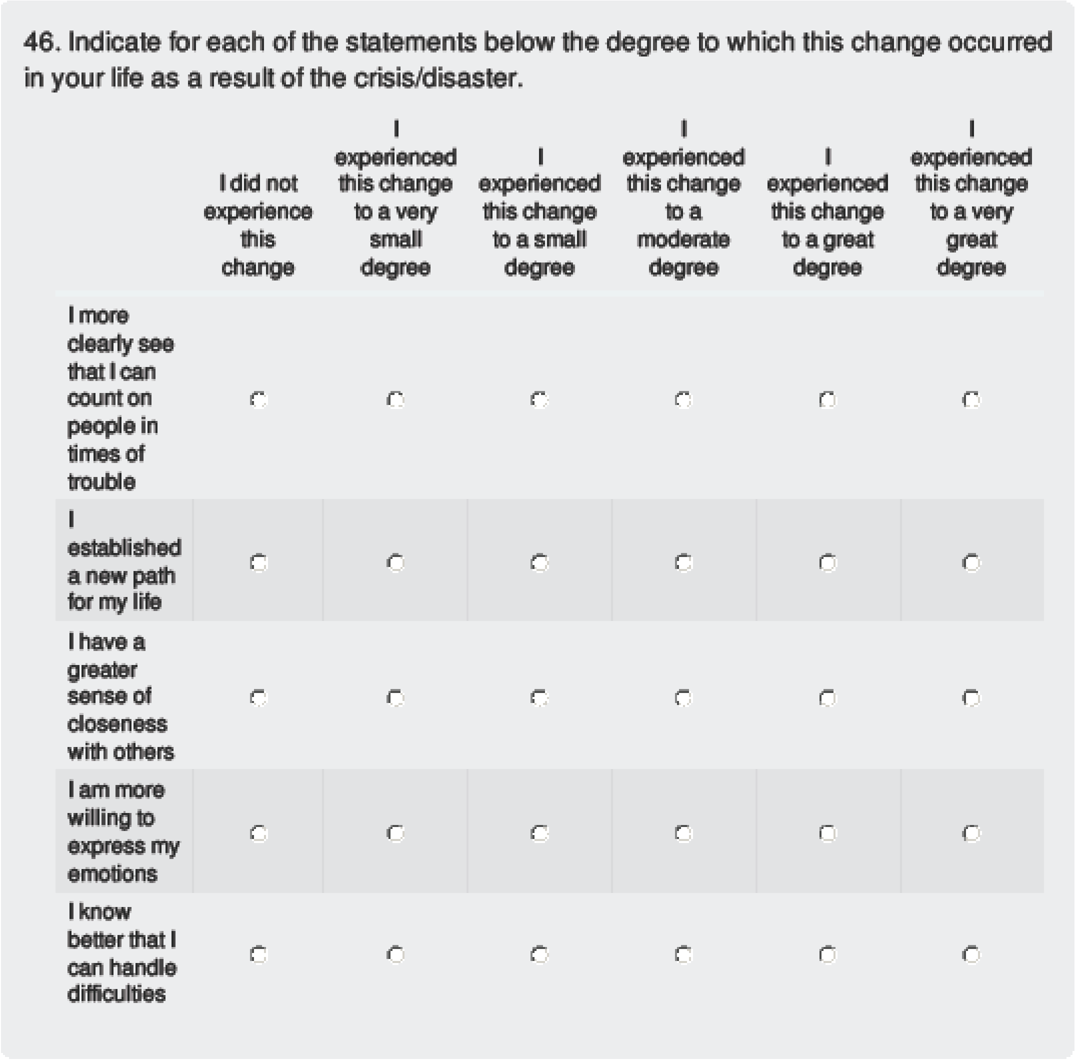
44. These items look at ways you cope with the stress in your life since you found out about your parent's cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with your parent's cancer. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been trying to find comfort in my religion or spiritual beliefs.	○	○	○	○
I've been trying to get advice or help from other people about what to do.	○	○	○	○
I've been learning to live with it.	○	○	○	○
I've been thinking hard about what steps to take.	○	○	○	○
I've been blaming myself for things that happened.	○	○	○	○
I've been praying or meditating.	○	○	○	○
I've been making fun of the situation.	○	○	○	○



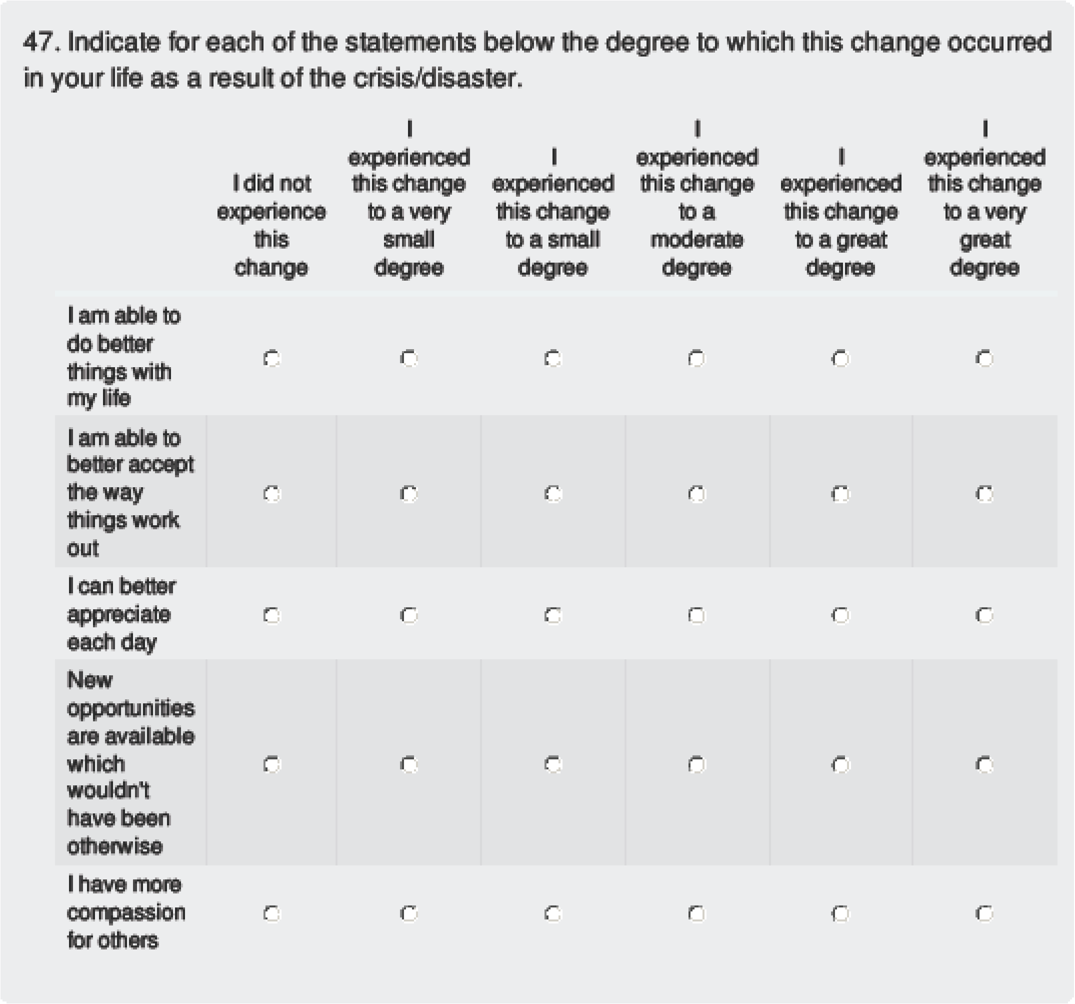
45. Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster.

	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I changed my priorities about what is important in life	○	○	○	○	○	○
I have a greater appreciation for the value of my own life	○	○	○	○	○	○
I developed new interests	○	○	○	○	○	○
I have a greater feeling of self-reliance	○	○	○	○	○	○
I have a better understanding of spiritual matters	○	○	○	○	○	○



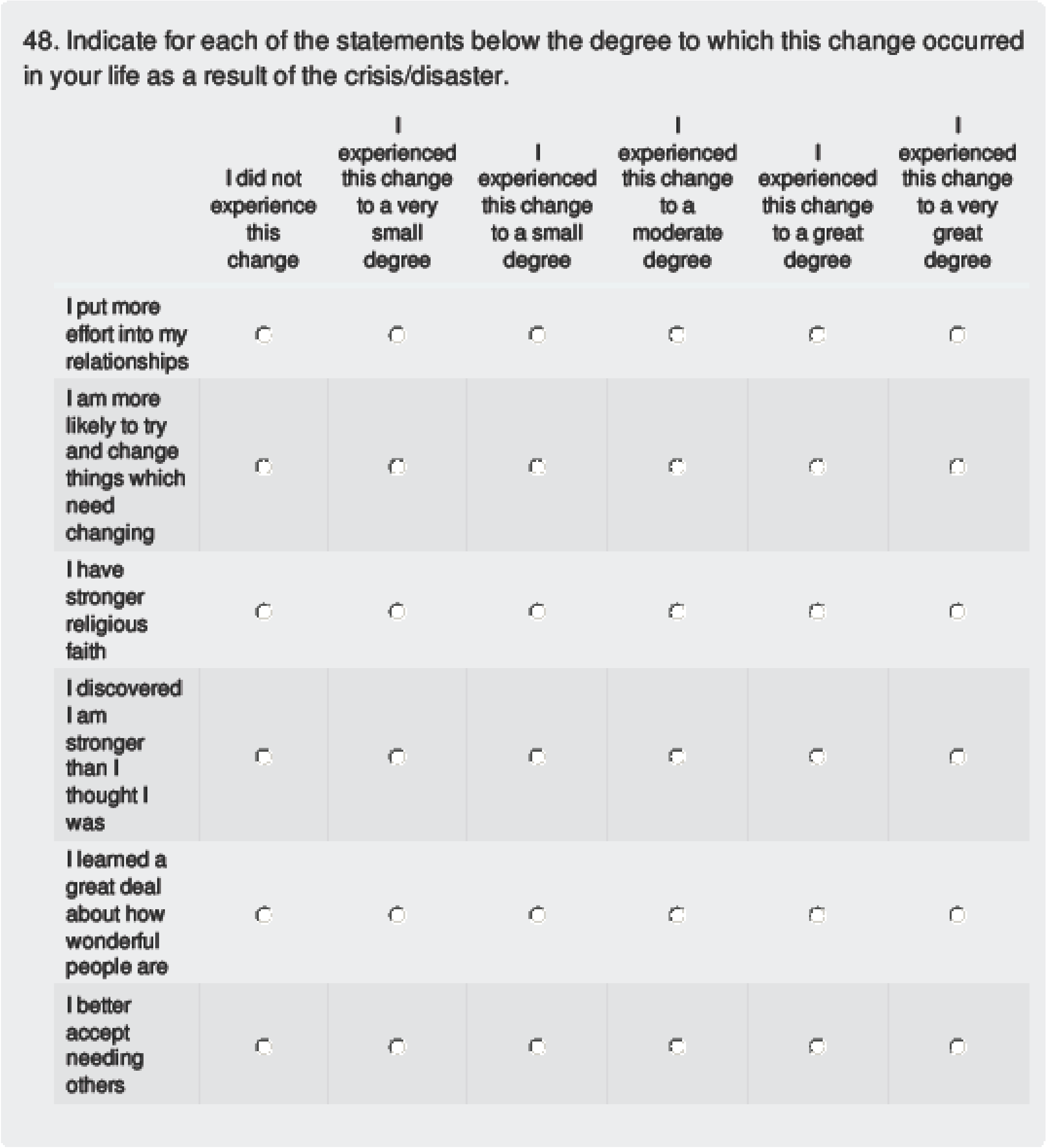
46. Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster.

	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I more clearly see that I can count on people in times of trouble	○	○	○	○	○	○
I established a new path for my life	○	○	○	○	○	○
I have a greater sense of closeness with others	○	○	○	○	○	○
I am more willing to express my emotions	○	○	○	○	○	○
I know better that I can handle difficulties	○	○	○	○	○	○



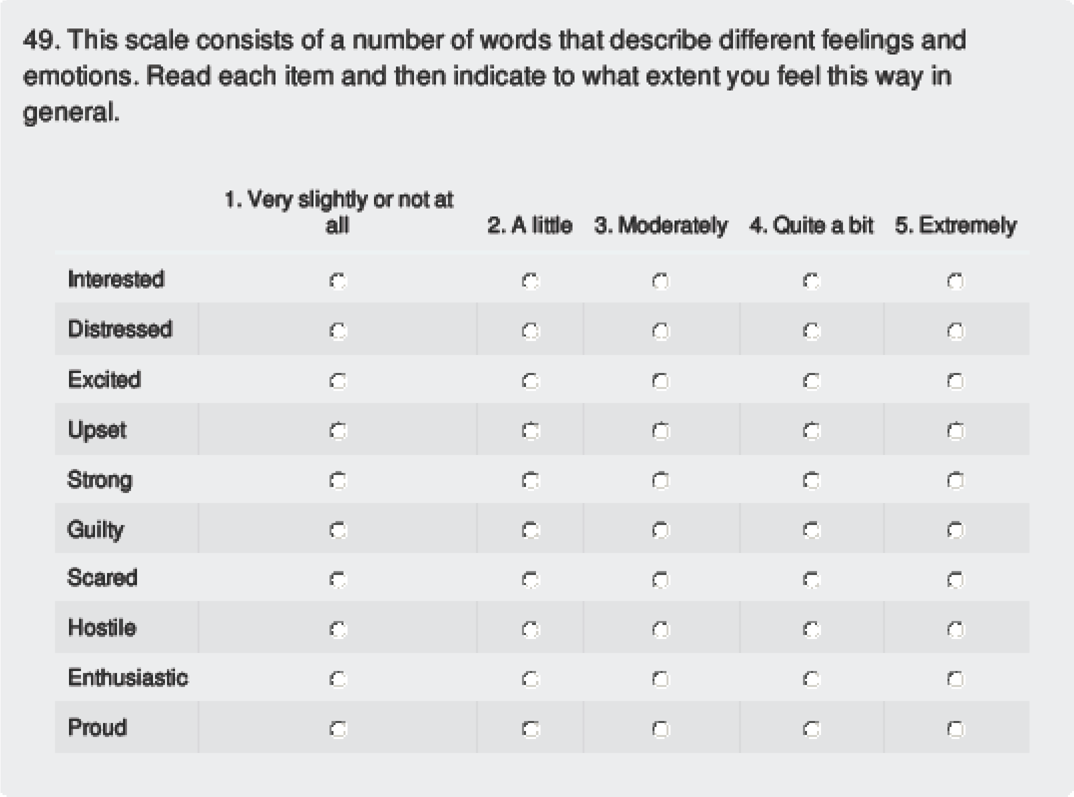
47. Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster.

	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I am able to do better things with my life	○	○	○	○	○	○
I am able to better accept the way things work out	○	○	○	○	○	○
I can better appreciate each day	○	○	○	○	○	○
New opportunities are available which wouldn't have been otherwise	○	○	○	○	○	○
I have more compassion for others	○	○	○	○	○	○



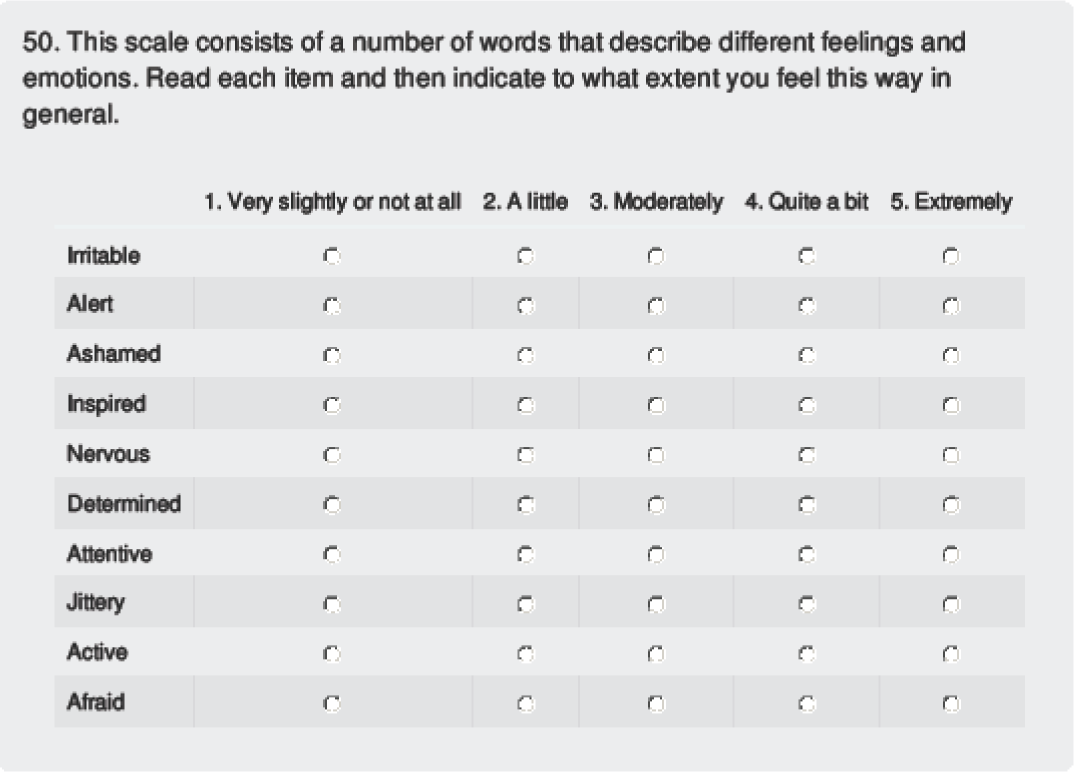
48. Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster.

	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I put more effort into my relationships	○	○	○	○	○	○
I am more likely to try and change things which need changing	○	○	○	○	○	○
I have stronger religious faith	○	○	○	○	○	○
I discovered I am stronger than I thought I was	○	○	○	○	○	○
I learned a great deal about how wonderful people are	○	○	○	○	○	○
I better accept needing others	○	○	○	○	○	○



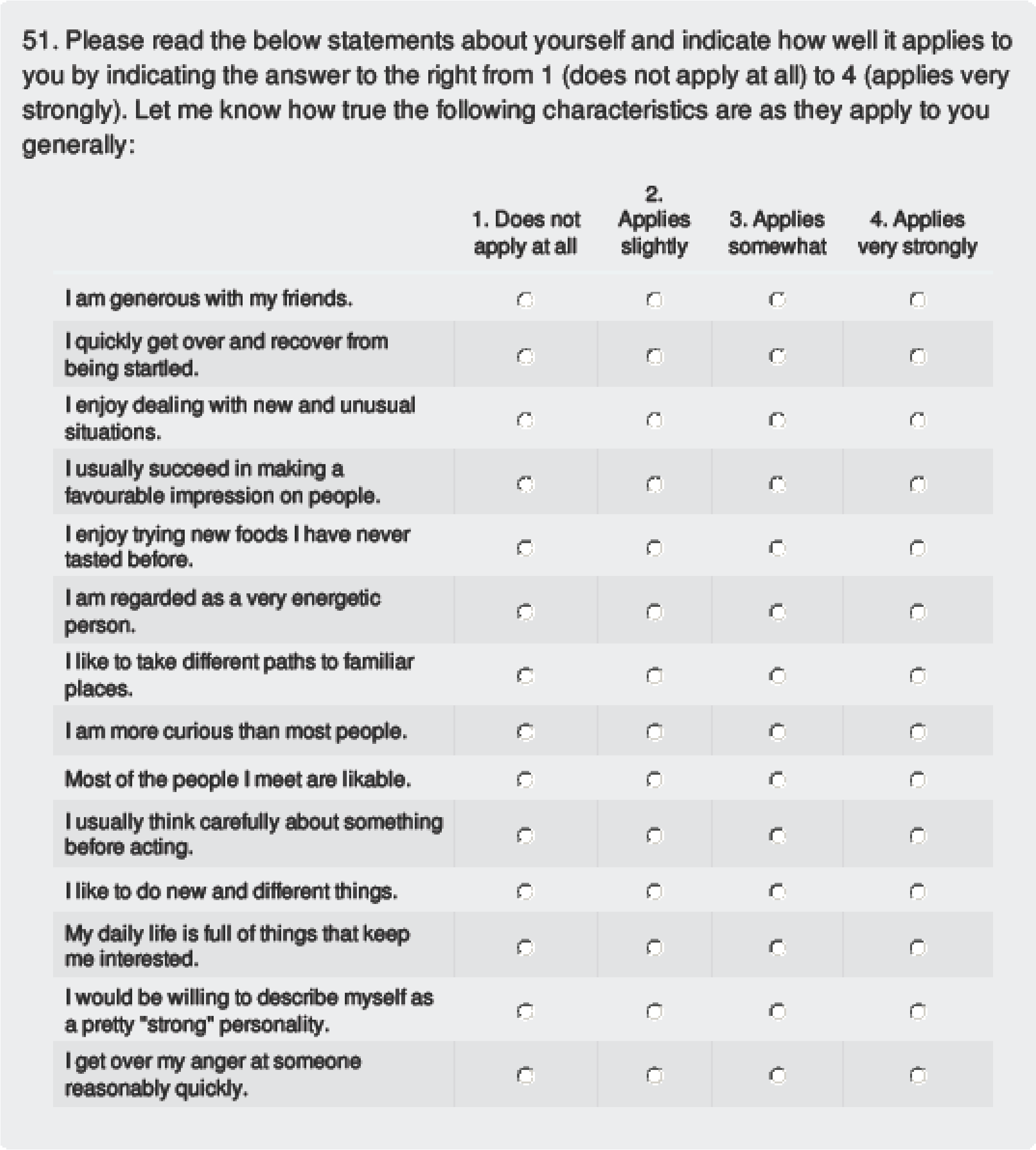
49. This scale consists of a number of words that describe different feelings and emotions. Read each item and then indicate to what extent you feel this way in general.

