

Review

Adolescents living with a parent with advanced cancer: a review of the literature

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Abstract

Objective: Families and children facing the death of a parent from cancer constitute a vulnerable population often overlooked by healthcare professionals and researchers. The purpose of this review is to provide a systematic analysis of the literature that examines the experiences of parents diagnosed with advanced cancer and their adolescent children.

Methods: Reviews of quantitative, qualitative, and mixed method publications between 2000 and 2013 were selected in order to obtain the most current and timely studies. Articles published before 2000 but found to be seminal works on this topic were also included. No time limits were set on intervention studies.

Results: Eighteen studies met the criteria for the content of this review, indicating the limited number of studies conducted on this topic. Articles were summarized using the following categories: original research on the impact on the family and parenting, original research on the impact on the child/adolescent, and interventions for families facing incurable cancer. The analysis was organized around the major themes found in the literature within each category.

Conclusions: These themes will allow healthcare professionals to understand implications for clinical practice and apply the knowledge gained from this analysis of literature to guide future research. Copyright © 2014 John Wiley & Sons, Ltd.

Received: 15 October 2013

Revised: 2 April 2014

Accepted: 14 April 2014

Cancer is the second leading cause of death in the USA and is responsible for approximately one of every four deaths [1]. These statistics, along with the fact that close to 25% of cancer cases occur in individuals 21–55 years of age, prime childbearing and parenting years, highlight the importance of creating resources for families dealing with a cancer diagnosis [2]. Furthermore, it is estimated that close to 55,000 children may experience the death of a parent from cancer each year in the USA [3]. Families and children facing the death of a parent from advanced cancer constitute a vulnerable population often overlooked by healthcare professionals and researchers.

The diagnosis of cancer in a parent triggers psychological and social pressure in children. Children and adolescents are severely impacted by a parent's cancer diagnosis in all domains of child functioning, in particular emotional well-being [4]. As cancer becomes more of a chronic issue due to advances in cancer treatment, children and adolescents are potentially dealing with the long-term consequences of this disease for a substantial portion of their childhood [5]. The continuous threat of a parent's cancer recurring, or the threat of death of their parent, may cause long-term negative psychosocial outcomes for children and adolescents [6].

Adolescents are considered to be the group most susceptible to negative psychosocial outcomes when faced with a parent's illness [7]. Findings suggest that adolescents dealing with parental cancer demonstrate greater anxiety,

depression, and emotional distress than school-age children [4,6]. Developmentally, adolescence creates fundamental changes in the family structure as youth strive for increased autonomy. Having a parent with cancer may require typical developmental tasks to be placed on hold, thus posing a significant threat to the adolescents' normal growth and development [8]. Adolescents' increased cognitive abilities and aptitude for abstract thought make them susceptible to distress because they are more knowledgeable about the potential future consequences of cancer than younger children [9]. Furthermore, adolescents' increased cognitive and empathic capacities enable them to be more conscious of losses and of the parent's physical and emotional pain [10,11]. Adolescents are also more able to accept additional household responsibilities, which may detract from involvement in extracurricular activities with peers that support their positive development [9,12–15].

In the case of advanced cancer, the family faces common stressors shared by all cancer diagnoses. Parents often focus their physical, emotional, and psychological resources on dealing with the demands of illness. However, the family must also deal with the uncertainties and emotional challenges an incurable diagnosis entails. The terminal phase of a parent's illness is a time of significantly higher psychological distress for family members, than even the period following the actual loss [16]. Moreover, several studies of cancer-bereaved youth have shown significant long-term consequences

in this population. These include twice the risk of self-injury compared with non-bereaved peers and higher levels of posttraumatic stress symptoms when compared with pediatric cancer survivors [17,18]. These findings suggest that the end stages of a parent's illness may be a particularly vulnerable period for adolescents. These youth experience many losses when a parent is diagnosed with advanced cancer: the loss of a healthy parent, the loss of both parent's emotional and physical availability, and the loss of normalcy in their family lives. Yet, there has been extremely limited research on the adolescents' adjustment to advanced parental cancer.

The literature on the impact of parental cancer on adolescents was synthesized by two research teams [5,7]. These reviews found that adolescents express a need for information and support related to their parent's cancer. A lack of this support is consistently associated with negative psychosocial adjustment [5,7]. Recent reviews have found that cancer stage has seldom been considered in studies that have addressed the impact of parental cancer on adolescents, despite the fact that recurrence and illness progression have been found to be critical factors in adolescents' adjustment to parental cancer [7,19]. This literature review will differ from past reviews because the focus will be on the experiences of parents diagnosed with advanced cancer and their adolescent children.

Method

Search strategy

The search strategy surveyed a range of electronic bibliographic databases including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsychINFO, PubMed, ISI Web of Knowledge, Google Scholar, and MEDLINE. The search terms used were *parental cancer, advanced cancer, metastatic, advanced stage, recurring cancer, parental terminal illness, maternal terminal illness, paternal illness, cancer, neoplasm*, coping, adjustment, adolescent, and teen**. These keywords were utilized in various combinations to narrow the search to the content of the specific topic. The search was also limited to publications written in English and published in peer-reviewed journals. Review of quantitative, qualitative, and mixed method publications between 2000 and 2013 was selected in order to obtain the most current and timely studies. Articles published before 2000 but found to be seminal works on this topic were also included. No time limits were set on intervention studies. Reference lists of relevant publications were also examined.

