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How does parental cancer affect adolescent and young adult offspring? A systematic review



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ABSTRACT

Objectives: To i) identify and synthesise evidence published since 2007 regarding the impact of parental cancer on adolescent and young adult offspring, ii) identify methodological and evidence gaps addressed during this period and iii) highlight those requiring further attention.

Design: A systematic review and thematic synthesis of peer reviewed literature regarding the impact of parental cancer upon AYA offspring.

Data sources: Online searches of CINAHL, Embase, Medline, PsychInfo and Scopus databases were conducted. Reference lists of included articles were screened and additional searches by prominent authors were performed. Review methods: Study selection, data extraction and quality analysis was undertaken by three independent researchers. Extracted study data was iteratively reviewed and discussed to achieve consensus regarding thematic synthesis of included studies.

Results: Database and hand-searching yielded 1730 articles, 54 of which were included in the final synthesis. Included studies are discussed with respect to the following themes: i) study design and quality; ii) measurement and sampling; iii) positive and negative aspects of parental cancer; iv) needs; v) communication and information; vi) coping strategies; vii) interventions; and viii) family functioning and other predictors. Twenty-nine studies reported negative impacts related to parental cancer, while eight identified positive outcomes related to post-traumatic growth. Five returned null or mixed findings. Unmet needs were frequently explored and a new validated measure developed. Communication and information were particularly important for offspring, though these needs were often unmet and parents wanted guidance regarding discussions with their children. Offspring may adopt a variety of coping strategies, some of which appear maladaptive, and may cycle between different approaches. Few evaluations of interventions were identified, and further work in this area is needed. Further evidence has emerged that poorer family functioning and other family and illness-related factors predict worse psychosocial outcomes for offspring, however evidence for other predictors such as age and gender remain mixed.

Conclusions: Additional evidence for the negative psychosocial impact of parental cancer on adolescent and young adult offspring, their needs, and factors predicting psychosocial outcomes has emerged in the last decade. However, substantial gaps and methodological issues remain and evidence for the development, efficacy or implementation of interventions for this population is very limited. There is also a clear need for greater focus on bereaved and young adult offspring and those from non-western cultural groups, who remain under-represented in research conducted to date.

What is already known about the topic?

- The psychosocial impact of a cancer diagnosis extends to the family
 of patients; adolescent and young adult offspring appear to be particularly affected.
- Previous reviews largely discuss negative impacts and potential protective/risk factors, although there are inconsistencies between study findings.
- Earlier reviews identified substantial methodological limitations in the included studies.

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What this paper adds

- Review of 54 papers from previous decade indicates that parental cancer may have positive and negative impacts for offspring.
- Evidence for moderators varies in consistency, with mixed support for previously identified influences.
- Overall study quality appears to have improved, although limitations remain there is a particular lack of research on bereavement, non-Western cultural groups, and interventions to support offspring.

1. Introduction

Approximately 28,500 parenting age Australian adults were diagnosed with cancer in 2008, 72% of whom were estimated to have adolescent or young adult (AYA - 12-24 years old) offspring (Australian Institute of Health and Welfare A, 2011; de Vaus, 2004; ABS, 2011). Approximately 21,000 young Australians are therefore expected to be newly impacted by their parent's cancer each year (Australian Institute of Health and Welfare A, 2011; de Vaus, 2004; ABS, 2011). Parental cancer during the AYA years can be particularly challenging due to the dynamic nature of this life stage, characterised by significant cognitive, social and emotional development (Palmer et al., 2014). A young person's efforts to establish individual identity, pursue education and employment, form intimate relationships, and gain financial independence may be hampered (Zebrack, 2011) and additional responsibilities at home may draw them further into their family at a time when they are seeking greater autonomy (Grabiak et al., 2007). The psychosocial impact of parental cancer on AYAs has consequently been the subject of considerable research, which has been summarised in broad reviews by Grabiak and colleagues (Grabiak et al., 2007) and Osborn (Osborn, 2007) in 2007, as well as in several subsequent literature reviews with narrower foci (Krattenmacher et al., 2012; Phillips, 2014; Morris et al., 2016; Inhestern et al., 2016; Huang et al., 2014).