	1. Very slightly or not at all	2. A little	3. Moderately	4. Quite a bit	5. Extremely
Interested	○	○	○	○	○
Distressed	○	○	○	○	○
Excited	○	○	○	○	○
Upset	○	○	○	○	○
Strong	○	○	○	○	○
Guilty	○	○	○	○	○
Scared	○	○	○	○	○
Hostile	○	○	○	○	○
Enthusiastic	○	○	○	○	○
Proud	○	○	○	○	○



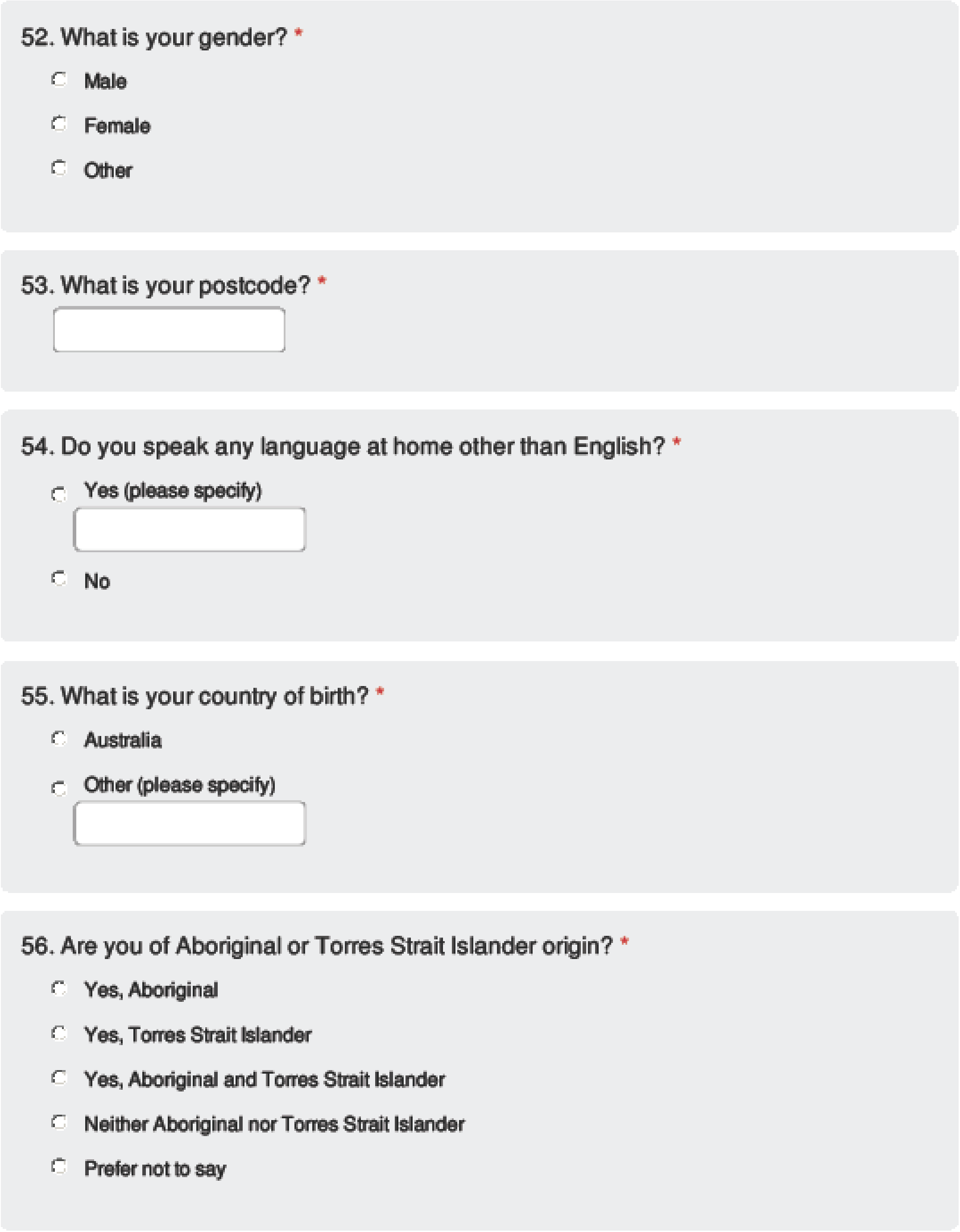
50. This scale consists of a number of words that describe different feelings and emotions. Read each item and then indicate to what extent you feel this way in general.

	1. Very slightly or not at all	2. A little	3. Moderately	4. Quite a bit	5. Extremely
Irritable	○	○	○	○	○
Alert	○	○	○	○	○
Ashamed	○	○	○	○	○
Inspired	○	○	○	○	○
Nervous	○	○	○	○	○
Determined	○	○	○	○	○
Attentive	○	○	○	○	○
Jittery	○	○	○	○	○
Active	○	○	○	○	○
Afraid	○	○	○	○	○



51. Please read the below statements about yourself and indicate how well it applies to you by indicating the answer to the right from 1 (does not apply at all) to 4 (applies very strongly). Let me know how true the following characteristics are as they apply to you generally:

	1. Does not apply at all	2. Applies slightly	3. Applies somewhat	4. Applies very strongly
I am generous with my friends.	○	○	○	○
I quickly get over and recover from being startled.	○	○	○	○
I enjoy dealing with new and unusual situations.	○	○	○	○
I usually succeed in making a favourable impression on people.	○	○	○	○
I enjoy trying new foods I have never tasted before.	○	○	○	○
I am regarded as a very energetic person.	○	○	○	○
I like to take different paths to familiar places.	○	○	○	○
I am more curious than most people.	○	○	○	○
Most of the people I meet are likable.	○	○	○	○
I usually think carefully about something before acting.	○	○	○	○
I like to do new and different things.	○	○	○	○
My daily life is full of things that keep me interested.	○	○	○	○
I would be willing to describe myself as a pretty "strong" personality.	○	○	○	○
I get over my anger at someone reasonably quickly.	○	○	○	○



52. What is your gender? *

- ○ Male
- ○ Female
- ○ Other

53. What is your postcode? *

☐

54. Do you speak any language at home other than English? *

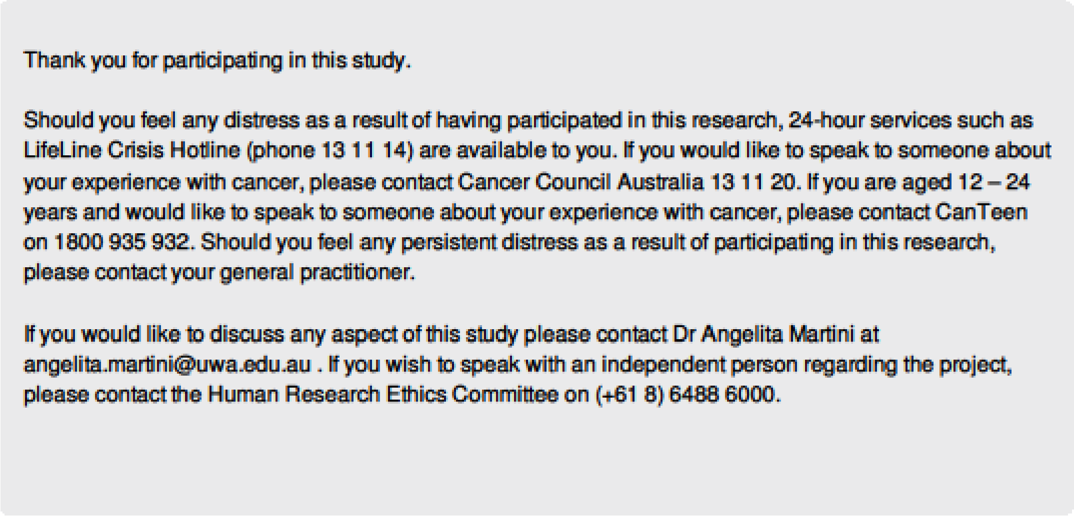
- ○ Yes (please specify) ☐
- ○ No

55. What is your country of birth? *

- ○ Australia
- ○ Other (please specify) ☐

56. Are you of Aboriginal or Torres Strait Islander origin? *

- ○ Yes, Aboriginal
- ○ Yes, Torres Strait Islander
- ○ Yes, Aboriginal and Torres Strait Islander
- ○ Neither Aboriginal nor Torres Strait Islander
- ○ Prefer not to say



Thank you for participating in this study.

Should you feel any distress as a result of having participated in this research, 24-hour services such as LifeLine Crisis Hotline (phone 13 11 14) are available to you. If you would like to speak to someone about your experience with cancer, please contact Cancer Council Australia 13 11 20. If you are aged 12 – 24 years and would like to speak to someone about your experience with cancer, please contact CanTeen on 1800 935 932. Should you feel any persistent distress as a result of participating in this research, please contact your general practitioner.

If you would like to discuss any aspect of this study please contact Dr Angelita Martini at angelita.martini@uwa.edu.au . If you wish to speak with an independent person regarding the project, please contact the Human Research Ethics Committee on (+61 8) 6488 6000.

APPENDIX D. STUDY 3 SURVEY STRUCTURE AND DISPLAY LOGIC

Section: Eligibility

Q1. Do you consent to participate	o Yes, I consent o No, I do not consent (disqualified)
Q2. What is your date of birth? (MMYYYY)	**_ _/_ _ _ _ (disqualified if <18)**
Q3. Which describes your parent's cancer?	o My parent currently has cancer **(moves to CURRENT CANCER questionnaire following Q4)** o My parent had cancer in the last 10 years **(moves to PAST CANCER questionnaire following Q4)**

Section: Dummy question

Q4: How did you hear about this survey?	o Facebook o Twitter o Email o Word of mouth o Other

Section: Cancer information

PAST CANCER		CURRENT CANCER	
Q5. Which of your parents had cancer in the last 10 years?	o Mum o Dad	Q5. Which of your parents has cancer?	o Mum o Dad

PAST AND CURRENT CANCER

Q6. How old were you when your parent was diagnosed?	○ XX years ○ Unsure				
	PAST CANCER		**CURRENT CANCER**		
Q7. How many years did your parent have cancer?	○ XX years ○ Unsure		Q7. How many years has your parent had cancer?	○ XX years ○ Unsure	
Q8. What was their main or primary cancer?	○ Anal ○ Bladder ○ Bone ○ Bowel ○ Brain ○ Breast ○ Cervical ○ Colon ○ Colorectal ○ Gallbladder ○ Head and neck	○ Mouth ○ Multiple Myeloma ○ Multiple primary ○ Non-Hodgkin lymphoma ○ Non-melanoma skin ○ Oesophageal	Q8. What is their main or primary cancer?	○ Anal ○ Bladder ○ Bone ○ Bowel ○ Brain ○ Breast ○ Cervical ○ Colon ○ Colorectal ○ Gallbladder	○ Mouth ○ Multiple Myeloma ○ Multiple primary ○ Non-Hodgkin lymphoma ○ Non-melanoma skin ○ Oesophageal ○ Other soft tissue ○ Ovarian ○ Pancreatic ○ Prostate

	o Hodgkin lymphoma o Kidney o Laryngeal o Lip o Liver o Leukaemia o Lung o Melanoma o Other soft tissue o Ovarian o Pancreatic o Prostate o Rectal o Stomach o Testicular o Thyroid o Tongue o Unknown primary o Uterine o Other (please specify_) o Unsure		o Head and neck o Hodgkin lymphoma o Kidney o Laryngeal o Lip o Liver o Leukaemia o Lung o Melanoma o Rectal o Stomach o Testicular o Thyroid o Tongue o Unknown primary o Uterine o Other (please specify_) o Unsure
Q9. How often did you worry about their disease?	o Never o Rarely o Sometimes o Often o All of the time	Q9. How often do you worry about their disease?	o Never o Rarely o Sometimes o Often o All of the time

Q10. What type of support (if any) did you use to help you with your parent's cancer? Select as many that apply.	o Bereavement support o Face-to-face support o Family program o Group support (e.g. peer groups, recreation days) o Hospital-based support o Information and resources o Online support (e.g. discussion forums, online counselling) o worry School based support o Telephone/video-conference support o Other (please specify_)	Q10. What type of support (if any) have you used to help you with your parent's cancer? Select as many that apply.	o Bereavement support o Face-to-face support o Family program o Group support (e.g. peer groups, recreation days) o Hospital-based support o Information and resources o Online support (e.g. discussion forums, online counselling) o worry School based support o Telephone/video-conference support o Other (please specify_)
Section: Family information			
PAST AND CURRENT CANCER			
Q11. Which of the following best describes you?	o Firstborn child o Middle child o Youngest child o Only child		
PAST CANCER		**CURRENT CANCER**	

Q12. Did you live with your parent whilst they had cancer?	o Yes, full time o Yes, part time o No, I did not live with my parent **(moves to Q14)**	Q12. Do you live with your parent who has cancer?	o Yes, full time o Yes, part time o No, I do not live with my parent **(moves to Q14)**
Q13. Who else lived with you and your parent during your parent's cancer? Select as many that apply	o No one else, only my parent and I o Sibling(s) o Other parent o Parent's partner o Other family member o Other (please specify_)	Q13. Who else lives with you and your parent who has cancer? Select as many that apply	o No one else, only my parent and I o Sibling(s) o Other parent o Parent's partner o Other family member o Other (please specify_)
PAST AND CURRENT CANCER			
Q14. What was your parent's marital status at the time of their cancer diagnosis?	o Married/in a de-facto relationship o Never married o Separated o Widowed o Divorced		
PAST CANCER		**CURRENT CANCER**	
Q15. Did your parent's marital status change over the course of their cancer?	o Yes o No **(moves to Q18)** o Unsure **(moves to Q18)**	Q15. Has your parent's marital status change over the course of their cancer	o Yes o No **(moves to Q18)** o Unsure **(moves to Q18)**

Q16. Was the change in your parent’s marital status because of their cancer?	o Yes o No **(moves to Q18)** o Unsure	Q16. Is the change in your parent’s marital status because of their cancer?	o Yes o No **(moves to Q18)** o Unsure
Q17. Please describe how your parent’s marital status changed over the course of their cancer:	o (open ended answer)	Q17. Please describe how your parent’s marital status has changed over the course of their cancer:	o (open ended answer)
Section: Relationship with parent			
PAST CANCER		**CURRENT CANCER**	
Q18. Is your parent who had cancer your biological parent, adoptive parent, or step-parent?	o They are my biological parent o They are my adoptive parent o They are my step-parent	Q18. Is your parent who has cancer your biological parent, adoptive parent, or step-parent?	o They are my biological parent o They are my adoptive parent o They are my step-parent
Q19. How often did you typically see your parent during the course of their cancer?	o At least once a week o At least fortnightly or monthly o At least once a year o Less than once a year or never	Q19. How often do you typically see your parent who has cancer?	o At least once a week o At least fortnightly or monthly o At least once a year o Less than once a year or never

Q20. I could openly talk with my parent about their cancer	o Strongly agree o Somewhat agree o Neither agree nor disagree o Somewhat disagree o Strongly disagree	Q20. I can openly talk with my parent about their cancer	o Strongly agree o Somewhat agree o Neither agree nor disagree o Somewhat disagree o Strongly disagree
Section: Cancer information part 2			
PAST CANCER		**CURRENT CANCER**	
Q21. Was their cancer recurrent? (did the cancer come back following treatment or remission)	o Yes o No o Unsure	Q21. Is their cancer recurrent? (did the cancer come back following treatment or remission)	o Yes **(moves to Q25)** o No **(moves to Q25)** o Unsure **(moves to Q25)**
PAST CANCER			
Q22. Has your parent passed away?	o Yes o No **(moves to Q25)**		
Q23. Was your parent's death because of their cancer or due to another cause?	o Cancer related death o Non-cancer related death **(moves to Brief COPE)** o Unsure **(moves to Brief COPE)** o Other (please specify_) **(moves to Brief COPE)**		

Q24. How old were you when your parent passed away?	o XX (moves to Brief COPE)		
PAST CANCER		**CURRENT CANCER**	
Q25. How would you describe their cancer?	o My parent is having palliative care o My parent has cancer, and is being treated o My parent has cancer, but is not being treated o My parent went into remission (the cancer was still there, but signs and symptoms reduced or disappeared) o My parent was cured (as a result of treatment, their cancer disappeared) o Other (please specify _) o Unsure	Q25. How would you describe their cancer?	o My parent is having palliative care o My parent has cancer, and is being treated o My parent has cancer, but is not being treated o My parent has gone into remission (the cancer was still there, but signs and symptoms reduced or disappeared) o Other (please specify _) o Unsure
Section: Brief COPE			
PAST CANCER		**CURRENT CANCER**	
These items look at ways you've coped with the stress in your life at the time of your parent's cancer diagnosis. There are many ways to		These items look at ways you cope with the stress in your life since you found out about your parent's cancer. There are many	

try to deal with problems. These items ask what you did to cope with your parent’s cancer. Obviously, different people deal with things in different ways, but I'm interested in how you tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you did what the item says, at the time of your parent’s cancer. How much or how frequently. Don't answer on the basis of whether it seemed to work or not—just whether or not you did it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1= I did not do this at all
2= I did this a little bit
3= I did this a medium amount
4= I did this a lot

----

1. I turned to work or other activities to take my mind off things.
2. I concentrated my efforts on doing something about the situation I was in

ways to try to deal with problems. These items ask what you’ve been doing to cope with your parent’s cancer. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you’ve been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you’re doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1= I haven’t been doing this at all
2= I’ve been doing this a little bit
3= I’ve been doing this a medium amount
4= I’ve been doing this a lot

----

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.

3. I said to myself "this isn't real".
4. I used alcohol or other drugs to make myself feel better.
5. I sought emotional support from others.
6. I gave up trying to deal with it.
7. I took action to try to make the situation better.
8. I refused to believe that it had happened.
9. I said things to let my unpleasant feelings escape.
10. I sought help and advice from other people.
11. I used alcohol or other drugs to help me get through it.
12. I tried to see it in a different light, to make it seem more positive.
13. I criticised myself.
14. I tried to come up with a strategy about what to do.
15. I sought comfort and understanding from someone.
16. I gave up the attempt to cope.
17. I looked for something good in what was happening.
18. I made jokes about it.
19. I did things to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I accepted the reality of the fact that it has happened.

3. I've been saying to myself "this isn't real.".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I’ve been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I’ve been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.

21. I expressed my negative feelings.
22. I tried to find comfort in my religion or spiritual beliefs.
23. I tried to get advice or help from other people about what to do.
24. I learned to live with it.
25. I thought hard about what steps to take.
26. I blamed myself for things that happened.
27. I prayed or meditated.
28. I made fun of the situation.

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I’ve been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I’ve been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Section: PTGI

PAST AND CURRENT CANCER

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.

0 = I did not experience this change as a result of my crisis.

1 = I experienced this change to a very small degree as a result of my crisis.

2 = I experienced this change to a small degree as a result of my crisis.

3 = I experienced this change to a moderate degree as a result of my crisis.

4 = I experienced this change to a great degree as a result of my crisis.

5 = I experienced this change to a very great degree as a result of my crisis.

Possible Areas of Growth and Change

1. I changed my priorities about what is important in life
2. I have a greater appreciation for the value of my own life
3. I developed new interests
4. I have a greater feeling of self-reliance
5. I have a better understanding of spiritual matters
6. I more clearly see that I can count on people in times of trouble
7. I established a new path for my life.
8. I have a greater sense of closeness with others
9. I am more willing to express my emotions
10. I know better that I can handle difficulties
11. I am able to do better things with my life
12. I am able to better accept the way things work out
13. I can better appreciate each day
14. New opportunities are available which wouldn’t have been otherwise.

15. I have more compassion for others
16. I put more effort into my relationships
17. I am more likely to try and change things which need changing
18. I have stronger religious faith
19. I discovered I am stronger than I thought I was
20. I learned a great deal about how wonderful people are
21. I better accept needing others

Section: PANAS

PAST AND CURRENT CANCER

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. Indicate to what extent you have felt this way over the past week.