Inclusion criteria

The articles selected for review met the following criteria: (a) the population of interest included adolescents exposed

to parents with advanced cancer; (b) advanced cancer was defined as incurable, terminal, Stage IV, or metastatic disease; (c) psychosocial issues for the children and adolescents aged 12–18 years and/or parenting issues were key outcome measures; and (d) intervention studies used some method of analysis to evaluate the intervention's outcomes. Studies were excluded if data for families with advanced cancer were aggregated with other stages of disease and main results could not be derived specific to the target population. Studies were also excluded if the main outcome measures focused solely on the adjustment of patient or spouse without reference to the child/adolescent. Finally, studies were excluded if the sample/outcome measure was bereavement rather than issues related to adjustment pre-death. The quality of each study reviewed was assessed using the QualSyst tool. This is a standard quality assessment tool for evaluating primary research papers with a broad range of study designs [20]. Studies were not required to meet a quality threshold because of concerns about presenting an overly restricted picture of this modest research area. However, the summary score for each included study is reported in Tables 1 and 2. Because of the lack of quantitative methods used in the included studies, a meta-analysis was considered inappropriate, and a structured narrative approach has been taken.

Results

The comprehensive search and review revealed 82 studies. Eighteen studies met the criteria for the content of this review, indicating the limited number of studies conducted on this topic. Fourteen studies were published within the last 10 years, 2003–2012. The majority of studies were cross-sectional (15) and/or qualitative (12). There were five quantitative studies with inclusion of a comparison group [16,21–24], one mixed method study [25], and two longitudinal in design [16,26]. Only four of the studies exclusively examined the adolescents' experience [10,21,24,27]. Most studies examined mixed advanced cancer diagnosis with two studies examining only parents with breast cancer [25,28] and one focused on patients diagnosed with colorectal cancer [29]. Sample sizes ranged from 6 to 120 participants. Twelve studies used some type of outcome measure for the children/adolescents, and only four intervention studies were found that focused on parental advanced cancer. Articles were summarized in tables using the following categories:

1. original research on the impact on the family and parenting—six articles (Table 1)
2. original research on the impact on the child/adolescent—eight articles (Table 2)
3. interventions—four articles (Table 3)

Table 1. Parent outcomes

Source(year)/country	Subject description/sample (N)	Study design/purpose	Measures/methodology	Results/findings
Bell & Ristovski-Slijepcevic [26] Canada Metastatic cancer and mothering: being a mother in the face of a contracted future QualSyst score = 14/20	Mixed metastatic cancer (breast, blood, colorectal, ovarian, uterine, stomach, and lung cancers) Support group: N = 6–12 ill women Interviews: N = 4 of the group members with children ages 4–18 years	Qualitative—longitudinal Ethnographic exploration of the impact of metastatic cancer on women who are mothers of dependent children	Support groups, interviews of women with metastatic cancer: Ethnographic fieldwork	This article reflects on the experience of mothers facing metastatic disease, which seems entrenched in cultural discourse on mothering. These women are forced to choose between focusing solely on their children's needs and focusing on themselves, and both seemed unrealistic. <i>Hierarchy of suffering</i> —living with metastatic cancer: was far worse when the women had dependent children Need to <i>maintain sense of normalcy</i> — pressure identified by the mothers to maintain normalcy for their children above and beyond their own needs with failure resulting in maladjusted children <i>'Glam parenting' and 'making memories'</i> — race against time, parenting may feel artificial, inauthentic as you try to cram 20 years worth of parenting into a few short years, trying to create as many memories as possible in a short amount of time
O'Callaghan et al. [33] Australia Resounding attachment: cancer inpatients' song lyrics for their children in music therapy QualSyst score = 17/20	Metastatic or hematological cancer—inpatient N = 12 (3 fathers, 9 mothers) N = 23 children ages 1–18 years	Qualitative to explore how song writing may support parents and children through the cancer experience, according to attachment, developmental, and bereavement theories	Date = song lyrics written by ill parent Grounded theory—comparative analysis	Parents' song lyrics messages may support their children during the parent's illness and through the children's developmental transitions and bereavement. A catharsis for parents and to encourage attachment to parent after death. Song Lyric Categories 1. Affirmation, support, and encouragement 2. Play songs 3. Parents describe and compliment children 4. Express long-standing, enduring love 5. Description of parent's effort, worry, loss, sadness, and grief 6. Compliments and descriptions of others 7. Children can help their parents 8. Hopes and wishes for children 9. Messages and requests for comfort, support, and existential beliefs 10. Positive reminiscences and predictions

