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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

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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

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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