1. Very slightly or not at all
2. a little
3. Moderately
4. Quite a bit
5. Extremely

___________ 1. Interested

___________ 2. Distressed

___________ 3. Excited

___________ 11. Irritable

___________ 12. Alert

___________ 13. Ashamed

___________ 4. Upset

___________ 5. Strong

___________ 6. Guilty

___________ 7. Scared

___________ 8. Hostile

___________ 9. Enthusiastic

___________ 10. Proud

___________ 14. Inspired

___________ 15. Nervous

___________ 16. Determined

___________ 17. Attentive

___________ 18. Jittery

___________ 19. Active

___________ 20. Afraid

Section: ER-89

PAST AND CURRENT CANCER

Please read the below statements about yourself and indicate how well it applies to you by circling the answer to the right from 1 (does not apply at all) to 4 (applies very strongly). Let me know how true the following characteristics are as they apply to you generally:

Characteristics About You

1. I am generous with my friends
2. I quickly get over and recover from being startled
3. I enjoy dealing with new and unusual situations
4. I usually succeed in making a favourable impression on people
5. I enjoy trying new foods I have never tasted before
6. I am regarded as a very energetic person

7. I like to take different paths to familiar places
8. I am more curious than most people
9. Most of the people I meet are likable
10. I usually think carefully about something before acting
11. I like to do new and different things
12. My family life is full of things that keep me interested
13. I would describe myself as a pretty “strong” personality
14. I get over my anger at someone reasonably quickly

Section: Demographics

PAST AND CURRENT CANCER

What is your gender?	o Male o Female o Other
What is your postcode?	o XXXX
Do you speak any language at home other than English?	o Yes (please specify _) o No
What is your country of birth?	o Australia o Other (please specify_)

Are you of Aboriginal or Torres Strait Islander origin?	o Yes, Aboriginal o Yes, Torres Strait Islander o No

APPENDIX E. STUDY ONE PUBLICATION

The published version of Chapter 4 is on the following pages. Publication details:

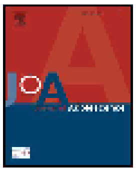
Morris J, Turnbull D, Preen D, Zajac I, Martini A. (2018). *The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10–24 at time of diagnosis: A systematic review.* Journal of Adolescence. 2018; 65:61-71. doi: 10.1016/j.adolescence.2018.03.001

Journal of Adolescence 65 (2018) 61–71

Contents lists available at ScienceDirect

Journal of Adolescence

journal homepage: www.elsevier.com/locate/adolescence



Review article

The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10–24 at time of diagnosis: A systematic review

Julia Morris[a,*], Deborah Turnbull[a], David Preen[b], Ian Zajac[c], Angelita Martini[b]

[a] *School of Psychology, The University of Adelaide, North Terrace, SA 5005, Australia*
[b] *School of Population and Global Health, The University of Western Australia, 35 Stirling Hwy, Crawley, WA 6009, Australia*
[c] *Nutrition and Health Program, Health & Biosecurity, CSIRO, PO Box 10041, Adelaide BC, SA, 5000, Australia*

ARTICLE INFO

Keywords:
Adolescent
Young adult
Parental cancer
Offspring
Systematic review

ABSTRACT

This study reviewed the literature regarding the psychological, social, and behavioural impact of parental cancer on offspring aged 10–24 years, at the time of the parent's first diagnosis. A systematic literature review was conducted following 2015 PRISMA guidelines. Seven studies met inclusion criteria. Offspring were impacted by their parent's cancer and experienced psychological and behavioural problems. Daughters and offspring who experienced more problems at their parent's diagnosis appeared to be most impacted. Offspring refrained from communicating their disease-related concerns, but expected their parents to communicate openly. Turning to oneself and peer-support were coping strategies used by offspring. The majority of offspring were significantly impacted by their parent's cancer. The paucity of literature focusing on offspring aged 10–24 years at the time of their parent's incident cancer diagnosis indicates that research has overlooked offspring age at their parent's cancer onset as a factor that may influence their future outcomes.

1. Background

A parent's cancer is experienced as stressful (Compas et al., 1994) and disruptive by offspring (Lewis, 2011). As a result of parental cancer, offspring face increased emotional and behavioural problems (Möller et al., 2014). Longitudinal data has demonstrated offspring whose parents are diagnosed with cancer access more psychiatric services and do so at an earlier age compared to offspring of healthy parents (Niemelä et al., 2012). They are also found to have an increased rate of death due to cancer and non-cancer related causes (Chen et al., 2015b).

Offspring respond differently to parental cancer as a result of their age (Hauken, Senneseth, Dyregrov, & Dyregrov, 2017) in terms of variability in functioning (Visser, Huizinga, Hoekstra-Weebers, van der Graaf, & Hoekstra, 2004), coping and support needs (Ellis, Wakefield, Antill, Burns, & Patterson, 2016), psychological issues (Compas et al., 1994) and comfort (Mosher & Danoff-Burg, 2005). Research has demonstrated adolescents and young adults have higher levels of anxiety and depression than preadolescent children (Compas et al., 1994). Furthermore, older offspring tend to experience greater household and caregiving responsibilities as a result of their parent's illness, and report more activity restrictions, isolation, daily hassles and stress than offspring of healthy parents (Houck, Rodrigue, & Lobato, 2007; Sieh, Visser-Meily, & Meijer, 2013). Older children with a parent affected by cancer are also found to

---

[*] Corresponding author.

E-mail addresses: julia.morris@adelaide.edu.au (J. Morris), deborah.turnbull@adelaide.edu.au (D. Turnbull), david.preen@uwa.edu.au (D. Preen), ian.zajac@csiro.au (I. Zajac), angelita.martini@uwa.edu.au (A. Martini).

https://doi.org/10.1016/j.adolescence.2018.03.001
Received 2 June 2017; Received in revised form 12 February 2018; Accepted 4 March 2018

struggle at school, where they have a lower grade point average compared to the norm (Sieh et al., 2013).

The stress and coping theory posits that the threat of parental illness is a continuous stressor that can exceed children's coping resources and increase problematic behaviour (Sieh, Meijer, Oort, Visser-Meily, & Van der Leij, 2010). The perceived stressfulness of parental illness depends on child related factors, including age (Lazarus, 1974). As children experience puberty and adolescence, they make significant advances in cognitive and physical development (Sieh et al., 2010). During this time, they also learn to acquire appropriate emotional regulatory skills to deal with stressors (Silvers et al., 2012). Given that the overall impact of a parent's illness on their offspring varies with offspring's age (Korneluk & Lee, 1998; Su & Ryan-Wenger, 2007), it is plausible that offspring age at the time of a parent's incident (i.e., first) cancer diagnosis may have significant and unique implications for their ability to respond and cope with their parent's illness. Younger children may be shielded by a lack of understanding whereas older children possess advanced cognitive and empathetic capacities that increase their awareness of potential loss and their parent's physical and emotional pain (Christ, Siegel, & Sperber, 1994). Therefore, older children might experience greater and potentially more prolonged impact because of their ability to critically appraise the situation and its implications. Additionally, adolescent and young adult offspring are concurrently contending with developmental challenges. Specifically, adolescence represents a critical period of transition (Spear, 2000; World Health Organisation [WHO], 2016) underpinned by heightened vulnerability (Steinberg, 2005); and young adulthood represents a period of instability as one establishes independence and structure (Arnett, 2000). Experiencing a parent's cancer diagnosis during adolescence or young adulthood could potentially impact these normative milestones and lead to developmental ramifications.

Currently, there is a dearth of literature that systematically considers what impact a parent's cancer has on offspring in their adolescence and young adulthood at their parent's incident diagnosis. Studies to date that claim to have focused on the impact of parental cancer on adolescent and young adult offspring have suffered significant limitations, including not-specifying the age of participants in their sample, or adopting a broad approach and exploring the impact across all ages-a methodological weakness identified as far back as 15 years ago (Nelson & While, 2002). For example, reviews with prescribed adolescent and young adult offspring samples have included children as young as infants (e.g. Walczak, McDonald, Patterson, Dobinson, & Allison, 2017), toddlers (e.g. Osborn, 2007) or young children (e.g. Phillips, 2014); or have included children whose age is not explicitly stated in the original research (e.g. Grabiak, Bender, & Puskar, 2007). Thus, what is assumedly known regarding the impact of parental cancer on adolescent or young adult offspring is arguably based on skewed interpretations. Maintaining focus on adolescent and young adult offspring impacted by parental cancer can only be achieved if the sample consists of adolescents and young adults. This can be achieved by focusing on offspring in their adolescence or young adulthood at their parent's incident cancer diagnosis. This approach would control for the varying responses to parental cancer that occur as a function of age (Korneluk & Lee, 1998; Su & Ryan-Wenger, 2007). Therefore, the aim of this current study was to systematically review the evidence regarding the psychological, social, and behavioural impact a parent's cancer has on adolescent and young adult offspring aged 10–24 years at their parent's incident cancer diagnosis. This age span was chosen because it aligns with the World Health Organisation (WHO) definitions of young people and adolescence (WHO, 2016).

2. Methods

2.1. *Search strategy*

Electronic databases were selected for their focus on health and psychology disciplines and included PubMed, PsycINFO, Embase and The Cumulative Index to Nursing and Allied Health Literature (CINAHL). Predefined key search terms were developed in collaboration with a Research Librarian at the University of Adelaide's School of Psychology. Detailed search algorithms and indexing language used under each database are outlined in Table 1. Electronic database searches ran for a period of nine months (02 June 2016–15 February 2017) and targeted original research in English language that was published in peer-reviewed journals. No time restrictions on publication date were applied. Reference lists of relevant studies (e.g. reviews) and studies that met inclusion criteria were screened for additional articles.

2.2. *Inclusion and exclusion criteria*

Studies met inclusion criteria if they reported on the impact a parent's cancer has on offspring aged 10–24 years at the time of the parent's diagnosis, were written in English, published in a peer-reviewed journal, and constituted original research (i.e. not review articles). This review did not consider offspring 10–24 years at the time of a recurrent diagnosis because recurrence is itself a predictor of offspring distress (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005; Phillips, 2014; Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2006), thus may bias results. Separately, as time from diagnosis impacts adjustment (Huang, O'Connor, & Lee, 2014), offspring younger than 10 years at the time of their parent's first diagnosis would arguably experience their parent's recurrent or ongoing cancer differently. Therefore, this review excluded offspring who were outside the target age range (10–24 years) at their parent's first cancer diagnosis. Studies could consider offspring of parents with any type of cancer and at any stage, and include bereaved or non-bereaved offspring. Studies considering parenting experiences were included if they investigated the impact of parenting on offspring. No restrictions were placed on date of publication or study design.

Studies were excluded if offspring age at diagnosis was not specified, as the purpose of this review was to evaluate the impact of parental cancer on offspring aged 10–24 years at the time of the incident diagnosis. Offspring outside of this age at the time of the incident cancer diagnosis have arguably different experiences relating to their parent's cancer due to the developmental trajectory

Table 1
Database search algorithms and indexing language.

Database	Search terms
PubMed	(Neoplasms [mh] OR Neoplasm*[tiab] OR Cancer*[tiab] OR Oncolog*[tiab] OR Malignan*[tiab] OR Tumor* [tiab] OR Tumor*[tiab] OR carcinoma*[tiab]) AND (Parents [mh] OR "Parent-Child Relations" [mh] OR mother*[tiab] OR parent*[tiab] OR father*[tiab]) AND ("child of impaired parents" [mh] OR child [mh:noexp] OR adolescent [mh] OR "young adult" [mh] OR son [tiab] OR sons [tiab] OR daughter*[tiab] OR child*[tiab] OR adolescen*[tiab] OR young adult*[tiab] OR teen*[tiab] OR youth [tiab]) NOT (children with cancer*[ti] OR child with cancer* [ti] OR childhood cancer*[ti] OR paediatric oncolog*[ti] OR paediatric oncolog*[ti] OR pediatric cancer*[ti] OR paediatric cancer*[ti])
PsycINFO	(Neoplasms.sh OR Neoplasm*.ti, ab OR Cancer*.ti, ab OR Oncolog*.ti, ab OR Malignan*.ti, ab OR Tumor*.ti, ab OR Tumor*.ti, ab OR carcinoma*.ti,ab) AND (Parent child relations.sh OR mother*.ti, ab OR parent*.ti, ab OR father*.ti,ab) AND (Daughters.sh OR Sons.sh OR Son.ti, ab OR Sons.ti, ab OR daughter*.ti, ab OR child*.ti, ab OR adolescen*.ti, ab OR young adult*.ti, ab OR teen*.ti, ab OR youth.ti,ab) NOT (Children with cancer*.ti OR child with cancer*.ti OR childhood cancer*.ti OR pediatric oncolog*.ti OR paediatric oncolog*.ti OR paediatric cancer*.ti OR paediatric cancer*.ti)
Embase	("Cancer diagnosis"/exp OR Neoplasm/exp OR Neoplasm*:ti, ab OR Cancer*:ti, ab OR Oncolog*:ti, ab OR Malignan*:ti, ab OR Tumor:ti, ab OR Tumor:ti, ab OR Carcinoma*:ti,ab) AND ("child parent relation"/exp OR mother*:ti, ab OR parent*:ti, ab OR father*:ti,ab) AND (Child/exp OR son:ti, ab OR daughter*:ti, ab OR child:ti, ab OR adolescen*:ti, ab OR "young adult*":ti, ab OR teen:ti, ab OR youth:ti,ab) NOT ("childhood cancer"/exp OR "children with cancer*":ti, ab OR "child with cancer*":ti, ab OR "childhood cancer*":ti, ab OR "paediatric oncolog*":ti, ab OR "paediatric oncolog*":ti, ab OR "paediatric cancer*":ti, ab OR "paediatric cancer*":ti,ab)
CINAHL	((MH neoplasms) OR TI Neoplasm* OR AB Neoplasm* OR TI Cancer* OR AB Cancer* OR TI Oncolog* OR AB Oncolog* OR TI Malignan* OR AB Malignan* OR TI Tumor* OR AB Tumor* OR TI Tumour* OR AB tumour* OR TI carcinoma* OR AB carcinoma*) AND ((MH "parent-child relations") OR TI mother* OR AB mother* OR TI parent* OR AB parent* OR TI father* OR AB father*) AND ((MH "Children of impaired parents") OR TI sons OR AB sons OR TI son OR AB son OR TI daughter* OR AB daughter* OR TI child* OR AB child* OR TI adolescen* OR AB adolescen* OR "TI young adult*" OR "AB young adult*" TI teen OR AB teen OR TI youth OR AB youth) NOT ((MH "childhood neoplasms") OR TI "children with cancer" OR TI "child with cancer" OR "AB childhood cancer" OR " TI paediatric oncolog*" OR "TI paediatric oncolog*" OR "TI paediatric cancer*" OR "TI paediatric cancer*")

associated with being of latency-age or in adulthood. Thus, eliminating studies that did not define offspring age at the time of the incident diagnosis was a means for controlling offspring age. It was decided among the research team that methodological quality would be the highest among studies which had undergone peer-review. Therefore, studies were excluded if they were commentaries, reports, book chapters or dissertations. Studies were also excluded if they focused on health professionals, school staff, or the impact on parents, as these were not pertinent to the purpose of the review.

2.3. *Methodological quality*

Due to the small body of literature concerning offspring aged 10–24 years at the time of their parent's cancer diagnosis, studies of qualitative, quantitative and mixed-method designs were included. Methodological quality was assessed using the Mixed Method Appraisal Tool (MMAT) (Pluye et al., 2011). Studies were assessed under three MMAT methodological domains: mixed-method, qualitative, and quantitative. Under each domain, relevant criteria must be met for the study to be deemed high methodological quality (see http://mixedmethodsappraisaltoolpublic.pbworks.com for criteria). Each criterion is worth 25%, such that if all four are met, the study will receive a score of 100% (high methodological quality). The majority of studies (n = 5) had high methodological quality with the exception of one study scoring 75% and another scoring 50% (Table 2).

2.4. *Data analysis*

A total of 12,906 records published between 1915 and 2017 were captured across the database searches. Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines were followed; details of which are presented in Fig. 1. Records were exported to citation management software Endnote ×7, in which duplicates were identified and removed, and screening of references was undertaken. One investigator screened titles and abstracts for inclusion suitability, and a second investigator reviewed a subset of excluded titles. Through this process, consensus was reached on which studies to include.

Given the heterogeneity of data across studies, a narrative approach was taken. Studies that met inclusion criteria underwent thematic analysis: a systematic process for analysing and interpreting data that identifies features or 'codes' within the data that contribute to overarching 'themes' or patterns of meaning (Clarke & Braun, 2017). Studies were exported to the qualitative data analysis software, NVivo (QSR International Pty Ltd., 2012). Each study was manually coded to reveal elements and key features. The codes were then classified and reassembled in terms of similarity into a coherent order of subthemes. Following this, the subthemes were grouped into one of five master themes: Learning about the cancer and its impact on the family and normality; Offspring communication; Behavioural and psychological impact; Gender differences; and Sources of Support. These five themes guide the results section.

3. Results

Seven studies met inclusion criteria for the review. Study designs were quantitative (n = 4), qualitative (n = 2), and mixed method (n = 1). All studies were from different countries, with research originating from Malaysia, Iran, the United States of America, the United Kingdom, the Netherlands, Norway, and Germany. Offspring age at their parent's diagnosis was ranged from 10

Table 2
Studies considering the impact of a parent's cancer on offspring (10–24 years).

Author (year) Country	Aim	Participants	Offspring age at (i) study, (ii) diagnosis	Parent cancer types; stage	Study design Data collection method/tool	Key findings	MMAT Score (Limitations)*
Ainuddin et al. (2012), Malaysia	Cancer impact on offspring QoL.	95 offspring	(i) 13–18yrs) (ii) 13–18 yrs	Colorectal, lung, breast; Stage I-IV	Quantitative PedsQL	- Offspring scored lowest on emotional and school functioning domains. - Sons had better physical functioning and total QoL. - Offspring whose mothers had cancer had worse school functioning. - Household income was negatively associated with emotional functioning, school functioning, psychosocial HRQoL, and total QoL.	75% (4.2)*
Azarbarzin et al. (2015), Iran	Effect of supportive-educative program on offspring QoL.	30 offspring	(i) 11–20 yrs (ii) 10–20 yrs	Not specified	Quantitative SF-36	- Following the program, there were statistically significant differences in physical functioning, energy/fatigue, emotional wellbeing, social functioning, pain, general health, and psychological and physical health subcategories. - No statistically significant differences in role limitation due to physical or psychosocial health following program.	100%
Clemmens (2009) United States	Offspring coping	11 offspring	(i) 13–19 yrs (ii) 12–19 yrs	Breast	Qualitative In depth, semi-structured interviews	- All offspring experienced distress. - Five main themes identified: life changed; turning to self (self-reliance and coping behaviours); learning to be with my mother (new ways of being close to the parent); needing to normalise; speaking openly-the importance of communication.	50% (1.3; 1.4)*
Finch and Gibson (2009) United Kingdom	How offspring learn of parent's cancer	7 offspring	(i)14–18 yrs (ii) 14–18 yrs	Breast, acute myeloid leukaemia, non-Hodgkin's lymphoma	Qualitative Semi-structured interviews	- Offspring advocated for open and honest communication. - Six themes identified: first hearing about diagnosis; vulnerability of self and others (family roles and relationships were threatened); communication within the family (dependent on attitudes, beliefs and comfort); feeling supported in experience; experience and support of school; experience and support of hospital.	100%
Huizinga et al. (2010) Netherlands	Offspring stress response symptoms	49 offspring 37 parents with cancer 37 partners	(i) 11–18 yrs (ii) 10–18 yrs	Breast, testicular, gynaecological, sarcoma, melanoma, haematological, rectal, renal, thyroid	Quantitative IES YSR CBCL	- Offspring SRS were at clinical levels for 29% of offspring at T1, 16% at T2, 14% at T3. - Moderate to large correlations were found between initial SRS and future emotional and cognitive problems. - Parents observed less SRS in offspring than in offspring self-report. - Daughters experienced more SRS.	100%

(continued on next page)

Table 2 (continued)

Author (year) Country	Aim	Participants	Offspring age at (i) study, (ii) diagnosis	Parent cancer types; stage	Study design Data collection method/tool	Key findings	MMAT Score (Limitations)*
						- Offspring age, patient gender, treatment intensity and duration were unrelated to SRS.	
Jeppesen, Bjelland, Fossa, Loge, Dahl (2013), Norway	Offspring QoL	29 offspring 26 parents with cancer 19 partners	(i) 13–19 yrs (ii) 12–19 yrs	Breast, lymphoma, Hodgkin's lymphoma.	Quantitative KIDSCREEN Rosenberg self-esteem questionnaire- short form SCL-5 FAD	- Offspring had significantly poorer physical wellbeing score than norms. - Social support and peers scores improved over time. - Daughters scored significantly lower on the HRQoL psychological wellbeing subscale. - Self-esteem had a significant and positive association with HRQoL.	100%
Kühne et al. (2013) Germany	Family functioning in families by disease stage (palliative, other)	Palliative: 31 offspring 46 parents with cancer 59 partners Non-palliative 33 offspring 89 parents with cancer 65 partners	(i) 11–18 yrs (ii) 10–18 yrs	Breast, gynaecological, digestive organs (unspecified).	Mixed-method FAD	- 15–26% of family members reported dysfunctional general functioning. - Offspring observed more dysfunctional communication than parents - Patients and partners observed more role dysfunction than offspring - Palliative-parent families had higher scoring agreement than non-palliative families.	100%

Note: CBCL: Child Behaviour Checklist; FAD: Family Assessment Device; HRQoL: Health Related Quality of Life; IES: Impact of Events Scale; PedsQL: Paediatric Quality of Life Inventory; QoL: Quality of Life; SCL-5: Hopkin's Symptoms Checklist; SF-36: Short Form Health Survey; T1: 4 months after parent's diagnosis; T2: 10 months after parent's diagnosis; T3: 16 months after parent's diagnosis; YSR: Youth Self Report.