Grabiak and colleagues' review (Grabiak et al., 2007) discussed the impact of parental cancer on adolescent offspring (10-20 years old) in relation to emotions and behaviours, perceptions and knowledge of parental cancer, role changes and coping. It concluded that parental cancer had a largely negative emotional and behavioural impact on AYA offspring, with internalising problems being common and externalising problems associated with poor family functioning and communication (Grabiak et al., 2007). Offspring viewed diagnosis and treatment as the most difficult stages of parental cancer, with timely and trustworthy information being desirable soon after diagnosis and throughout the cancer trajectory (Grabiak et al., 2007). Coping strategies adopted by AYA offspring included emotion- and problem-focused coping (Grabiak et al., 2007). By contrast, Osborn's review focused on psychosocial difficulties arising from early-stage parental cancer in offspring aged 5-18 (Osborn, 2007). Inconsistencies in the included literature led this review to draw the cautious conclusion that offspring were at "slightly increased risk" of internalising problems compared to reference groups (Osborn, 2007). Whilst disease and treatment factors appeared unrelated to offspring psychosocial difficulties, family communication, parental mood and adjustment, and gender played an important role. Adolescent daughters impacted by parental cancer were found to be more negatively impacted in psychosocial domains, and difficulties self-reported by offspring exceeded those reported by parents (Osborn, 2007).

More recently, narrower systematic reviews have been conducted looking at the well-being of children (0–18 years) affected by parental cancer (Morris et al., 2016), the impact of advanced parental cancer on adolescents (12–18 years) (Phillips, 2014), and predictors of psychosocial adjustment to parental cancer in offspring of all ages (Krattenmacher et al., 2012). Krattenmacher et al.' review reaffirmed previously identified familial risk and protective factors for offspring psychosocial adjustment, which was positively associated with family

functioning and negatively associated with parental depressive mood (Krattenmacher et al., 2012). Phillips' review highlighted the vulnerability of offspring and identified both negative impacts and positive gains resulting from parental cancer, including greater appreciation for family and increased independence (Phillips, 2014). Morris and colleagues' review highlighted that children were significantly impacted by their parent's cancer, with the gender of the child appearing to influence how this impact presented (Morris et al., 2016). Parental characteristics and family functioning were also noted as mediators of the impact of parental cancer on the child (Morris et al., 2016).

Later, Huang and colleagues' meta-synthesis identified common themes from qualitative studies on non-terminal parental cancer, including disruption and adjustment, information and support seeking, and emotional impacts and concerns (Huang et al., 2014). Additionally, Inhestern and colleagues' review identified interventions available to families affected by parental cancer, and highlighted barriers and facilitators for involvement (Inhestern et al., 2016). Finally, Ellis and colleagues' review of children's (0–18 years) psychosocial needs and available interventions recommended that those developing future interventions should consider the need for age-appropriate information, support in communicating with family and healthcare professionals, and supportive environments that normalise their experiences (Ellis et al., 2017).

These previous reviews have identified substantial methodological limitations within the existing literature. These have variously included largely inadequate sample sizes, cross-sectional design limitations, conflicting or absent definitions of the studied age ranges, inconsistent measurement approaches, and a dearth of knowledge regarding the impact on AYAs of parental cancers other than breast cancer (Grabiak et al., 2007; Osborn, 2007; Krattenmacher et al., 2012; Phillips, 2014; Morris et al., 2016). More recent reviews have had narrower foci, covering only psychosocial adjustment(Krattenmacher et al., 2012), advanced cancer (Phillips, 2014), children(Morris et al., 2016), qualitative studies (Huang et al., 2014) and interventions (Inhestern et al., 2016; Ellis et al., 2017). This review therefore sought to update the findings of the two more comprehensive reviews published in 2007 with a focus on a broad AYA age range and parental disease continuum, as well as to integrate all relevant findings for this population.

AYAs affected by parental cancer are particularly vulnerable to negative psychosocial outcomes as they may be more aware of the seriousness and implications of a cancer diagnosis, but may not yet have developed the ability to cope with the situation (Karlsson et al., 2013). However, despite previous indications of this heightened impact, the distress and needs of offspring may be overlooked by both family members and medical professionals (Davey et al., 2011). The aim of this systematic review was therefore to identify and synthesise evidence published since 2007 regarding the impact of parental cancer on AYA offspring. Secondary aims were to provide a broad overview of outcomes and risk/protective factors for clinical attention, assess potential avenues for intervention, and highlight the emergence and resolution of methodological and evidence gaps including those requiring further attention.

2. Methods

2.1. Search strategy

Database and manual searches were undertaken to identify relevant English language articles. Searches of CINAHL, Embase, Medline, PsycInfo and Scopus were performed on 28 July and 12 August 2015 using the following terms: (Cancer OR Malignan* OR Neoplasm) AND (offspring OR son OR daughter OR child*) AND (unmet needs OR distress OR impact OR bereave* or deceased). Search results were updated on 21 October 2016 using the same terms. Search results were limited to peerreviewed research in humans published since 2007. Reference lists of included articles were screened and additional searches by author were

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