MMAT Limitations*: 1.1 Source of data; 1.3 Consideration of data collection context; 1.4: Consideration of researchers' influence; 3.1: Participant recruitment; 4.2: Sample representativeness.

NB: Key findings in quantitative and mixed-method study based on statistical significance ($p < 0.05$).

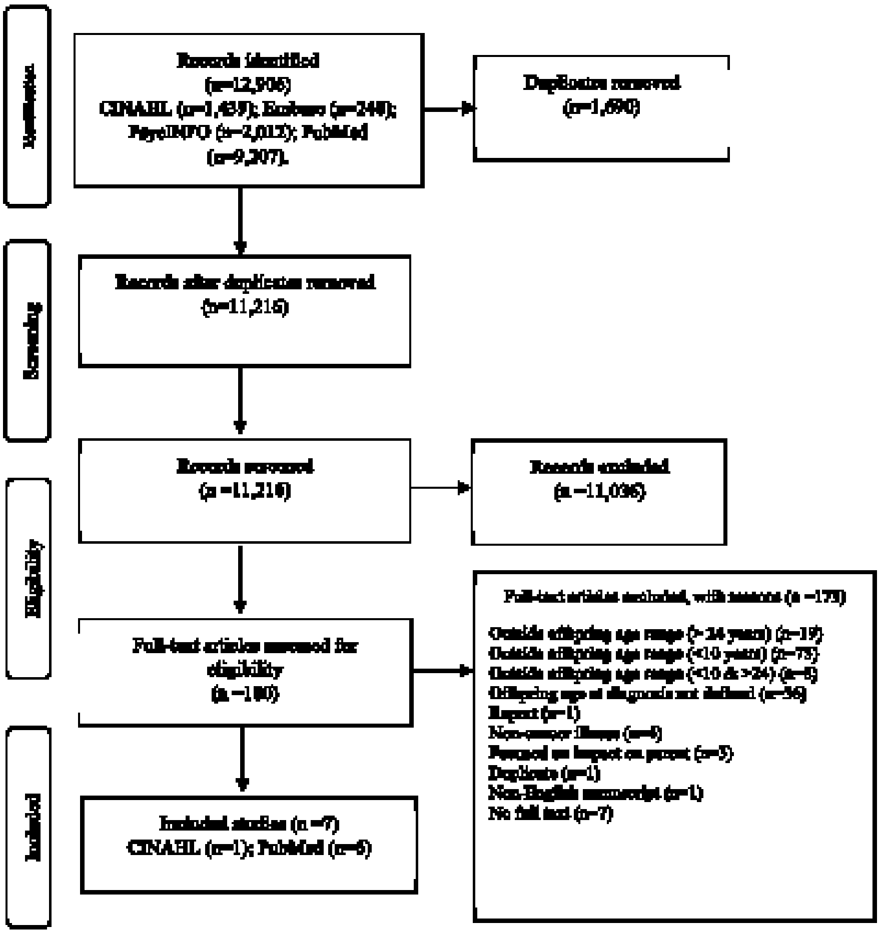


Fig. 1. Article selection and exclusion process, based on the PRISMA Framework.

to 20 years. Four studies observed the impact of a parent's cancer from the perspective of the offspring, and the other three included perspectives of offspring, parents with cancer, and their partners. Across the studies, the most common parental cancer was breast (n = 6), followed by gynaecological (n = 2). Studies focused on health-related quality of life (HRQoL) (Jeppesen, Bjelland, Fossa, Loge, & Dahl, 2016), overall quality of life (QoL) (Ainuddin, Loh, Low, Sapihis, & Roslani, 2012), and QoL following a supportive-educative program (Azarbarzin, Malekian, & Taleghani, 2015). Studies also focused on offspring coping (Clemmens, 2009), stress response symptoms (Huizinga et al., 2010), and how offspring learn about their parent's cancer (Finch & Gibson, 2009). Details of included studies and their key findings are outlined in Table 2. Through thematic analysis, five themes were identified from the included papers.

Learning about the cancer and its impact on the family and normality. The diagnosis of a parent's cancer was experienced as a loss (Finch & Gibson, 2009) and distressing (Clemmens, 2009) by offspring. Fear of parental death was connected to offspring first learning of their parent's diagnosis and was perceived as a real and constant threat (Finch & Gibson, 2009). Thirty percent of offspring in one study experienced clinically elevated stress response symptoms in the first few months of their parent's diagnosis (Huizinga et al., 2010). Offspring felt fear jointly for their parent and for themselves (Clemmens, 2009). They saw themselves and their family members as vulnerable (Finch & Gibson, 2009) and perceived the uncertainties associated with the disease as life threatening (Finch & Gibson, 2009). As a result of the cancer, offspring's normal patterns of life had changed (Clemmens, 2009). Offspring expressed family roles had also changed (Finch & Gibson, 2009) but parents reported more role dysfunction than offspring (Kühne et al., 2013). Offspring reported their ill parent was noticeably absent and their parenting was affected (Clemmens, 2009). Offspring attempted to normalise the cancer within their lives (Finch & Gibson, 2009) and believed life would return to normal if their ill parent had a good day or when their treatments had finished (Clemmens, 2009). Notably, offspring whose parents had been diagnosed 12 months prior fared better in terms of intrusion, avoidance, and total distress than offspring whose parents were diagnosed 1–5 years previously (Huizinga et al., 2010).

Offspring reported that their parents needed looking after (Finch & Gibson, 2009). They had an intense desire to stay close to their ill parent (Clemmens, 2009), and stayed home more, or selected colleges closer to home upon finishing high school (Clemmens, 2009). The desire to stay close to their parent was especially important among offspring whose parents were in palliative disease stages (Kühne et al., 2013). Families whose parents were in palliative disease stages had more consistent reports regarding family functioning than those in non-palliative disease stages (Kühne et al., 2013). Offspring desired closeness to their parent, but found it challenging as it drew attention to the illness, its severity, and potential loss (Clemmens, 2009).

Offspring communication. Communication among family members was dependent on the family's attitudes, beliefs, and comfort in discussing the cancer (Finch & Gibson, 2009). Offspring encouraged open and honest family communication about their parent's cancer (Clemmens, 2009; Finch & Gibson, 2009), which fostered understanding (Clemmens, 2009; Finch & Gibson, 2009), helped offspring make sense of the disease (Finch & Gibson, 2009), and increased their feelings of security (Clemmens, 2009). However, offspring reported more dysfunctional family communication than their parents (Kühne et al., 2013). Offspring used open communication to cope with their parent's cancer and reported that talking about the cancer was essential (Clemmens, 2009). In contrast, offspring refrained from discussing their own fears about the disease (Finch & Gibson, 2009) and hid their emotional reactions (Clemmens, 2009) in order not to burden their ill parent. Offspring were careful not to contribute to their parent's problems or worry them and thus would be self-reliant or turn inward (Clemmens, 2009). Offspring believed they needed to modify their behaviour and stay emotionally strong for the sake of their parent (Finch & Gibson, 2009). They moved their attention away from their parent's cancer (Clemmens, 2009) or did not think about it to reduce their stress (Finch & Gibson, 2009). Parents interpreted their offspring's withdrawal to mean they were unaffected by their diagnosis (Clemmens, 2009) and consequently also reported less emotional and behavioural problems in offspring than in offspring self-report (Huizinga et al., 2010). Offspring sensed their parent's misinterpretation of this behaviour and felt misunderstood if they tried to cope independently or normalise their daily life (Clemmens, 2009).

Behavioural and psychological impact. Prior to engaging in a support program, offspring had normal QoL scores on the dimensions physical functioning, role limitation due to physical health, and role limitation due to emotional problems and pain (Azarbarzin et al., 2015). Also, parental cancer only appeared to have a moderate effect on their offspring's HRQoL (Jeppesen et al., 2016). Although 42% of offspring reported a low score on at least one HRQoL dimension, corresponding normative data were missing, thus its comparative significance was undetermined (Jeppesen et al., 2016). At the individual level, a parent's cancer diagnosis impacted school functioning (i.e. performance; truancy (Varni, Seid, & Kurtin, 2001)) if their mother had cancer (Ainuddin et al., 2012). Also, offspring reported a diminished capacity to focus or concentrate (Clemmens, 2009). Stress response symptoms were associated with emotional and behavioural problems, and future emotional and cognitive problems (Huizinga et al., 2010). In the first year following diagnosis, the relationship between stress response and somatic complaints increased (Huizinga et al., 2010). Ill parents and partners observed more emotional and behavioural problems in offspring with higher stress response symptoms, but these were to a lesser degree than offspring reported for themselves (Huizinga et al., 2010). Offspring age, parent gender, and treatment intensity and length was unrelated to offspring stress response symptoms (Huizinga et al., 2010). Offspring self-esteem was significantly correlated with HRQoL (Jeppesen et al., 2016). Offspring had poor emotional functioning scores (i.e. negative emotional affect) (Ainuddin et al., 2012) but normal emotional wellbeing (Azarbarzin et al., 2015). Lastly, the lower the household income, the poorer the emotional, school, and psychosocial HRQoL, and total QoL (Ainuddin et al., 2012).

Gender differences. Daughters whose parents had cancer had significantly lower self-esteem (Jeppesen et al., 2016), physical functioning, and QoL (Ainuddin et al., 2012) than sons. More daughters reported clinically elevated stress response symptoms at 4 months following diagnosis, and daughters also reported higher rates of intrusion than sons at 6 months following diagnosis (Huizinga et al., 2010). Compared to sons whose parent had been diagnosed 1–5 years earlier (reference group), sons whose parent had been diagnosed 12 months earlier had less intrusion, avoidance and total distress (Huizinga et al., 2010). Compared to the reference group, daughters reported significantly less intrusion and less total distress at 12 months (Huizinga et al., 2010). Female family members and partners reported more family dysfunction regarding problem solving and general functioning (Kühne et al., 2013).

Sources of support. Offspring sought support from friends (Finch & Gibson, 2009). Although offspring engaged less with their friends than they had prior to their parent's diagnosis, participating in activities with their peers assisted their coping (Clemmens, 2009). Daughters reported significantly poorer HRQoL in terms of social support and peers than sons, but over time, this score improved for both genders (Jeppesen et al., 2016). At 4 and 6 months following diagnosis, offspring who experienced more stress-response symptoms reported more problems on all self-report scales except for social problems (Huizinga et al., 2010). Offspring turned inward and relied on themselves for problem solving, decision making, and to escape (Clemmens, 2009), thus being their own source of support. For other offspring, one study found that religious faith and church affiliations were helpful (Clemmens, 2009). In regard to healthcare support, offspring felt they had no role within the hospital environment and believed it offered no emotional or psychosocial component of care (Finch & Gibson, 2009). Offspring preferred to speak to friends or family about the cancer than seek support from medical staff (Finch & Gibson, 2009). One supportive educative program, developed by oncologists and researchers, reported a significant increase on almost all QoL scores among offspring (Azarbarzin et al., 2015). In terms of their school, offspring felt that they received little support from their teachers. Rather, a teacher's acknowledgement was limited to their asking after the offspring's parent (Finch & Gibson, 2009). However, offspring had mixed views on the level of support they would have liked from their teachers (Finch & Gibson, 2009).

4. Discussion

Each of the reviewed studies demonstrated that offspring aged 10–24 years at their parent's incident diagnosis are significantly impacted in some way by their parent's cancer. In regard to which offspring are most impacted by parental cancer, the literature to date suggests that daughters struggled more than sons (Ainuddin et al., 2012; Huizinga et al., 2010; Jeppesen et al., 2016); a finding echoed in other research focusing on different age groups (McDonald et al., 2016; Morris, Martini, & Preen, 2016; Osborn, 2007; Visser et al., 2004). There is evidence to suggest that daughters fare worse if their mother has cancer (Morris et al., 2016), and one reviewed study supported this (Ainuddin et al., 2012), but this finding may demonstrate a response bias resulting from the large number of mothers in the study (45 mothers; 5 fathers). Parental cancer research is dominated by the impact of maternal breast cancer, and is likely due to the commonality of breast cancer during child-rearing years. In this review, most included studies (n = 6) having more mothers affected by cancer than fathers (one study failed to mention parents' gender). It is speculated that offspring may suffer more if their father has cancer, because the nature of a father's prognosis is poorer than that of a mother's breast cancer diagnosis (Thastum et al., 2009). Future research should attempt to recruit larger samples of both male and female offspring to establish whether parent gender impacts offspring.

In terms of the degree of impact parental cancer had on offspring, some reviewed evidence suggested that offspring showed little affect to their parent's cancer (Azarbarzin et al., 2015; Jeppesen et al., 2016). This has been reiterated in other research, which found offspring whose parents have cancer display no more psychological problems (Jeppesen, Bjelland, Fossa, Loge, & Dahl, 2013) risk behaviours, externalising behaviours (Jantzer et al., 2013), or psychiatric problems (Niemelä et al., 2016) than the norm. Other reviewed evidence suggested that offspring were impacted by their parent's cancer, but only in terms of acute reactions to the time of diagnosis (Clemmens, 2009; Huizinga, van der Graaf, Visser, Dijkstra, & Hoekstra-Weebers, 2003; Kühne et al., 2013), and overall, they adjusted well (Jantzer et al., 2013; Kühne et al., 2013). On the contrary, evidence also suggested that the impact of a parent's cancer was more pervasive (Ainuddin et al., 2012; Clemmens, 2009; Huizinga et al., 2010). The lingering impact of a parent's cancer diagnosis was apparent in offspring experiencing more problems if their parent was diagnosed farther back in time (Huizinga et al., 2010). It also suggests that offspring may be affected by uncertainty and fear of recurrence in the aftermath of the disease: a phenomena reported in cancer survivors (Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006).

Evidence suggested that offspring may be predisposed to future problems if they experience more problems at the time of their parent's diagnosis. For example, through the increasing association between somatic complaints and stress response symptoms (Huizinga et al., 2010). Gazendam-Donofrio, Hoekstra, van der Graaf. van de Wiel, Visser, Huizinga (2011) found that emotional reactions were unrelated to later emotional or behavioural problems, but total problems were related to later dysfunction. This is similar to findings that offspring's total burden of illness predicted future problems (Visser et al., 2007). These findings contribute to the notion that only some offspring experience severe strain as a result of their parent's cancer (Jantzer et al., 2013). Conversely, other research indicates that compared to the norm, parental cancer impacts all offspring to some degree. Longitudinal population-based studies have reported that offspring whose parents have cancer have a higher rate of injury (Chen et al., 2015a), access more psychiatric support (Niemelä et al., 2012), and have an increased rate of death due to all causes (Chen et al., 2015b) compared to the norm. The inconsistencies around which offspring are impacted by parental cancer may be due to the significant variation in research design across studies, child-characteristics (e.g. age, perceived maturity), or even family characteristics (e.g. single versus coupled-parent families) that either protect or exacerbate the impact of parental cancer. Given the inconsistencies around which offspring are impacted by parental cancer, further research is warranted to better understand if a subgroup of offspring are vulnerable, or if all offspring are at risk.

Adolescence and young adulthood is a time in which offspring acquire more independence and are seen to move away from the family. A parent's cancer resulted in offspring sacrificing this independence by staying home more or by choosing colleges nearer to their home (Clemmens, 2009). Arguably, this is akin to 'parentification', a coping strategy in which offspring compromise their own needs or emotions for the sake of their parent (Davey, Askew, & Godette, 2003; Phillips & Lewis, 2015; Thastum, Johansen, Gubba, Olesen, & Romer, 2008). Parentification can be destructive for offspring as it can indicate an absence of reciprocity, acknowledgement, and support within the family (Thastum et al., 2008). Parents reported more role dysfunction than offspring (Kühne et al., 2013), meaning they perceived more dysfunction in relation to established behaviour patterns, assigned tasks and responsibilities. This may reflect that parents sensed their offspring had assumed a role beyond that of being the child because of the cancer. Alternatively, it may reflect parent's feelings of guilt about failing to be a 'good parent' (Morris et al., 2016). Overall, it appeared that the cancer drew offspring towards their parents, but this closeness did not necessarily imply a stronger or more supportive relationship between parents and their children.

Open and honest communication is not only encouraged (Clemmens, 2009; Finch & Gibson, 2009) but is essential in minimising their suffering and supporting offspring (Morris et al., 2016). Thus, communication is key to minimising the impact of a parent's cancer on children. The evidence illustrated a problematic dynamic in which offspring's expectations juxtapose their own communicative behaviours. In other words, offspring expected their parents to communicate, but were unwilling to reciprocate in terms of open and honest communication, out of fear of upsetting their parent. This led to parents underestimating the impact that their cancer had on their children (Clemmens, 2009; Huizinga et al., 2010); a finding which is reiterated in the literature (Morris et al., 2016; Osborn, 2007). Offspring in one of the reviewed studies reported more dysfunctional communication than their parents, (Kühne et al., 2013), which may reflect parent's misunderstanding that offspring need to communicate. It is important that offspring are supported to communicate with their parents (Ellis et al., 2016), and families may benefit from receiving guidance about how to support and communicate with their children.

The deficit in support strategies for offspring was evident in this review. Offspring perceived no emotional or psychosocial support for themselves in their parent's care (Finch & Gibson, 2009), and only one study reported on the outcome of a supportive care program (Azarbarzin et al., 2015). Health professionals have an obligation to support the coping and wellbeing of offspring (Jeppesen et al., 2016), and offspring are in need of such support (Ellis et al., 2016). Positive outcomes were reported as a result of the aforementioned supportive care program, which demonstrates the benefit of small group or one-on-one support to minimise the burden of cancer (Azarbarzin et al., 2015). One study indicated that there was less dysfunction in families affected by palliative parental cancer (Kühne et al., 2013), which may be a result of palliative support strategies. However, this outcome may also be due to a natural progression resulting from these families spending more time together as the disease became more dominant (Kühne et al., 2013), and their main concern being a lack of time together (Sheehan & Draucker, 2011). Regardless, support must be tailored and provided to families affected by palliative and non-palliative parental cancer and on a long-term basis, to counteract any pervasive impact of parental cancer. It should also be made available to families of lower socioeconomic status, where offspring quality of life was reported to be lower (Ainuddin et al., 2012); a finding which is reiterated across research concerning children of chronically ill parents (Sieh et al., 2010). Besides support from healthcare, a school can play a helpful role in helping offspring facing a parent's cancer (Chalmers et al., 2000) as it can offer ongoing and stable support. This is especially important given that offspring struggle in terms of their focus, concentration (Clemmens, 2009), and school functioning (Ainuddin et al., 2012).

The included studies were somewhat limited in the extent to which they identified what part of a parent's cancer impacts their offspring. A parent's cancer has many facets but research has largely approached parental cancer as a single event. Rolland's (1987) psychosocial typology of illness describes dimensions of illness that exist on a continuum: onset (acute versus gradual); course (episodic/relapse, constant, or progressive); outcome (terminal or not); and degree of incapacitation (e.g. cognitive, sensation, movement, energy etc.) (Rolland, 1987). Depending on the dimension, the family must perform different adaptive behaviours and face various psychosocial demands (Chen, 2017; Korneluk & Lee, 1998). Where the two included qualitative studies approached parental cancer on a continuum and explored the impact on offspring as a function of diagnosis as well as the ensuing illness (Clemmens, 2009; Finch & Gibson, 2009), the quantitative and mixed-method studies were restricted by their design. Two of these latter studies did investigate course and outcome (treatment duration and type; palliative versus non-palliative) on their outcome variables (stress response symptoms and family functioning, respectively) (Huizinga et al., 2010; Kühne et al., 2013), but the other studies were limited by only describing dimensions of the illness (e.g. type and stage, treatment, palliation or non-palliation) and analysing the impact of a parent's cancer as the outcome of an all-encompassing event (Ainuddin et al., 2012; Azarbarzin et al., 2015; Jeppesen et al., 2016). From the available research, one can imply that offspring are first impacted at the parent's diagnosis, and are challenged by ongoing exposure to the illness, incapacitation of their parents, and uncertainty regarding their parents' mortality. Reasonably, offspring are also impacted by the flexibility they must proffer in adapting to these challenges, all whilst negotiating their normal developmental milestones. Approaching parental cancer as a whole is, in some ways, demonstrating that all elements of the illness are equivalent in their impact on parents and their offspring. However, identifying at what point and for what reason offspring experience negative consequences as a result of parental cancer may be of significance for supportive care strategies so as to identify offspring at risk and know when is necessary to intervene.

The studies which met the inclusion criteria largely described the negative impact of parental cancer, which contributes to the overwhelming focus on psychopathology (Mosher & Danoff-Burg, 2005) or negative incidents in this research area. Conversely, there was little investigation of positive or protective factors that may mediate the burden of a parent's cancer. One study indicated that self-esteem was related to better HRQoL (Jeppesen et al., 2016), thus self-esteem may be a protective factor for wellbeing. Interestingly, one study found scores for social support improved over time (Jeppesen et al., 2016), and another study found that stress response symptoms were related to all other problems but social issues (Huizinga et al., 2010). Such findings indicate that offspring may place great significance on social support and it may offset the negative impact of parental cancer. Similarly, offspring in one study found solace in religious or spiritual connections (Clemmens, 2009). However, this finding may be reflective of religion being more culturally significant within an American sample. Research should attempt to better understand the presence of positive or protective factors that attribute to improved wellbeing for these offspring.

4.1. Limitations of current research

Through undertaking this review, shortcomings in the extant research were apparent. The exclusion of a large number of studies due to offspring age (see Fig. 1) highlights the extent to which research has failed to address the experiences of offspring in their adolescence and young adulthood *at the time* of their parent's incident cancer diagnosis. No studies in this review considered young adults aged 21–24 years, and papers (n = 19) were excluded because they were limited to adults above 24 years. Additionally, 73 studies were excluded for including dependent offspring below 10 years. The paucity of research relating to this cohort (10–24 years) exposes the need for further investigation.

Many studies (n = 56) were excluded from this review because they failed to define offspring age at diagnosis. Omitting such key information undermines the usability of study outcomes, as offspring developmental stages are overlooked. This limitation calls for consideration in regards to the age of offspring at the time of the parent's incident cancer diagnosis as a factor that may affect the degree to which they are impacted by their parent's illness. It also calls for contemporary methods of research to assess offspring on a longitudinal basis.

Studies were limited by their definition of family. All but one study failed to define the type of relationship parents and their offspring had (i.e. biological, adoptive, or step). Also, studies considered parents in partnered relationships (n = 1), a mix of two-parent and one-parent families (n = 4), or failed to define the family structure (n = 2). Given the nuclear family is becoming less dominant (Cohen, 2015; de Vaus, 2004), it is important that non-traditional families are better researched. This includes same-sex parents, and biological, adoptive, and step-offspring. However, this may only be suitable to Western countries.

4.2. Limitations of this review

This review had some limitations. In order to accurately summarise the impact that a parent's incident cancer diagnosis has on their adolescent and young adult offspring, a stringent inclusion criteria was created. The WHO's definition of adolescents and young adults was adopted, thus studies were excluded if offspring were outside the ages of 10 and 24 at first diagnosis, or if they failed to specify offspring age at diagnosis. The reason for this latter criteria was to control for developmentally different responses due to being offspring being latency-aged (< 10 years) or in adulthood (> 24 years) at the time diagnosis. Subsequently, few studies met the offspring age requirement for inclusion, and a significant number of studies (n = 56) were excluded because they failed to specify offspring age at the incident diagnosis.

Although most studies originated from Western countries, two studies were based in Iran and Malaysia, respectively. This has implications for the findings, as strategies such as open communication to support offspring may be less applicable outside of Western culture.

In this type of research, parents are often concerned about creating more distress for their child. Therefore, findings may be based on offspring who have accustomed well to the disease, rather than those who are struggling. In three studies, offspring included sibling informants, which may have biased findings. In another three studies, it was not defined whether sibling informants were used. Also, one study was limited to only using families with partnered parents, thus not representing single-parent households.

5. Conclusions

To our knowledge, this was the first review that specifically considered the impact of a parent's cancer on offspring in their adolescence or young adulthood (10–24 years) at the time of their parent's incident diagnosis. These offspring represent an age range characterised by turbulence resulting from increasing independence and maturity. Significantly, the paucity of studies uncovered in this systematic literature review demonstrated a methodological weakness in the extant literature related to the oversight of offspring age at the time of a parent's first cancer diagnosis.

Given the small number of studies uncovered in this review and differences that may have arisen from cross-cultural comparisons, findings should be treated with caution. This review illustrated that almost all offspring in the included studies were impacted by their parent's cancer diagnosis, but daughters and offspring who reported more initial problems appear to be most impacted. Reviewed studies focused on the psychopathological or negative impact that a parent's cancer has on offspring, rather than protective or positive factors. Future research may benefit by establishing what components of the parents cancer impacts offspring to better inform supportive care strategies.

References[1]

Ainuddin, H. A., Loh, S. Y., Low, W. Y., Sapihis, M., & Roslani, A. C. (2012). Quality of life of multiethnic adolescents living with a parent with cancer. *Asian Pacific Journal of Cancer Prevention, 13*(12), 6289–6294. http://dx.doi.org/10.7314/APJCP.2012.13.12.6289.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 5*(55), http://dx.doi.org/10.1037//0003-066X.55.5.469.

Azarbarzin, M., Malekian, A., & Taleghani, F. (2015). Effects of supportive-educative program on quality of life of adolescents living with a parent with cancer. *Iranian Journal of Nursing and Midwifery Research, 20*(5), 577–581. http://dx.doi.org/10.4103/1735-9066.164510.

Chalmers, K. I., Kristjanson, L. J., Woodgate, R., Taylor-Brown, J., Nelson, F., Ramserran, S., et al. (2000). Perceptions of the role of the school in providing information and support to adolescent children of women with breast cancer. *Journal of Advanced Nursing, 31*(6), 1430–1438. http://dx.doi.org/10.1046/j.1365-2648.2000.01449.x.

Chen, C. Y. C. (2017). Effects of parental chronic illness on Children's psychosocial and educational functioning: A literature review. *Contemporary School Psychology, 21*(2), 166–176. http://dx.doi.org/10.1007/s40688-016-0109-7.

Chen, R., Regodón, A., Sjölander, A., Valdimarsdóttir, U., Ye, W., Tiemeier, H., ... Fang, F. (2015a). Childhood injury after a parental cancer diagnosis. *eLife, 4*. http://dx.doi.org/10.7554/eLife.08500.

Chen, R., Sjölander, A., Valdimarsdóttir, U., Varnum, C., Almqvist, C., Ye, W., ... Fang, F. (2015b). Parental cancer diagnosis and child mortality–A population-based cohort study in Sweden. *Cancer Epidemiology, 39*(1), 79–85. https://doi.org/10.1016/j.canep.2014.11.011.

Christ, G. H., Siegel, K., & Sperber, D. (1994). Impact of parental terminal cancer on adolescents. *American Journal of Orthopsychiatry, 64*(4), 604–613. http://dx.doi.org/10.1037/h0079569.

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology, 12*(3), 297–298. http://dx.doi.org/10.1080/17439760.2016.1262613.

Clemmens, D. (2009). The significance of motherhood for adolescents whose mothers have breast cancer. *Oncology Nursing Forum, 36*(5), 571–577. http://dx.doi.org/10.1188/09.ONF.571-577.

Cohen, P. (2015). *The family: Diversity, inequality, and social change.* New York: Norton, W. W. & Company, Inc.

Compas, B. E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D. C., et al. (1994). When mom or dad has Cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology, 13*(6), 507-515. http://dx.doi.org/10.1037/0278-6133.13.6.507.

Davey, M., Askew, J., & Godette, K. (2003). Parent and adolescent responses to non-terminal parental cancer: A retrospective multiple-case pilot study. *Families, Systems & Health: The Journal of Collaborative Family HealthCare, 21*(3), 245. http://dx.doi.org/10.1037/1091-7527.21.3.245.

Ellis, S. J., Wakefield, C. E., Antill, G., Burns, M., & Patterson, P. (2016). Supporting children facing a parent's cancer diagnosis: A systematic review of children's psychosocial needs and existing interventions. *European Journal of Cancer Care*, 1–22. http://dx.doi.org/10.1111/ecc.12432.

Finch, A., & Gibson, F. (2009). How do young people find out about their parent's cancer diagnosis: A phenomenological study. *European Journal of Oncology Nursing, 13*(3), 213–222. http://dx.doi.org/10.1016/j.ejon.2009.03.010.

Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., van de Wiel, H. B., Visser, A., Huizinga, G. A., et al. (2011). Adolescents' emotional reactions to parental cancer: Effect on emotional and behavioral problems. *Journal of Pediatric Psychology, 36*(3), 346–359. http://dx.doi.org/10.1093/jpepsy/jsq090.

Grabiak, B. R., Bender, C. M., & Puskar, K. (2007). The impact of parental cancer on the adolescent: An analysis of the literature. *Psycho-Oncology, 16*(2), 127–137. http://dx.doi.org/10.1002/pon.1083.

---

[1] Studies preceded by an asterisk were included in the systematic review.

Houken, M. A., Sennerath, M., Dyregrov, A., & Dyregrov, K. (2017). Anxiety and the quality of life of children living with parental cancer. *Cancer Nursing, 00*(0), http://dx.doi.org/10.1097/ncc.0000000000000467.

Houck, C. D., Rodrigue, J. R., & Lobato, D. (2007). Parent-adolescent communication and psychological symptoms among adolescents with chronically ill parents. *Journal of Pediatric Psychology, 32*(5), 596–604. http://dx.doi.org/10.1093/jpepsy/jsl048.

Huang, X., O'Connor, M., & Lee, S. (2014). School-aged and adolescent children's experience when a parent has non-terminal cancer: A systematic review and meta-synthesis of qualitative studies. *Psycho-Oncology, 23*(5), 493–506. http://dx.doi.org/10.1002/pon.3457.

Huizinga, G. A., van der Graaf, W. T. A., Visser, A., Dijkstra, J. S., & Hoekstra-Weebers, H. J. (2003). Psychosocial consequences for children of a parent with cancer: A pilot study. *Cancer Nursing, 26*(3), 195–202. http://dx.doi.org/10.1097/00002820-200306000-00004.

Huizinga, G. A., Visser, A., van der Graaf, W. T., Hoekstra, H. J., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2010). Stress response symptoms in adolescents during the first year after a parent's cancer diagnosis. *Supportive Care in Cancer, 18*(11), 1421–1428. http://dx.doi.org/10.1007/s00520-009-0764-6.

Huizinga, G. A., Visser, A., van der Graaf, W. T., Hoekstra, H. J., & Hoekstra-Weebers, J. E. (2005). The quality of communication between parents and adolescent children in the case of parental cancer. *Annals of Oncology, 16*(12), 1956–1961. http://dx.doi.org/10.1093/annonc/mdi395.

Jantzer, V., Groß, J., Stute, F., Parzer, P., Brunner, R., Willig, K., ... Resch, F. (2013). Risk behaviors and externalizing behaviors in adolescents dealing with parental cancer—a controlled longitudinal study. *Psycho-Oncology, 22*(11), 2611–2616. http://dx.doi.org/10.1002/pon.3327.

Jeppesen, E., Bjelland, I., Fosså, S. D., Loge, J. H., & Dahl, A. A. (2013). Psychosocial problems of teenagers who have a parent with cancer: A population-based case-control study (young-HUNT study). *Journal of Clinical Oncology, 31*(32), 4099–4104. http://dx.doi.org/10.1200/jco.2013.50.7061.

Jeppesen, E., Bjelland, I., Fosså, S. D., Loge, J. H., & Dahl, A. A. (2016). Health-related quality of life in teenagers with a parent with cancer. *European Journal of Oncology Nursing, 22*, 46–53. http://dx.doi.org/10.1016/j.ejon.2016.03.004.

Korneluk, Y. G., & Lee, C. M. (1998). Children's adjustment to parental physical illness. *Clinical Child and Family Psychology Review, 1*(3), 179–193. http://dx.doi.org/10.1023/A:1022654831666.

Kühne, F., Krattenmacher, T., Bergelt, C., Beierlein, V., Herzog, W., Klitzing, K. V., & Möller, B. (2013). "There is still so much ahead of us"—family functioning in families of palliative cancer patients. *Families, Systems & Health, 31*(2), 181–193. http://dx.doi.org/10.1037/a0032274.

Lazarus, R. S. (1974). Psychological stress and coping in adaptation and illness. *International Journal of Psychiatry in Medicine, 5*(4), 321–333. http://dx.doi.org/10.2190/t43t-84p3-qdur-7rjp.

Lewis, F. M. (2011). *Therapy for parental cancer and dependent children. Handbook of psychotherapy in cancer care.* John Wiley & Sons, Ltd225–234. http://dx.doi.org/10.1002/9780470975176.ch19.

McDonald, F., 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. http://dx.doi.org/10.1002/pon.3942.

Möller, B., Barkmann, C., Krattenmacher, T., Kühne, F., Bergelt, C., Beierlein, V., ... Romer, G. (2014). Children of cancer patients: Prevalence and predictors of emotional and behavioral problems. *Cancer, 120*(15), 2361–2370. http://dx.doi.org/10.1002/cncr.28644.

Morris, J. N., Martini, A., & Preen, D. (2016). The well-being of children impacted by a parent with cancer: An integrative review. *Supportive Care in Cancer, 24*(7), 3235–3251. http://dx.doi.org/10.1007/s00520-016-3214-2.

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. https://doi.org/10.1016/j.cpr.2004.12.003.

Nelson, E., & While, D. (2002). Children's adjustment during the first year of a parent's cancer diagnosis. *Journal of Psychosocial Oncology, 20*(1), 15–36. http://dx.doi.org/10.1300/J077v20n01_02.

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. http://dx.doi.org/10.1002/ijc.27466.

Niemelä, M., Paananen, R., Hakko, H., Merikukka, M., Gissler, M., & Rasanen, S. (2016). Mental disorder diagnoses of offspring affected by parental cancer before early adulthood: The 1987 Finnish birth cohort study. *Psycho-Oncology.* http://dx.doi.org/10.1002/pon.4088.

Osborn, T. (2007). The psychosocial impact of parental cancer on children and adolescents: A systematic review. *Psycho-Oncology, 16*(2), 101–126. http://dx.doi.org/10.1002/pon.1113.

Phillips, F. (2014). Adolescents living with a parent with advanced cancer: A review of the literature. *Psycho-Oncology, 23*(12), 1323–1339. http://dx.doi.org/10.1002/pon.3570.

Phillips, F., & Lewis, F. M. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. *Palliative Medicine, 29*(9), 851–858. http://dx.doi.org/10.1177/0269216315578989.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., ... Rousseau, M. C. (2011). *A mixed methods appraisal tool for systematic mixed studies reviews.* Montreal, Canada: Department of Family Medicine, McGill University.

QSR International Pty Ltd (2012). *NVivo qualitative data analysis Software.* Version 10.

Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process, 26*(2), 203–221. http://dx.doi.org/10.1111/j.1545-5300.1987.00203.x.

Sheehan, D. K., & Draucker, C. B. (2011). Interaction patterns between parents with advanced cancer and their adolescent children. *Psycho-Oncology, 20*(10), 1108–1115. http://dx.doi.org/10.1002/pon.1831.

Sieh, D. S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M. A., & Van der Leij, D. A. V. (2010). Problem behavior in children of chronically ill parents: A meta-analysis. *Clinical Child and Family Psychology Review, 13*(4), 384–397. http://dx.doi.org/10.1007/s10567-010-0074-z.

Sieh, D. S., Visser-Meily, J. M., & Meijer, A. M. (2013). Differential outcomes of adolescents with chronically ill and healthy parents. *Journal of Child and Family Studies, 22*(2), 209–218. http://dx.doi.org/10.1007/s10826-012-9570-8.

Silvers, J. A., McRae, K., Gabrieli, J. D., Gross, J. J., Remy, K. A., & Ochsner, K. N. (2012). Age-related differences in emotional reactivity, regulation, and rejection sensitivity in adolescence. *Emotion, 12*(6), 1235–1247. http://dx.doi.org/10.1037/a0028297.

Spear, L. P. (2000). The adolescent brain and age-related behavioral manifestations. *Neuroscience & Biobehavioral Reviews, 24*(4), 417–463. http://dx.doi.org/10.1016/S0149-7634(00)00014-2.

Steinberg, L. (2005). Cognitive and affective development in adolescence. *Trends in Cognitive Sciences, 9*(2), 69–74. http://dx.doi.org/10.1016/j.tics.2004.12.005.

Su, Y., & Ryan-Wenger, N. (2007). Children's adjustment to parental cancer: A theoretical model development. *Cancer Nursing, 30*(5), 362–381. http://dx.doi.org/10.1097/01.NCC.0000290817.37442.e6.

Thastum, M., Johansen, M. B., Gubba, L., Olesen, L. B., & Romer, G. (2008). Coping, social relations, and communication: A qualitative exploratory study of children of parents with cancer. *Clinical Child Psychology and Psychiatry, 13*(1), 123–138. http://dx.doi.org/10.1177/1359104507086345.

Thastum, M., Watson, M., Kienbacher, C., Piha, J., Steck, B., Zachariae, R., & Romer, G. (2009). Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer. *Cancer, 115*(17), 4030–4039. http://dx.doi.org/10.1002/cncr.24449.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the pediatric quality of life inventory™ version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*(8), 12. http://dx.doi.org/10.1097/00005650-200108000-00006.

de Vaus, D. (2004). In Australia Government (Ed.). *Diversity and change in Australian families: Statistical profiles* (pp. 352). Melbourne, Australia: Australian Institute of Family Studies (AIFS).

Visser, A., Huizinga, G. A., Hoekstra-Weebers, J. E., van der Graaf, W. T., & Hoekstra, H. J. (2004). The impact of parental cancer on children and the family: A review of the literature. *Cancer Treatment Reviews*, (8), 683–694. http://dx.doi.org/10.1016/j.ctrv.2004.06.001.

Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2007). Emotional and behavioral problems in children of parents recently diagnosed with cancer: A longitudinal study. *Acta Oncologica, 46*(1), 67–76.

Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., & Hoekstra-Weebers, J. E. (2006). Parental cancer: Characteristics of parents as predictors for child functioning. *Cancer, 106*(5), 1178–1187. http://dx.doi.org/10.1002/cncr.21691.

Walczak, A., McDonald, F., Patterson, P., Dobinson, K., & Allison, K. (2017). How does parental cancer affect adolescent and young adult offspring? A systematic review. *International Journal of Nursing Studies, 77*, 54–80.

Wonghongkul, T., Dechaprom, N., Phumivichuvate, L., & Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing, 29*(3), 250–257.

World Health Organization (2016). *Adolescent development. Maternal, newborn, child and adolescent health.* from http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/.

References

Adelson, D. L. (2012). The effects of maternal breast cancer on daughters' body image and sexual functioning. *Dissertation Abstracts International: Section B Sciences and Engineering, 72,* 7034.

Ainuddin, H. A., Loh, S. Y., Low, W. Y., Sapihis, M., & Roslani, A. C. (2012). Quality of life of multiethnic adolescents living with a parent with cancer. *Asian Pacific Journal of Cancer Prevention, 13,* 6289-6294. doi: 10.7314/apjcp.2012.13.12.6289

Albaum, G., & Smith, S. M. (2012). Why People Agree to Participate in Surveys *Handbook of Survey Methodology for the Social Sciences* (pp. 179-193). New York, NY: Springer New York.

Antoni, M. H., Lehman, J. M., Kilbourn, K. M., Boyers, A. E., Culver, J. L., Alferi, S. M., . . . Carver, C. S. (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychol, 20,* 20-32. doi: 10.1037/0278-6133.20.6.458a

Armistead, L., Klein, K., & Forehand, R. (1995). Parental physical illness and child functioning. *Clinical Psychology Review, 15,* 409-422. doi: 10.1016/0272-7358(95)00023-I

Arnett, J. J. (2000). Emerging Adulthood: A Theory of Development From the Late Teens Through the Twenties. *American Psychologist, 55,* 469-480.

Arnholdt, J., & Haier, J. (2017). Cancer patients' preferences for therapy decisions can be grouped into categories and separated by demographic factors. *J Cancer Res Clin Oncol, 143,* 1573-1584. doi: 10.1007/s00432-017-2390-x

Ashurst, K. L., Hans, J. D., & Smith, D. R. (2009). The resilience factor: What extension can learn from adolescents coping with parental cancer. *Journal of Extension, 47.*

Australian Bureau of Statistics. (2008). Internet Access at Home *Australian Social Trends, 2008*. Canberra, Australia: ABS.

Australian Bureau of Statistics. (2011). Remoteness Structure *Australian Statistical Geography Standard (ASGS)*. Canberra, Australia: ABS.

Australian Bureau of Statistics. (2013). Socioeconomic Indexes for Areas (SEIFA). Retrieved from http://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa

Australian Bureau of Statistics. (2015). Family Characteristics and Transitions, Australia, 2012-13. Canberra, Australia: ABS.

Australian Bureau of Statistics. (2016, 22/09/2016). 3101.0 - Australian Demographic Statistics, Mar 2016. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0

Australian Bureau of Statistics. (2018). *Population Estimates by Remoteness Area, (2007 to 2017)*. Retrieved from: http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3218.02016-17?OpenDocument

Australian Institute of Health and Welfare. (2008). Cancer survival and prevalence in Australia. Canberra, Australia: AIHW.

Australian Institute of Health and Welfare. (2011). Young Australians: their health and wellbeing 2011. Canberra, Australia: AIHW.

Australian Institute of Health and Welfare. (2017). Cancer in Australia 2017. Canberra, Australia: AIHW.

Australian Institute of Health and Welfare. (2018). Australia’s Health 2018. Canberra, Australia: AIHW.

Australian Institute of Health and Welfare. (2018). Cancer in Aboriginal & Torres Strait Islander people of Australia. Canberra, Australia: AIHW.

Azarbarzin, M., Malekian, A., & Taleghani, F. (2015). Effects of supportive-educative program on quality of life of adolescents living with a parent with cancer. *Iran J Nurs Midwifery Res, 20*, 577-581. doi: 10.4103/1735-9066.164510

Banks, P., Cogan, N., Deeley, S., Hill, M., Riddell, S., & Tisdall, K. (2001). Seeing the Invisible Children and Young People Affected by Disability. *Disability & Society, 16*, 797-814. doi: 10.1080/09687590120083967

Barkmann, C., Romer, G., Watson, M., & Schulte-Markwort, M. (2007). Parental Physical Illness as a Risk for Psychosocial Maladjustment in Children and Adolescents: Epidemiological Findings From a National Survey in Germany. *Psychosomatics, 48*, 476-481. doi: 10.1176/appi.psy.48.6.476

Bartfai Jansson, K., & Anderzen-Carlsson, A. (2017). Adolescents' Perspectives of Living With a Parent's Cancer: A Unique and Personal Experience. *Cancer Nurs, 40*, 94-101. doi: 10.1097/ncc.0000000000000358

Baxter, J. (2016). The modern Australian family. Retrieved from https://aifs.gov.au/publications/modern-australian-family

Beatty, L., Koczwara, B., & Wade, T. (2016). Evaluating the efficacy of a self-guided Web-based CBT intervention for reducing cancer-distress: a randomised controlled trial. *Support Care Cancer, 24*, 1043-1051. doi: 10.1007/s00520-015-2867-6

Bell, J., Reed, S. C., Blackmon, E., Kim, K. K., & Joseph, J. G. (2016). Parenting experiences of cancer survivors with young children in the 2012 LIVESTRONG Survey for People Affected by Cancer. *Journal of Clinical Oncology*, 189. doi: 10.1200/jco.2016.34.3_suppl.189

Berggren, U. J., & Hanson, E. (2016). Children as Next of Kin: A Scoping Review of Support Interventions for Children Who have a Parent with a Serious Physical Illness. *Child Care in Practice*, 277-295. doi: 10.1080/13575279.2015.1102125

Block, J., & Kremen, A. M. (1996). IQ and ego-resiliency: conceptual and empirical connections and separateness. *Journal of Personality and Social Psychology, 70*, 349-361.

Booth, M. L., Bernard, D., Quine, S., Kang, M. S., Usherwood, T., Alperstein, G., & Bennett, D. L. (2004). Access to health care among Australian adolescents young people's perspectives and their sociodemographic distribution. *J Adolesc Health, 34*, 97-103.

Boyd, J. H., Randall, S. M., Ferrante, A. M., Bauer, J. K., McInneny, K., Brown, A. P., . . . Semmens, J. B. (2015). Accuracy and completeness of patient pathways- the benefits of national data linkage in Australia. *BMC Health Services Research, 15*. doi: 10.1186/s12913-015-0981-2

Bray, F., & Parkin, D. M. (2009). Evaluation of data quality in the cancer registry: Principles and methods. Part I: Comparability, validity and timeliness. *European Journal of Cancer*, *45*, 747-755. doi: https://doi.org/10.1016/j.ejca.2008.11.032

Brownlow, C. (2005). *SPSS explained*. New York: Routledge.

Bylund-Grenklo, T., Kreicbergs, U., Uggla, C., Valdimarsdóttir, U. A., Nyberg, T., Steineck, G., & Fürst, C. J. (2015). Teenagers want to be told when a parent's death is near: A nationwide study of cancer-bereaved youths' opinions and experiences. *Acta Oncologica, 54*, 944-950 947p. doi: 10.3109/0284186X.2014.978891

Bylund-Grenklo, T., Kreicbergs, U. C., Valdimarsdóttir, U. A., Nyberg, T., Steineck, G., & Fürst, C. J. (2013). Communication and trust in the care provided to a dying parent: a nationwide study of cancer-bereaved youths. *Journal of Clinical Oncology, 31*, 2886-2894. doi: 10.1200/JCO.2012.46.6102

Camp Quality. (2014). Media and news. Retrieved from https://www.campquality.org.au/about-us/media-and-news/national/26-national/119-

camp-quality-will-be-first-australian-charity-to-support-children-under-13-who-have-a-parent-with-cancer

Campbell-Sills, L., Cohan, S. L., & Stein, M. B. (2006). Relationship of resilience to personality, coping, and psychiatric symptoms in young adults. *Behaviour Research and Therapy, 44*, 585-599. doi: 10.1016/j.brat.2005.05.001

Cancer Australia, & CanTeen. (2008). National Service Delivery Framework for Adolescents and Young Adults with Cancer.

CanTeen. (2016). Cancer's different in a young person's world. Retrieved from https://www.canteen.org.au/

CanTeen Australia. (2018). CanTeen is here for you if you're 12-25 and cancer has turned your world upside down. Retrieved from https://www.canteen.org.au/

Cappelli, M., Verma, S., Korneluk, Y., Hunter, A., Tomiak, E., Allanson, J., . . . Humphreys, L. (2005). Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer. *Clinical Genetics, 67*, 481-491. doi: 10.1111/j.1399-0004.2005.00456.x

Carpenter, K. M., Stoner, S. A., Schmitz, K., McGregor, B. A., & Doorenbos, A. Z. (2014). An online stress management workbook for breast cancer. *Journal of Behavioral Medicine, 37*, 458-468. doi: 10.1007/s10865-012-9481-6

Carver, C. S. (1997). You want to measure coping but your protocol's too long: consider the brief COPE. *International Journal of Behavioral Medicine, 4*, 92-100. doi: 10.1207/s15327558ijbm0401_6

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology, 56*, 267-283. doi: 10.1037//0022-3514.56.2.267

Cataldo, J. K., & Brodsky, J. L. (2013). Lung cancer stigma, anxiety, depression and symptom severity. *Oncology, 85*, 33-40. doi: 10.1159/000350834

Chalmers, K. I., Kristjanson, L. J., Woodgate, R., Taylor-Brown, J., Nelson, F., Ramserran, S., & Dudgeon, D. (2000). Perceptions of the role of the school in providing information and support to adolescent children of women with breast cancer. *Journal of Advanced Nursing, 31*, 1430-1438. doi: 10.1046/j.1365-2648.2000.01449.x

Chen, C. M., Du, B. F., Ho, C. L., Ou, W. J., Chang, Y. C., & Chen, W. C. (2017). Perceived Stress, Parent-Adolescent/Young Adult Communication, and Family Resilience Among Adolescents/Young Adults Who Have a Parent With Cancer in Taiwan: A Longitudinal Study. *Cancer Nurs*. doi: 10.1097/ncc.0000000000000488

Chen, R., Regodón, A., Sjölander, A., Valdimarsdóttir, U., Ye, W., Tiemeier, H., . . . Fang, F. (2015). Childhood injury after a parental cancer diagnosis. *eLife, 4*. doi: 10.7554/eLife.08500

Chen, R., Sjölander, A., Valdimarsdóttir, U., Varnum, C., Almqvist, C., Ye, W., . . . Fang, F. (2015). Parental cancer diagnosis and child mortality-A population-based cohort study in Sweden. *Cancer Epidemiology, 39*, 79-85. doi: 10.1016/j.canep.2014.11.011

Chen, Y. (2017). Effects of Parental Chronic Illness on Children’s Psychosocial and Educational Functioning: a Literature Review. *Contemporary School Psychology, 21*, 166-176. doi: 10.1007/s40688-016-0109-7

Chesney, M. A., Chambers, D. B., Taylor, J. M., Johnson, L. M., & Folkman, S. (2003). Coping effectiveness training for men living with HIV: results from a randomized clinical trial testing a group-based intervention. *Psychosom Med, 65*, 1038-1046. doi: 10.1097/01.psy.0000097344.78697.ed

Christ, G. H., Siegel, K., & Sperber, D. (1994). Impact of parental terminal cancer on adolescents. *American Journal of Orthopsychiatry, 64,* 604-613. doi: doi.org/10.1037/h0079569

Clark, A., Preen, D. B., Ng, J. Q., Semmens, J. B., & Holman, C. D. (2010). Is Western Australia representative of other Australian States and Territories in terms of key socio-demographic and health economic indicators? *Australian Health Review, 34,* 210-215. doi: 10.1071/ah09805

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology, 12,* 297-298. doi: 10.1080/17439760.2016.1262613

Clemmens, D. (2009). The Significance of Motherhood for Adolescents Whose Mothers Have Breast Cancer. *Oncology Nursing Forum, 36,* 571-577. doi: doi.org/10.1188/09.onf.571-577

Cohen, M. M., Wellisch, D. K., Ormseth, S. R., & Yarema, V. G. (2017). The father-daughter relationship in the wake of maternal death from breast cancer. *Palliat Support Care,* 1-8. doi: 10.1017/s1478951517000906

Cohen, P. (2013). *The Family: Diversity, Inequality, and Social Change* New York: Norton.

Cohen, S., Alper, C. M., Doyle, W. J., Treanor, J. J., & Turner, R. B. (2006). Positive Emotional Style Predicts Resistance to Illness After Experimental Exposure to Rhinovirus or Influenza A Virus. *Psychosomatic Medicine, 68,* 809-815. doi: 10.1097/01.psy.0000245867.92364.3c

Cohen, S., & Pressman, S. D. (2006). Positive Affect and Health. *Current Directions in Psychological Science, 15,* 122-125. doi: doi:10.1111/j.0963-7214.2006.00420.x

Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H., & Wadsworth, M. E. (2001). Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. *Psychol Bull, 127*, 87-127. doi: 10.1037//0033-2909.127.1.87

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*, 507-515. doi: doi.org/10.1037/10338-011

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*, 167-175. doi: 10.1037//0278-6133.15.3.167

Conrad, F., Blair, J., & Tracy, E. (1999). *Verbal reports are data! A theoretical approach to cognitive interviews.* Paper presented at the Proceedings of the Federal Committee on Statistical Methodology Research Conference.

Corney, R., Puthussery, S., & Swinglehurst, J. (2016). Couple relationships in families with dependent children after a diagnosis of maternal breast cancer in the United Kingdom: Perspectives from mothers and fathers. *Journal of Psychosocial Oncology, 34*, 413-431. doi: 10.1080/07347332.2016.1199080

Costas-Muniz, R. (2012). Hispanic adolescents coping with parental cancer. *Supportive Care in Cancer, 20*, 413-417. doi: 10.1007/s00520-011-1283-9

Crone, E., & Dahl, R. (2012). *Understanding adolescence as a period of social-affective engagement and goal flexibility*.

Crosnoe, R., & Johnson, M. K. (2011). Research on Adolescence in the Twenty-First Century. *Annu Rev Sociol, 37*, 439-460. doi: 10.1146/annurev-soc-081309-150008

Crowe, J. (2016, 19 September). RegEx Patterns for Complex Validation. Retrieved from https://help.surveygizmo.com/help/textbox-answer-formats#setting-up-regex

Davey, M., Askew, J., & Godette, K. (2003). Parent and Adolescent Responses to Non-Terminal Parental Cancer: A Retrospective Multiple-Case Pilot Study. *Families, Systems & Health: The Journal of Collaborative Family HealthCare, 21*, 245. doi: 10.1037/1091-7527.21.3.245

Davey, M., Gulish, L., Askew, J., Godette, K., & Childs, N. (2005). Adolescents coping with mom's breast cancer: Developing family intervention programs. *J. Marital Fam. Ther., 31*, 247-258.

Davey, M. P., Tubbs, C. Y., Kissil, K., & Nino, A. (2011). 'We are survivors too': African-American youths' experiences of coping with parental breast cancer. *Psycho-Oncology, 20*, 77-87. doi: 10.1002/pon.1712

de Vaus, D. (2004). Diversity and change in Australian families: Statistical profiles (pp. 352). Melbourne, Australia: Australian Institute of Family Studies (AIFS).

Dempsey, D. (2013). *Same-sex parented families in Australia*. Melbourne, Australia: Australian Institute of Family Studies (AIFS).

Department of the Attorney General. (2017). Births, Deaths and Marriages. Retrieved from http://www.bdm.dotag.wa.gov.au

DeVellis, R. F. (2011). *Scale Development: Theory and Applications*: SAGE Publications.

Diehl, M., Hay, E. L., & Berg, K. M. (2011). The Ratio between Positive and Negative Affect and Flourishing Mental Health across Adulthood. *Aging & Mental Health, 15*, 882-893. doi: 10.1080/13607863.2011.569488

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, Phone, Mail, and Mixed-Mode Surveys: The Tailored Design Method*. Hoboken: NJ: Wiley.

Donaldson, S. I., Dollwet, M., & Rao, M. A. (2015). Happiness, excellence, and optimal human functioning revisited: Examining the peer-reviewed literature linked to positive psychology. *The Journal of Positive Psychology, 10*, 185-195. doi: 10.1080/17439760.2014.943801

Downey, F., & Gee, V. (2006). Guidelines for Completion of the Notification of Case Attended Health Act (Notification by Midwife) Regulations Form No.2. In Department of Health (Ed.).

Drennan, J. (2002). Cognitive interviewing: Verbal data in the design and pretesting of questionnaires. *Journal of Advanced Nursing, 42*, 57-63. doi: 10.1046/j.1365-2648.2003.02579.x

Duan, W., Guo, P., & Gan, P. (2015). Relationships among Trait Resilience, Virtues, Post-traumatic Stress Disorder, and Post-traumatic Growth. *PLOS ONE, 10*, e0125707. doi: 10.1371/journal.pone.0125707

Duchnick, J. J., Letsch, E. A., & Curtiss, G. (2009). Coping effectiveness training during acute rehabilitation of spinal cord injury/dysfunction: A randomized clinical trial. *Rehabilitation Psychology, 54*, 123-132. doi: 10.1037/a0015571

Duffecy, J., Sanford, S., Wagner, L., Begale, M., Nawacki, E., & Mohr, D. C. (2013). Project onward: an innovative e-health intervention for cancer survivors. *Psycho-Oncology, 22*, 947-951. doi: doi:10.1002/pon.3075

Edwards, L., Watson, M., James-Roberts, I., Ashley, S., Tilney, C., Brougham, B., . . . Romer, G. (2008). Adolescent's stress responses and psychological functioning when a parent has early breast cancer. *Psycho-Oncology, 17*, 1039-1047. doi: http://dx.doi.org/10.1002/pon.1323

Eitelhuber, T. (2016). *Theory of Data Linkage Methods: Characterising Populations Using Linked Health Data*. Powerpoint presentation. Western Australia Data Linkage Service.

Ellis, S. J., Wakefield, C. E., Antill, G., Burns, M., & Patterson, P. (2016). Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions. *European Journal of Cancer Care*, 1-22. doi: 10.1111/ecc.12432

Fennell, K. M., Turnbull, D. A., Bidargaddi, N., McWha, J. L., Davies, M., & Olver, I. (2016). The consumer-driven development and acceptability testing of a website designed to connect rural cancer patients and their families, carers and health professionals with appropriate information and psychosocial support. *European Journal of Cancer Care*, 1-15. doi: 10.1111/ecc.12533

Finch, A., & Gibson, F. (2009). How do young people find out about their parent's cancer diagnosis: A phenomenological study. *European Journal of Oncology Nursing, 13*, 213-222. doi: 10.1016/j.ejon.2009.03.010

Fisher, C. L., Wolf, B. M., Fowler, C., & Canzona, M. R. (2017). Experiences of "openness" between mothers and daughters during breast cancer: implications for coping and healthy outcomes. *Psycho-Oncology, 26*, 1872-1880. doi: 10.1002/pon.4253

Folkman, S., & Lazarus, R. S. (1988). Coping as a mediator of emotion. *J Pers Soc Psychol, 54*, 466-475.

Folkman, S., & Lazarus, R. S. (1988). The relationship between coping and emotion: Implications for theory and research. *Social Science & Medicine, 26*, 309-317. doi: https://doi.org/10.1016/0277-9536(88)90395-4

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *J Pers Soc Psychol, 50*, 571-579.

Forster-Jones, J. (2007, 2007). Family diversification in Australia: the increasing share of blended and step families. Retrieved from http://arrow.monash.edu.au/hdl/1959.1/482071

Fredrickson, B. L. (1998). What Good Are Positive Emotions? *Review of general psychology: journal of Division 1, of the American Psychological Association, 2,* 300-319. doi: 10.1037/1089-2680.2.3.300

Fredrickson, B. L. (2004). The broaden-and-build theory of positive emotions. *Philosophical Transactions of the Royal Society B: Biological Sciences, 359,* 1367-1378. doi: 10.1098/rstb.2004.1512

Fredrickson, B. L., & Joiner, T. (2002). Positive emotions trigger upward spirals toward emotional well-being. *Psychological Science, 13*, 172-175. doi: 10.1111/1467-9280.00431

Garland, E. L., Fredrickson, B., Kring, A. M., Johnson, D. P., Meyer, P. S., & Penn, D. L. (2010). Upward spirals of positive emotions counter downward spirals of negativity: insights from the broaden-and-build theory and affective neuroscience on the treatment of emotion dysfunctions and deficits in psychopathology. *Clin Psychol Rev, 30,* 849-864. doi: 10.1016/j.cpr.2010.03.002

Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., van de Wiel, H. B., Visser, A., Huizinga, G. A., & Hoekstra-Weebers, J. E. (2011). Adolescents’ Emotional Reactions to Parental Cancer: Effect on Emotional and Behavioral Problems. *Journal of Pediatric Psychology, 36*, 346-359. doi: 10.1093/jpepsy/jsq090

Gee, D. G., Humphreys, K. L., Flannery, J., Goff, B., Telzer, E. H., Shapiro, M., . . . Tottenham, N. (2013). A Developmental Shift from Positive to Negative Connectivity in Human Amygdala–Prefrontal Circuitry. *The Journal of Neuroscience, 33*, 4584-4593. doi: 10.1523/jneurosci.3446-12.2013

Giesbers, J., Verdonck-de Leeuw, I. M., van Zuuren F. J., Kleverlaan N., & H., v. d. L. M. (2010). Coping with parental cancer: web-based peer support in children. *Psycho-Oncology, 19*, 887-892. doi: 10.1002/pon.1636

Gloria, C. T., & Steinhardt, M. A. (2016). Relationships Among Positive Emotions, Coping, Resilience and Mental Health. *Stress and Health, 32*, 145-156. doi: 10.1002/smi.2589

Graber, J. A., Brooks-Gunn, J., & Petersen, A. C. (1996). *Transitions Through Adolescence: Interpersonal Domains and Context*: Taylor & Francis Group.

Haggar, F. A. A. (2016). *Cancer in the adolescent and young adult population of Western Australia.* (Ph.D Doctoral Thesis), The University of Western Australia.

Haigh M, Burns J, Potter C, Elwell M, Hollows M, Mundy J, . . . S, T. (2018). Review of cancer among Aboriginal and Torres Strait Islander people. *Australian Indigenous HealthBulletin, 18*.

Hall, S. E., Holman, C. D. a., & Sheiner, H. (2004). The influence of socio-economic and locational disadvantage on patterns of surgical care for lung cancer in Western Australia 1982-2001. *Australian Health Review, 27,* 68-79. doi: 10.1071/ah042720068

Hauken, M. A., Pereira, M., & Senneseth, M. (2017). The Effects on Children's Anxiety and Quality of Life of a Psychoeducational Program for Families Living With Parental Cancer and Their Network: A Randomized Controlled Trial Study. *Cancer Nurs*. doi: 10.1097/ncc.0000000000000529

Hauken, M. A., Senneseth, M., Dyregrov, A., & Dyregrov, K. (2017). Anxiety and the Quality of Life of Children Living With Parental Cancer. *Cancer Nursing, 00*. doi: 10.1097/ncc.0000000000000467

Heathcote, K. E., & Armstrong, B. K. (2007). Disparities in cancer outcomes in regional and rural Australia *Cancer Forum* (Vol. 31). Sydney, Australia: Cancer Council Australia,.

Helgeson, V. S., Reynolds, K. A., & Tomich, P. L. (2006). A Meta-Analytic Review of Benefit Finding and Growth. *Journal of Consulting and Clinical Psychology, 74,* 797-816.

Hirooka, K., Fukahori, H., Akita, Y., & Ozawa, M. (2016). Posttraumatic Growth Among Japanese Parentally Bereaved Adolescents: A Web-Based Survey. *American Journal of Hospice and Palliative Medicine*, 1-7. doi: 10.1177/1049909115627776

Hoeg, B. L., Appel, C. W., von Heymann-Horan, A. B., Frederiksen, K., Johansen, C., Boge, P., . . . Bidstrup, P. E. (2017). Maladaptive coping in adults who have experienced early parental loss and grief counseling. *J Health Psychol, 22*, 1851-1861. doi: 10.1177/1359105316638550

Hoffman, J. M., Bombardier, C. H., Graves, D. E., Kalpakjian, C. Z., & Krause, J. S. (2011). A longitudinal study of depression from 1 to 5 years after spinal cord injury. *Arch Phys Med Rehabil, 92*, 411-418. doi: 10.1016/j.apmr.2010.10.036

Hoffnung, M., Hoffnung, R., Seifert, K. L., Hine, A., Ward, L., Pausé, C., . . . Burton Smith, R. (2015). *Lifespan Development: a chronological approach*. Brisbane, Australia: Wiley.

Holman, C. D., Bass, A. J., Rouse, I. L., & Hobbs, M. S. (1999). Population-based linkage of health records in Western Australia: development of a health services research linked database. *Australian and New Zealand Journal of Public Health, 23*, 453-459.

Houck, C. D., Rodrigue, J. R., & Lobato, D. (2007). Parent-adolescent communication and psychological symptoms among adolescents with chronically ill parents. *J Pediatr Psychol, 32*, 596-604. doi: 10.1093/jpepsy/jsl048

Howell, K., Barrett-Becker, E., Burnside, A., Wamser-Nanney, R., Layne, C., & Kaplow, J. (2016). Children Facing Parental Cancer Versus Parental Death: The Buffering Effects of Positive Parenting and Emotional Expression. *J Child Fam Stud, 25*, 152-164. doi: 10.1007/s10826-015-0198-3

Hoyt, J. E., & Winn, B. A. (2004). Understanding Retention and College Student Bodies: Differences Between Drop-Outs, Stop-Outs, Opt-Outs, and Transfer-Outs. *NASPA Journal, 41*, 395-417. doi: 10.2202/1949-6605.1351

Huang, X., O'Connor, M., & Lee, S. (2014). School-aged and adolescent children's experience when a parent has non-terminal cancer: a systematic review and meta-synthesis of qualitative studies. *Psycho-Oncology, 23*, 493-506. doi: 10.1002/pon.3457

Huizinga, G. A., Van der Graaf, W. T. A., Visser, A., Dijkstra, J. S., & Hoekstra-Weebers, H. J. (2003). Psychosocial Consequences for Children of a Parent With Cancer: A Pilot Study. *Cancer Nursing, 26*, 195-202. doi: 10.1097/00002820-200306000-00004

Huizinga, G. A., Visser, A., van der Graaf, W. T., Hoekstra, H. J., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2010). Stress response symptoms in adolescents during the first year after a parent's cancer diagnosis. *Supportive Care in Cancer, 18,* 1421-1428. doi: 10.1007/s00520-009-0764-6

Huizinga, G. A., Visser, A., van der Graaf, W. T., Hoekstra, H. J., & Hoekstra-Weebers, J. E. (2005). The quality of communication between parents and adolescent children in the case of parental cancer. *Annals of Oncology, 16*, 1956-1961. doi: 10.1093/annonc/mdi395

Hulbert-Williams, N., McHugh, R., Semlyen, J., Flowers, P., Storey, L., Ream, E., & Neal, R. (2014). *What are the experiences of cancer care in gay, lesbian and bisexual patients, and how do these differ from heterosexual cancer patients?* Paper presented at the NCRI Cancer Conference, Liverpool, UK.

Inbar, C., Ety, B., Ayala, H., & Tamer, P. (2013). The mental health of breast cancer survivors and their adolescent daughters. *Psycho-Oncology, 22*, 1236-1241. doi: 10.1002/pon.3127

Inoue, I., Higashi, T., Iwamoto, M., Heiney, S. P., Tamaki, T., Osawa, K., . . . Matoba, M. (2015). A national profile of the impact of parental cancer on their children in Japan. *Cancer Epidemiology, 39*, 838. doi: 10.1016/j.canep.2015.10.005

Institute of Medicine, & National Research Council. (2015). *Investing in the Health and Well-Being of Young Adults*. Washington, DC: The National Academies Press.

Ireland, M. J., & Pakenham, K. I. (2010). The nature of youth care tasks in families experiencing chronic illness/disability: development of the Youth Activities of Caregiving Scale (YACS). *Psychol Health, 25*, 713-731. doi: 10.1080/08870440902893724

Ireland, M. J., & Pakenham, K. I. (2010). Youth adjustment to parental illness or disability: the role of illness characteristics, caregiving, and attachment. *Psychol Health Med, 15*, 632-645. doi: 10.1080/13548506.2010.498891

Jantzer, V., Groß, J., Stute, F., Parzer, P., Brunner, R., Willig, K., . . . Resch, F. (2013). Risk behaviors and externalizing behaviors in adolescents dealing with parental cancer—a controlled longitudinal study. *Psycho-Oncology, 22*, 2611-2616. doi: 10.1002/pon.3327

Jeppesen, E., Bjelland, I., Fossa, S. D., Loge, J. H., & Dahl, A. A. (2013). Psychosocial problems of teenagers who have a parent with cancer: a population-based case-control study (young-HUNT study). *Journal of Clinical Oncology, 31*, 4099-4104. doi: 10.1200/jco.2013.50.7061

Jeppesen, E., Bjelland, I., Fossa, S. D., Loge, J. H., & Dahl, A. A. (2016). Health-related quality of life in teenagers with a parent with cancer. *European Journal of Oncology Nursing, 22*, 46-53. doi: 10.1016/j.ejon.2016.03.004

Joergensen, A. C., Kjaer Urhoj, S., & Nybo Andersen, A. M. (2018). Primary school achievement and socioeconomic attainment in individuals affected by parental cancer in childhood or adolescence: a Danish nationwide register-based study. *J Epidemiol Community Health*. doi: 10.1136/jech-2018-210472

Johnston, M., Martin, D., Martin, M., & Gumaer, J. (1992). Long-term parental illness and children: Perils and promises. *School Counselor, 39*, 225-231.

Kaplow, J. B., Howell, K. H., & Layne, C. M. (2014). Do circumstances of the death matter? Identifying socioenvironmental risks for grief-related psychopathology in bereaved youth. *J Trauma Stress, 27*, 42-49. doi: 10.1002/jts.21877

Kapp, J. M., Peters, C., & Oliver, D. P. (2013). Research recruitment using Facebook advertising: big potential, big challenges. *Journal of Cancer Education, 28*, 134-137. doi: 10.1007/s13187-012-0443-z

Kashani, F. L., Vaziri, S., Akbari, M. E., Jamshidifar, Z., & Sanaei, H. (2014). Stress Coping Skills Training and Distress in Women with Breast Cancer. *Procedia - Social and Behavioral Sciences, 159*, 192-196. doi: 10.1016/j.sbspro.2014.12.355

Kelman, C. W., Bass, A. J., & Holman, C. D. (2002). Research use of linked health data-a best practice protocol. *Australian and New Zealand Journal of Public Health, 26*, 251-255. doi: 10.1111/j.1467-842x.2002.tb00161.x

Kennedy, P., Duff, J., Evans, M., & Beedie, A. (2003). Coping effectiveness training reduces depression and anxiety following traumatic spinal cord injuries. *Br J Clin Psychol, 42*, 41-52. doi: 10.1348/014466503762842002

Kennedy, P., & Kilvert, A. (2017). Coping Effectiveness Training *Practical Psychology in Medical Rehabilitation* (pp. 423-432). Cham: Springer International Publishing.

Kennedy, V. L., & Lloyd-Williams, M. (2009). How children cope when a parent has advanced cancer. *Psycho-Oncology, 18*, 886-892. doi: 10.1002/pon.1455

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*, 118-121.

Kim, J. H., & Park, E. C. (2014). Influence of offspring on quality of life among cancer patients and survivors: results from the Korean longitudinal study of aging (KLoSA), 2008-2011. *Asian Pac J Cancer Prev, 15*, 10531-10537. doi: 10.7314/apjcp.2014.15.23.10531

Kissil, K., Niño, A., Jacobs, S., Davey, M., & Tubbs, C. Y. (2010). 'It has been a good growing experience for me': growth experiences among African American youth coping with parental cancer. *Families, Systems & Health, 28*, 274-289. doi: 10.1037/a0020001

Kobayashi, M., Heiney, S. P., Osawa, K., Ozawa, M., & Matsushima, E. (2017). Effect of a group intervention for children and their parents who have cancer. *Palliative and Supportive Care*, 1-12. doi: 10.1017/s1478951516001115

Korneluk, Y. G., & Lee, C. M. (1998). Children's Adjustment to Parental Physical Illness. *Clinical Child and Family Psychology Review, 1*, 179-193. doi: 10.1023/A:1022654831666

Krattenmacher, T., Kuhne, F., Fuhrer, D., Beierlein, V., Brahler, E., Resch, F., . . . Moller, B. (2013). Coping skills and mental health status in adolescents when a parent has cancer: a multicenter and multi-perspective study. *J Psychosom Res, 74*, 252-259. doi: 10.1016/j.jpsychores.2012.10.003

Kristjanson, L. J., Chalmers, K. I., & Woodgate, R. (2004). Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum, 31*, 111.

Krosnick, J. A., & Presser, S. (2010). Question and Questionnaire Design *Handbook of Survey Research, Second Edition*: Emerald Group Publishing Limited.

Küçükoğlu, S., & Çelebioğlu, A. (2013). Identification of psychological symptoms and associated factors in adolescents who have a parent with cancer in Turkey. *European Journal of Oncology Nursing, 17*, 75-80. doi: 10.1016/j.ejon.2011.10.008

Kühne, F., Krattenmacher, T., Bergelt, C., Beierlein, V., Herzog, W., Klitzing, K. V., . . . Möller, B. (2013). “There Is Still So Much Ahead of Us”—Family Functioning in Families of Palliative Cancer Patients. *Families, Systems, & Health, 31*, 181-193. doi: 10.1037/a0032274

Laccetti, M., & Vessey, J. A. (2007). When a school-age child's parent has cancer. *Journal for Specialists in Pediatric Nursing, 12*, 297-299. doi: 10.1111/j.1744-6155.2007.00124.x

Landry-Dattee, N., Boinon, D., Roig, G., Bouregba, A., Delaigue-Cosset, M. F., & Dauchy, S. (2016). Telling the Truth...With Kindness: Retrospective Evaluation of 12 Years of Activity of a Support Group for Children and Their Parents With Cancer. *Cancer Nurs, 39*, E10-18. doi: 10.1097/ncc.0000000000000262

Lazarus, R. S. (1974). Psychological stress and coping in adaptation and illness. *Int J Psychiatry Med, 5*, 321-333. doi: 10.2190/t43t-84p3-qdur-7rtp

Lazarus, R. S. (1993). Coping theory and research: past, present, and future. *Psychosom Med, 55*, 234-247. doi: 10.1097/00006842-199305000-00002

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Leedham, B., & Meyerowitz, B. E. (1999). Responses to Parental Cancer: A Clinical Perspective. *Journal of Clinical Psychology in Medical Settings, 6*, 441-461. doi: 10.1023/A:1026228000254

Levesque, J. V., & Maybery, D. (2012). Parental Cancer: Catalyst for Positive Growth and Change. *Qualitative Health Research, 22*, 397-408. doi: 10.1177/1049732311421617

Levine, S. Z., Laufer, A., Stein, E., Hamama-Raz, Y., & Solomon, Z. (2009). Examining the relationship between resilience and posttraumatic growth. *Journal of Traumatic Stress, 22*, 282-286. doi: 10.1002/jts.20409

Lewandowski, L. A. (1996). A parent has cancer: needs and responses of children. *Pediatr Nurs, 22*, 518-521, 558.

Lewis, F. M. (2007). Parental cancer and dependent children: selected issues for future research. *Psycho-Oncology, 16*, 97-98. doi: 10.1002/pon.1141

Lewis, F. M. (2011). Therapy for Parental Cancer and Dependent Children *Handbook of Psychotherapy in Cancer Care* (pp. 225-234): John Wiley & Sons, Ltd.

Lewis, F. M., Brandt, P. A., Cochrane, B. B., Griffith, K. A., Grant, M., Haase, J. E., . . . Shands, M. E. (2015). The Enhancing Connections Program: A Six-State Randomized Clinical Trial of a Cancer Parenting Program. *Journal of Consulting & Clinical Psychology, 83*, 12-23. doi: 10.1037/a0038219

Lewis, P., Mooney-Somers, J., Patterson, P., Jordens, C. F. C., Bennett, D., McDonald, F. E. J., . . . Kerridge, I. (2014). Caring for young people with cancer: Practical implications of qualitative engagement with cancer survivors and members of the multidisciplinary team. *Australian Journal of Cancer Nursing, The, 15*, 39-42. Retrieved from: https://search.informit.com.au/documentSummary;dn=745514996180786;res=IELHEA

Liberati, A., Altman, D. G., Tetzlaff, J., & et al. (2009). The prisma statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *Annals of Internal Medicine, 151*, W-65-W-94. doi: 10.7326/0003-4819-151-4-200908180-00136

Lindqvist, B., Schmitt, F., Santalahti, P., Romer, G., & Piha, J. (2007). Factors associated with the mental health of adolescents when a parent has cancer. *Scandinavian Journal of Psychology, 48*, 345-351. doi: 10.1111/j.1467-9450.2007.00573.x

Lovely, M., Levinson Marks, A., LaMarre, A. K., Chang, S. M., Clarke, J., Patt, J., & Barani, E. (2016). Family Camp: A multi-disciplinary intervention for brain tumor patients and families. *Journal of Clinical Oncology, 34*, 240-240. doi: 10.1200/jco.2016.34.26_suppl.240

Lundquist, M. (2017). Fathers Facing Advanced Cancer: An Exploratory Study. *Journal of Social Work in End-of-Life & Palliative Care, 13*, 266-283. doi: 10.1080/15524256.2017.1403410

Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work. *Child Development, 71*, 543-562. doi: 10.1111/1467-8624.00164

Mandrekar, J. N., & Mandrekar, S. J. (2011). Systematic Reviews and Meta Analysis of Published Studies: An overview and Best Practices. *Journal of thoracic oncology : official publication of the International Association for the Study of Lung Cancer, 6*, 1301-1303. doi: 10.1097/JTO.0b013e31822461b0

Marks, N. F., Jun, H., & Song, J. (2007). Death of Parents and Adult Psychological and Physical Well-Being: A Prospective U.S. National Study. *Journal of family issues, 28*, 1611-1638. doi: 10.1177/0192513X07302728

Matud, M. P. (2004). Gender differences in stress and coping styles. *Personality and Individual Differences, 37*, 1401-1415. doi: 10.1016/j.paid.2004.01.010

Maynard, A., Patterson, P., McDonald, F. E. J., & Stevens, G. (2013). What Is Helpful to Adolescents Who Have a Parent Diagnosed with Cancer? *Journal of Psychosocial Oncology, 31*, 675-697 623p. doi: 10.1080/07347332.2013.835021

McDonald, F., 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*, 447-454. doi: 10.1002/pon.3942

Meadows, G. N., Enticott, J. C., Inder, B., Russell, G. M., & Gurr, R. (2015). Better access to mental health care and the failure of the Medicare principle of universality. *Med J Aust, 202*, 190-194. doi: 10.5694/mja14.00330

Medlow, S., & Patterson, P. (2015). Determining research priorities for adolescent and young adult cancer in Australia. *European Journal of Cancer Care, 24,* 590-599. doi: 10.1111/ecc.12291

Meriggi, F., Andreis, F., Liborio, N., Codignola, C., Rizzi, A., Prochilo, T., . . . Zaniboni, A. (2017). Parents with cancer: Searching for the right balance between telling the truth and protecting children. *Palliative & Supportive Care, 15,* 88-97. doi: 10.1017/S1478951516000444

Meyers, F. J., Carducci, M., Loscalzo, M. J., Linder, J., Greasby, T., & Beckett, L. A. (2011). Effects of a Problem-Solving Intervention (COPE) on Quality of Life for Patients with Advanced Cancer on Clinical Trials and their Caregivers: Simultaneous Care Educational Intervention (SCEI): Linking Palliation and Clinical Trials. *Journal of Palliative Medicine, 14,* 465-473. doi: 10.1089/jpm.2010.0416

Meyerson, D. A., Grant, K. E., Carter, J. S., & Kilmer, R. P. (2011). Posttraumatic growth among children and adolescents: A systematic review. *Clinical Psychology Review, 31,* 949-964. doi: 10.1016/j.cpr.2011.06.003

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., . . . Stewart, L. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic reviews, 4,* 1.

Moher, D., Tetzlaff, J., Tricco, A. C., Sampson, M., & Altman, D. G. (2007). Epidemiology and Reporting Characteristics of Systematic Reviews. *PLOS Medicine, 4,* e78. doi: 10.1371/journal.pmed.0040078

Möller, B., Barkmann, C., Krattenmacher, T., Kühne, F., Bergelt, C., Beierlein, V., . . . Romer, G. (2014). Children of cancer patients: Prevalence and predictors of emotional and behavioral problems. *Cancer, 120,* 2361-2370. doi: 10.1002/cncr.28644

Morris, J. N., Martini, A., & Preen, D. (2016). The well-being of children impacted by a parent with cancer: an integrative review. *Supportive Care in Cancer, 24*, 3235-3251. doi: 10.1007/s00520-016-3214-2

Morris, J. N., Ohan, J., & Martini, A. (2017). An investigation of support services available by Internet searching to families impacted by a parent's cancer. *Psychooncology*. doi: 10.1002/pon.4478

Mosher, C. E., & Danoff-Burg, S. (2005). Psychosocial impact of parental cancer in adulthood: A conceptual and empirical review. *Clinical Psychology Review, 25*, 365-382. doi: 10.1016/j.cpr.2004.12.003

National Cancer Institute. (2015, May 15). Adolescents and Young Adults with Cancer. Retrieved from https://www.cancer.gov/types/aya

Nelson, E., & While, D. (2002). Children's adjustment during the first year of a parent's cancer diagnosis. *Journal of Psychosocial Oncology, 20*, 15-36. doi: 10.1300/J077v20n01_02

Niemela, M., Paananen, R., Hakko, H., Merikukka, M., Gissler, M., & Rasanen, S. (2016). Mental disorder diagnoses of offspring affected by parental cancer before early adulthood: the 1987 Finnish Birth Cohort study. *Psychooncology*. doi: 10.1002/pon.4088

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*, 2117-2125. doi: 10.1002/ijc.27466

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, 25*, 1477-1484. doi: 10.1002/pon.4088

Olsson, M., Lundberg, T., Furst, C. J., Ohlen, J., & Forinder, U. (2017). Psychosocial Well-Being of Young People Who Participated in a Support Group Following the Loss of a Parent to Cancer. *J Soc Work End Life Palliat Care*, 1-17. doi: 10.1080/15524256.2016.1261755

Ong, A. D., Bergeman, C. S., Bisconti, T. L., & Wallace, K. A. (2006). Psychological resilience, positive emotions, and successful adaptation to stress in later life. *Journal of Personality and Social Psychology, 91*, 730-749. doi: 10.1037/0022-3514.91.4.730

Osborn, T. (2007). The psychosocial impact of parental cancer on children and adolescents: a systematic review. *Psycho-Oncology, 16*, 101-126. doi: 10.1002/pon.1113

Oxman, A. D., & Guyatt, G. H. (1993). The science of reviewing research. *Annals of the New York Academy of Sciences, 703*. doi: 10.1111/j.1749-6632.1993.tb26342.x

Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies, 49*, 47-53. doi: http://dx.doi.org/10.1016/j.ijnurstu.2011.07.002

Pakenham, K. I., & Cox, S. (2015). The effects of parental illness and other ill family members on youth caregiving experiences. *Psychology & Health, 30*, 857-878. doi: 10.1080/08870446.2014.1001390

Park, E. M., Check, D. K., Song, M. K., Reeder-Hayes, K. E., Hanson, L. C., Yopp, J. M., . . . Mayer, D. K. (2017). Parenting while living with advanced cancer: A qualitative study. *Palliat Med, 31*, 231-238. doi: 10.1177/0269216316661686

Park, E. M., Deal, A. M., Yopp, J. M., Edwards, T., Stephenson, E. M., Hailey, C. E., . . . Rosenstein, D. L. (2016). End-of-life parental communication priorities among bereaved fathers due to cancer. *Patient Education and Counseling*. doi: 10.1016/j.pec.2016.12.007

Paschen, B., Saha, R., Baldus, C., Haagen, M., Pott, M., Romer, G., & Probst, P. (2007). Evaluation eines präventiven Beratungskonzeptes für Kinder körperlich kranker Eltern. *Psychotherapeut, 52*, 265-272. doi: 10.1007/s00278-006-0525-7

Patel, M. X., Doku, V., & Tennakoon, L. (2018). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment, 9*, 229-238. doi: 10.1192/apt.9.3.229

Patterson, P., & McDonald, F. E. (2015). "Being Mindful": Does it Help Adolescents and Young Adults Who Have Completed Cancer Treatment? *Journal of Pediatric Oncology Nursing, 32*, 189-194. doi: 10.1177/1043454214563401

Patterson, P., McDonald, F. E., White, K. J., Walczak, A., & Butow, P. N. (2017). Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impacted by familial cancer. *Psychooncology*. doi: 10.1002/pon.4421

Patterson, P., McDonald, F. E. J., Butow, P., White, K. J., Costa, D. S. J., Pearce, A., & Bell, M. L. (2013). Psychometric evaluation of the Offspring Cancer Needs Instrument (OCNI): an instrument to assess the psychosocial unmet needs of young people who have a parent with cancer. *Supportive Care in Cancer, 21*, 1927-1938. doi: 10.1007/s00520-013-1749-z

Patterson, P., McDonald, F. E. J., Zebrack, B., & Medlow, S. (2015). Emerging Issues Among Adolescent and Young Adult Cancer Survivors. *Seminars in Oncology Nursing, 31*, 53-59. doi: 10.1016/j.soncn.2014.11.006

Patterson, P., Pearce, A., & Slawitschka, E. (2011). The initial development of an instrument to assess the psychosocial needs and unmet needs of young people who have a parent with cancer: piloting the offspring cancer needs instrument (OCNI). *Supportive Care in Cancer, 19*, 1165-1174. doi: 10.1007/s00520-010-0933-7

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

Patton, G. C., Sawyer, S. M., Santelli, J. S., Ross, D. A., Afifi, R., Allen, N. B., . . . Viner, R. M. (2016). Our future: a Lancet commission on adolescent health and wellbeing. *Lancet, 387*, 2423-2478. doi: 10.1016/s0140-6736(16)00579-1

Pederson, S., & Revenson, T. A. (2005). Parental illness, family functioning, and adolescent well-being: a family ecology framework to guide research. *J Fam Psychol, 19*, 404-419. doi: 10.1037/0893-3200.19.3.404

Phillips, F. (2014). Adolescents living with a parent with advanced cancer: a review of the literature. *Psycho-Oncology, 23*, 1323-1339. doi: 10.1002/pon.3570

Phillips, F. (2015). The experience of adolescents who have a parent with advanced cancer: A phenomenological inquiry. *Palliative & Supportive Care, 13*, 1057-1069.

Phillips, F., & Lewis, F. M. (2015). The adolescent's experience when a parent has advanced cancer: A qualitative inquiry. *Palliative Medicine, 29*, 851-858. doi: 10.1177/0269216315578989

Phillips, F., & Prezio, E. A. (2017). Wonders & Worries: evaluation of a child centered psychosocial intervention for families who have a parent/primary caregiver with cancer. *Psycho-Oncology, 26*, 1006-1012. doi: 10.1002/pon.4120

Pietrzak, R. H., & Cook, J. M. (2013). Psychological resilience in older U.S. veterans: results from the national health and resilience in veterans study. *Depress Anxiety, 30*, 432-443. doi: 10.1002/da.22083

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O’Cathain, A., Griffiths, F., . . . Rousseau, M. C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. Montreal, Canada: Department of Family Medicine, McGill University.

Preen, D. (2016). *Introductory Analysis of Linked Health Data: Principles and Hands-On Application*. Short Course Workbook. School of Population Health. The University of Western Australia.

QSR International Pty Ltd. (2012). NVivo qualitative data analysis Software, Version 10. (Version 10).

Rajandram, R. K., Jenewein, J., McGrath, C., & Zwahlen, R. A. (2011). Coping processes relevant to posttraumatic growth: an evidence-based review. *Supportive Care in Cancer, 19,* 583-589. doi: 10.1007/s00520-011-1105-0

Rattray, J., & Jones, M. C. (2005). Essential elements of questionnaire design. *Issues in Clinical Nursing, 16,* 234-243. doi: 10.1111/j.1365-2702.2006.01573.x

Rauch, P., & Moore, C. (2010). A population-based estimate of cancer survivors residing with minor children. *Cancer, 116,* 4218-4220. doi: 10.1002/cncr.25360

Renzi, C., Whitaker, K. L., & Wardle, J. (2015). Over-reassurance and undersupport after a ‘false alarm’: a systematic review of the impact on subsequent cancer symptom attribution and help seeking. *BMJ Open, 5*. doi: 10.1136/bmjopen-2014-007002

Richman, L. S., Kubzansky, L., Maselko, J., Kawachi, I., Choo, P., & Bauer, M. (2005). Positive emotion and health: going beyond the negative. *Health Psychology, 24,* 422-429. doi: 10.1037/0278-6133.24.4.422

Rolland, J. S. (1987). Chronic illness and the life cycle: a conceptual framework. *Fam Process, 26,* 203-221. doi: 10.1111/j.1545-5300.1987.00203.x

Romer, G., Kühne, F., Bergelt, C., & Möller, B. (2011). Seelische Gesundheitsvorsorge für Kinder krebskranker Eltern. *Psychotherapeut, 56,* 400. doi: 10.1007/s00278-011-0849-9

Ryan, R. G. (2009). Age differences in personality: Adolescents and young adults. *Personality and Individual Differences, 47,* 331-335. doi: 10.1016/j.paid.2009.03.023

Sansom-Daly, U. M., & Wakefield, C. E. (2013). Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review. *Translational Pediatrics, 2,* 167-197. doi: 10.3978/j.issn.2224-4336.2013.10.06

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,* 397-406. doi: 10.1002/j.1556-6678.2010.tb00039.x

Schrag, A., Morley, D., Quinn, N., & Jahanshahi, M. (2004). Development of a measure of the impact of chronic parental illness on adolescent and adult children. The Parental Illness Impact Scale (Parkinson's disease). *Parkinsonism & Related Disorders, 10,* 399-405. doi: 10.1016/j.parkreldis.2004.03.010

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 Psychol, 22*, 487-497. doi: 10.1037/0278-6133.22.5.487

Semple, C. J., & McCaughan, E. (2013). Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children. *European Journal of Cancer Care, 22,* 219-231. doi: 10.1111/ecc.12018

Senneseth, M., Dyregrov, A., Laberg, J., Matthiesen, S. B., Pereira, M., & Hauken, M. A. (2016). Facing spousal cancer during child-rearing years: The short-term effects of the Cancer-PEPSONE programme-a single-center randomized controlled trial. *Psychooncology*. doi: 10.1002/pon.4329

Senneseth, M., Hauken, M. A., Matthiesen, S. B., Gjestad, R., & Laberg, J. C. (2017). Facing Spousal Cancer During Child-Rearing Years: Do Social Support and Hardiness Moderate the Impact of Psychological Distress on Quality of Life? *Cancer Nurs, 40,* E24-E34. doi: 10.1097/ncc.0000000000000379

Sensis. (2017). Social Media Report May 2017: How Australian people and businesses are using social media. Melbourne, VIC.

Shah, B. K., Armaly, J., & Swieter, E. (2017). Impact of Parental Cancer on Children. *Anticancer Res, 37*, 4025-4028. doi: 0.21873/anticanres.11787

Sheehan, D. K., & Draucker, C. B. (2011). Interaction patterns between parents with advanced cancer and their adolescent children. *Psycho-Oncology, 20*, 1108-1115. doi: 10.1002/pon.1831

Shields, S. A. (2002). *Speaking from the heart: Gender and the social meaning of emotion*. Cambridge, UK: Cambridge University Press.

Shulman, S., & Ben-Artzi, E. (2003). Age-Related Differences in the Transition from Adolescence to Adulthood and Links with Family Relationships. *Journal of Adult Development, 10,* 217-226. doi: 10.1023/A:1026006025155

Sidhu, R., Passmore, A., & Baker, D. (2005). An investigation into parent perceptions of the needs of siblings of children with cancer. *J Pediatr Oncol Nurs, 22,* 276-287. doi: 10.1177/1043454205278480

Siegel, K., Karus, D., & Raveis, V. H. (1996). Adjustment of children facing the death of a parent due to cancer. *J Am Acad Child Adolesc Psychiatry, 35,* 442-450. doi: 10.1097/00004583-199604000-00010

Siegler, R. S. (2011). *How children develop*. New York: Worth Publishers.

Sieh, D. S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M. A., & Van der Leij, D. A. V. (2010). Problem Behavior in Children of Chronically Ill Parents: A Meta-Analysis. *Clinical Child and Family Psychology Review, 13,* 384-397. doi: 10.1007/s10567-010-0074-z

Sieh, D. S., Visser-Meily, J. M., & Meijer, A. M. (2013). Differential Outcomes of Adolescents with Chronically Ill and Healthy Parents. *J Child Fam Stud, 22*, 209-218. doi: 10.1007/s10826-012-9570-8

Silvers, J. A., McRae, K., Gabrieli, J. D., Gross, J. J., Remy, K. A., & Ochsner, K. N. (2012). Age-related differences in emotional reactivity, regulation, and rejection sensitivity in adolescence. *Emotion, 12*, 1235-1247. doi: 10.1037/a0028297

Skinner, E. A., & Zimmer-Gembeck, M. J. (2016). Age Differences and Changes in Ways of Coping across Childhood and Adolescence *The Development of Coping: Stress, Neurophysiology, Social Relationships, and Resilience During Childhood and Adolescence* (pp. 53-62): Springer International Publishing.

Sober, A. J., & Burstein, J. M. (1995). Precursors to skin cancer. *Cancer, 75*, 645-650. doi: 10.1002/1097-0142(19950115)75:2+<645::aid-cncr2820751405>3.0.co;2-1

Souto, R. Q., Khanassov, V., Hong, Q. N., Bush, P. L., Vedel, I., & Pluye, P. (2015). Systematic mixed studies reviews: Updating results on the reliability and efficiency of the mixed methods appraisal tool. *International Journal of Nursing Studies, 52*, 500-501. doi: 10.1016/j.ijnurstu.2014.08.010

Spear, L. P. (2000). The adolescent brain and age-related behavioral manifestations. *Neuroscience & Biobehavioral Reviews, 24*, 417-463. doi: 10.1016/S0149-7634(00)00014-2

Spira, M., & Kenemore, E. (2000). Adolescent Daughters of Mothers with Breast Cancer: Impact and Implications. *Clinical Social Work Journal, 28*, 183-195. doi: 10.1023/A:1005106301713

SPSS Inc. (2017). IBM SPSS Statistics (Version 24). New York: IBM Corp.

Stanton, A. L., Danoff-Burg, S., Sworowski, L. A., Collins, C. A., Branstetter, A. D., Rodriguez-Hanley, A., . . . Austenfeld, J. L. (2002). Randomized, controlled trial of written emotional expression and benefit finding in breast cancer patients. *J Clin Oncol, 20*, 4160-4168. doi: 10.1200/jco.2002.08.521

Steffens, R. F., & Andrykowski, M. A. (2014). Posttraumatic Growth Inventory: Overview *Comprehensive Guide to Post-Traumatic Stress Disorder* (pp. 1-14). Cham: Springer International Publishing.

Steinberg, L. (2005). Cognitive and affective development in adolescence. *Trends in Cognitive Sciences, 9*, 69-74. doi: 10.1016/j.tics.2004.12.005

Stinesen Kollberg, K., Wilderäng, U., Möller, A., & Steineck, G. (2014). Worrying about one's children after breast cancer diagnosis: desired timing of psychosocial intervention. *Supportive Care in Cancer, 22*, 2987-2995. doi: 10.1007/s00520-014-2307-z

Stone, P. W. (2002). What is a systemic review? *Applied Nursing Research, 15*, 52-53. doi: http://dx.doi.org/10.1053/apnr.2002.29531

Su, Y., & Ryan-Wenger, N. (2007). Children's Adjustment to Parental Cancer: A Theoretical Model Development. *Cancer Nursing September/October, 30*, 362-381. doi: 10.1097/01.NCC.0000290817.37442.e6

Sveen, J., Kreicbergs, U., Melcher, U., & Alvariza, A. (2015). Teenagers' reasoning about a parent's recent death in cancer. *Palliat Support Care*, 1-9. doi: 10.1017/s1478951515001054

Syse, A., Aas, G. B., & Loge, J. H. (2012). Children and young adults with parents with cancer: a population-based study. *Clinical Epidemiology, 4*, 41-52. doi: 10.2147/CLEP.S28984

Taylor, S. E., & Stanton, A. L. (2007). Coping Resources, Coping Processes, and Mental Health. *Annual Review of Clinical Psychology, 3*, 377-401. doi: 10.1146/annurev.clinpsy.3.022806.091520

Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress, 9*, 455-471. doi: 10.1002/jts.2490090305

Tedeschi, R. G., & Calhoun, L. G. (2004). Target Article: "Posttraumatic Growth: Conceptual Foundations and Empirical Evidence". *Psychological Inquiry, 15*, 1-18. doi: 10.1207/s15327965pli1501_01

Teixeira, R., & Pereira, M. (2016). Posttraumatic Stress Disorder Symptoms and Family Functioning in Adult Children Facing Parental Cancer: A Comparison Study. *Research and Theory for Nursing Practice, 30*, 212-228. doi: 10.1891/1541-6577.30.3.212

Teixeira, R. J., & Pereira, M. G. (2013). Factors contributing to posttraumatic growth and its buffering effect in adult children of cancer patients undergoing treatment. *J Psychosoc Oncol, 31*, 235-265. doi: 10.1080/07347332.2013.778932

Tew, M., Dalziel, K. M., Petrie, D. J., & Clarke, P. M. (2016). Growth of linked hospital data use in Australia: a systematic review. *Aust Health Rev*. doi: 10.1071/ah16034

Thastum, M., Johansen, M. B., Gubba, L., Olesen, L. B., & Romer, G. (2008). Coping, Social Relations, and Communication: A Qualitative Exploratory Study of Children of Parents with Cancer. *Clinical Child Psychology and Psychiatry, 13*, 123-138. doi: 10.1177/1359104507086345

Thastum, M., Watson, M., Kienbacher, C., Piha, J., Steck, B., Zachariae, R., . . . Romer, G. (2009). Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer. *Cancer, 115*, 4030-4039. doi: 10.1002/cncr.24449

Threlfall, T. J., & Thompson, J. R. (2015). Cancer incidence and mortality in Western Australia, 2014. In Department of Health (Ed.). Western Australia, Perth.

Torp, S., Thoresen, L., Grønningsæter, A., Grov, E., & Gustavsen, K. (2013). Financial and Social Effects on Children and Adolescents when a Parent is Diagnosed with Cancer. *Child and Adolescent Social Work Journal, 30*, 293-310. doi: 10.1007/s10560-012-0290-0

Tugade, M. M., & Fredrickson, B. L. (2004). Resilient Individuals Use Positive Emotions to Bounce Back From Negative Emotional Experiences. *Journal of Personality and Social Psychology, 86*, 320-333. doi: 10.1037/0022-3514.86.2.320

Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V., & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: what do parents want? *Palliat Support Care, 5*, 135-145. doi: 10.1017/s1478951507070204

Turner, N. (2017). Young people's perspectives on open communication between family members when a parent is dying. *Palliat Support Care,* 1-7. doi: 10.1017/s1478951517000578

Umberger, W. A., & Risko, J. (2016). "It didn't kill me. It just made me stronger and wiser": Silver Linings for Children and Adolescents of Parents with Chronic Pain. *Archives of Psychiatric Nursing, 30*, 138-143. doi: 10.1016/j.apnu.2015.08.001

United Nations. (2018). Methodology: Standard country or area codes for statistical use Retrieved from https://unstats.un.org/unsd/methodology/m49/

Van Teijlingen, E., & Hundley, V. (2002). The importance of pilot studies. *Nursing Standard, 16*, 33-336.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and Validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in Healthy and Patient Populations. *Medical Care, 39*, 12.

Venning, A., Eliott, J., Kettler, L., & Wilson, A. (2013). Complete Mental Health in South Australian Youth: Prevalence, Measurement, and Promotion *Mental Well-Being:*

International Contributions to the Study of Positive Mental Health (pp. 29-50). Dordrecht: Springer Netherlands.

Verkooijen, H. M., Ang, J. X., Liu, J., Czene, K., Salim, A., & Hartman, M. (2013). Mortality among offspring of women diagnosed with cancer: a population-based cohort study. *Int J Cancer, 132*, 2432-2438. doi: 10.1002/ijc.27899

Vestergaard, L. V., & Dieperink, K. B. (2017). *The use of an interactive cartoon web page to support communication between parents with cancer and their children.* Paper presented at the European Journal of Cancer.

Vinod, S. K., Hui, A. C., Esmaili, N., Hensley, M. J., & Barton, M. B. (2004). Comparison of patterns of care in lung cancer in three area health services in New South Wales, Australia. *Internal Medicine Journal, 34*, 677-683. doi: 10.1111/j.1445-5994.2004.00645.x

Visser, A., Huizinga, G. A., Hoekstra-Weebers, J. E., van der Graaf, W. T., & Hoekstra, H. J. (2004). The impact of parental cancer on children and the family: A review of the literature. *Cancer Treatment Reviews*, 683-694. doi: 10.1016/j.ctrv.2004.06.001

Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., Gazendam-Donofrio, S. M., & Hoekstra-Weebers, J. E. (2007). Emotional and behavioral problems in children of parents recently diagnosed with cancer: a longitudinal study. *Acta Oncol, 46*, 67-76. doi: 10.1080/02841860600949560

Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., & Hoekstra-Weebers, J. E. (2006). Parental cancer: characteristics of parents as predictors for child functioning. *Cancer, 106*, 1178-1187. doi: 10.1002/cncr.21691

Voogt, E., van der Heide, A., van Leeuwen, A. F., Visser, A. P., Cleiren, M. P. H. D., Passchier, J., & van der Maas, P. J. (2005). Positive and negative affect after diagnosis of advanced cancer. *Psycho-Oncology, 14*, 262-273. doi: 10.1002/pon.842

Walczak, A., McDonald, F., Patterson, P., Dobinson, K., & Allison, K. (2017). How does parental cancer affect adolescent and young adult offspring? A systematic review. *Int J Nurs Stud, 77*, 54-80. doi: 10.1016/j.ijnurstu.2017.08.017

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and Validation of Brief Measures of Positive and Negative Affect: The PANAS Scales. *Journal of Personality and Social Psychology, 54*, 1063-1070. doi: 10.1037/0022-3514.54.6.1063

Weaver, K. E., Rowland, J. H., Alfano, C. M., & McNeel, T. S. (2010). Parental cancer and the family. *Cancer, 116*, 4395-4401. doi: 10.1002/cncr.25368

Weisman, A. D., & Worden, J. W. (1976). Coping and Vulnerability in Cancer Patients Research Report *Project Omega*. Boston: Dept of Psychiatry, Harvard Medical School.

Werner-Lin, A., & Biank, N. (2009). Along the Cancer Continuum: Integrating Therapeutic Support and Bereavement Groups for Children and Teens of Terminally Ill Cancer Patients. *Journal of Family Social Work, 12*, 359-370. doi: 10.1080/10522150903321314

Western Australia Data Linkage. (2016, 26 February). Western Australia Data Linkage Information *About Data Linkage.* Retrieved from http://www.datalinkage-wa.org.au/

Western Australia Department of Health. (2018). Midwives Notification System. Retrieved from https://ww2.health.wa.gov.au/Articles/J_M/Midwives-Notification-System

Western Australia Department of Health. (2018). Western Australian Cancer Registry Statistical Methods. Retrieved from http://ww2.health.wa.gov.au/Articles/U_Z/Western-Australian-Cancer-Registry-Statistical-Methods

Windle, G., Bennett, K. M., & Noyes, J. (2011). A methodological review of resilience measurement scales. *Health and Quality of Life Outcomes, 9*, 8-8. doi: 10.1186/1477-7525-9-8

Wong, M., Looney, E., Michaels, J., Palesh, O., & Koopman, C. (2006). A preliminary study of peritraumatic dissociation, social support, and coping in relation to posttraumatic stress symptoms for a parent's cancer. *Psycho-Oncology, 15*, 1093-1098. doi: 10.1002/pon.1041

Wong, M. L., Cavanaugh, C. E., Macleamy, J. B., Sojourner-Nelson, A., & Koopman, C. (2009). Posttraumatic growth and adverse long-term effects of parental cancer in children. *Fam Syst Health, 27*, 53-63. doi: 10.1037/a0014771

Wonghongkul, T., Dechaprom, N., Phumivichuvate, L., & Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing, 29*, 250-257. doi: 10.1097/00002820-200605000-00014

Worden, J. W. (1996). *Children and Grief: When a Parent Dies*. New York: Guildford Press.

World Health, O. (2005). *ICD-10 international statistical classification of diseases and related health problems*. Geneva: World Health Organization.

World Health Organisation. (1986). Young people's health - a challenge for society *Health for All by the Year 2000*. Geneva: WHO.

World Health Organisation. (2015, February 2015). Cancer. *Fact sheets.* Retrieved from http://www.who.int/mediacentre/factsheets/fs297/en/

World Health Organisation. (2016). Adolescent development. Retrieved from http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/

World Health Organisation. (2017). Fact Sheets. Retrieved from http://www.who.int/mediacentre/factsheets/fs297/en/

World Health Organisation. (2018). Global Initiative for Cancer Registry Development. Retrieved from http://gicr.iarc.fr/en/

Wright, M. O. D., & Masten, A. S. (2005). Resilience Processes in Development *Handbook of Resilience in Children* (pp. 17-37). Boston: Springer.

Yopp, J. M., Mayer, D., & Park, E. M. (2016, Oct 09). *How do parents with advanced cancer communicate with their children? A qualitative study.* Paper presented at the Journal of Clinical Oncology.

Yu, X. Q., O'Connell, D. L., Gibberd, R. W., & Armstrong, B. K. (2008). Assessing the impact of socio-economic status on cancer survival in New South Wales, Australia 1996–2001. *Cancer Causes & Control, 19,* 1383-1390. doi: 10.1007/s10552-008-9210-1

Zaid, T., Burzawa, J., Basen-Engquist, K., Bodurka, D. C., Ramondetta, L. M., Brown, J., & Frumovitz, M. (2014). Use of social media to conduct a cross-sectional epidemiologic and quality of life survey of patients with neuroendocrine carcinoma of the cervix: a feasibility study. *Gynecologic Oncology, 132,* 149-153. doi: 10.1016/j.ygyno.2013.10.015

Zebrack, B., Kwak, M., Salsman, J., Cousino, M., Meeske, K., Aguilar, C., . . . Cole, S. (2015). The relationship between posttraumatic stress and posttraumatic growth among adolescent and young adult (AYA) cancer patients. *Psycho-Oncology, 24,* 162-168. doi: 10.1002/pon.3585

Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology — A critical review and introduction of a two component model. *Clinical Psychology Review, 26,* 626-653. doi: 10.1016/j.cpr.2006.01.008