Continues

Table 1. Continued

Source(year)/country	Subject description/sample (N)	Study design/purpose	Measures/methodology	Results/findings
Turner et al. [28] Australia Development of a resource for parents with advanced cancer: what do parents want? QualSyst score = 15/20	Advanced breast cancer N = 8 mothers Diagnosis of advanced cancer; 8 weeks–10 years Age of children at diagnosis: 2–13 years	Qualitative Determine the specific needs of parents with advanced cancer in relation to their children, access to resources, and relevance of existing research	Structured telephone interviews	Themes: Assistance offered by healthcare professionals (HCP) HCP avoid discussion about impact on children Offered a list of books Usefulness of existing resources Few addressed metastatic disease No way to assess quality Experiences of seeking assistance Counselors not aware of needs/helpful Peer support groups helpful Experiences of talking with children about cancer Children told about diagnosis of early cancer Need to maintain hope while being honest Responding to questions about death Need to maintain optimism Feeling they cannot be 100% honest Drawing on experience: women's experiences of not being told Personal experiences and those of others shaped communication decisions Things that have helped Honesty, staging information, routine, involvement of children in treatment, getting support for self, accepting help, telling the school
Houldin & Lewis [29] USA Salvaging their normal lives: a qualitative study of patients with recently diagnosed advanced colorectal cancer QualSyst score = 18/20	Advanced colorectal cancer (Stage III–IV) N = 14 patients (9 men and 5 women, and 10 had children ages 2–25 years)	Qualitative—Cross sectional Describe the experiences of patients living with newly diagnosed Stage III or IV colorectal cancer	Semi-structured interviews Inductive content analysis	Themes related to parenting Rethinking parenting Struggle with how to tell the children Spending more time with their children Wanting to reassure their children of positive outcomes Do things differently, listen more Worrying about family/kids
Turner et al. [25] Australia Psychosocial impact of newly diagnosed advanced breast cancer QualSyst score = 17/20 Qualitative 19/20 Quantitative	Advanced breast cancer N = 66 ill women 56% younger than 55 years 89% mothers 79% with metastatic disease Diagnosis of recurrent or metastatic disease.	Mixed methods—cross sectional Investigate key emotional concerns of women newly diagnosed with recurrent or metastatic breast cancer	Semi-structured interviews Content analysis HADS IES CARES-SF MSAS	Quantitative analyses based on number of children, sex of children, and mean age of children found none to be predictive of current distress of quality of life. Qualitative themes related to parenting The emotional impact 35.8% of women described the emotional impact on their family as the hardest thing about advanced cancer including

mean 9.7 weeks (standard deviation 8.9)
 Age of children: unspecified

their children's grief, and guilt and jealousy of missing out on future family time.
 Concerns about the family about the impact of the cancer on their children, including uncertainty about how to discuss the disease and concerns about children watching them deteriorate.
 56.7% of women younger than 55 years qualify as 'cases' on HADS compared with 34.5% of women aged over 55 years
 Women younger than 55 years had significantly higher levels of intrusive and avoid symptoms than women over 55 years
 Key themes: (a) difficulties in communicating with doctors; (b) perceived delay in diagnosis; (c) the emotional impact; (d) concerns about the family; (e) feelings about why the cancer developed; (f) other life stress and trauma; and (g) use of nonprescribed treatments

Sigal et al. [23] Canada	Breast cancer 45 non-metastatic 42 metastatic N = 27 children (16 sons, 11 daughters 6–11 years) N = 60 adolescents (30 sons, 30 daughters; 12–18 years) Comparison of metastatic versus non-metastatic	Cross-sectional To test the differences between mothers with metastasized breast cancer and mothers with non-metastatic cancer in their preoccupation with their illness and parenting behavior and the subsequent effects on the children's adjustment	CBCL YSR SWS—self-esteem PRQ—parenting IES CIQ—maternal preoccupation	No data reported on children's level of adjustment. Mothers with metastasized breast cancer reported fewer externalizing problems in their children and less poor parenting. Children rated mothers with metastatic disease lower on poor parenting scale than mothers with non-metastatic disease. For mothers with non-metastatic cancer, internalizing symptoms in their children were predicted by mood rather than parenting behavior.
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CARES-SF, Cancer Rehabilitation Evaluation System Short Form; CBCL, Child Behavior Checklist; CIQ, Cognitive Intrusive Questionnaire; HADS, Hospital Depression and Anxiety Scale; HRQoL, health-related quality of life; IES, Impact of Event Scale; MSAS, Memorial Symptom Assessment Scale; PRQ, Parent's Report Questionnaire; SWS, Self-Worth Scale; YSR, Youth Self-Report.

Table 2. Child outcomes

Source(year)/country	Subject description/sample (N)	Study design/purpose	Measures/methodology	Results/findings
Kuhn et al. [24] Germany	Mixed advanced cancer 18.4% digestive, 26.5% gynecological, 55.1% other (lung, blood)	Cross-sectional Multisite (five study centers) To determine the psychosocial impact of parental cancer in palliative versus other disease stages on adolescents and young adults	SDQ—behavioral Kidscreen—HRQoL, global well-being Kidcope—coping strategies HADS—anxiety and depression FAD—family functioning	Community M (SD) 43.44 (7.13) Not reported Not reported Not reported
Parental palliative cancer: psychosocial adjustment and health- related quality of life in adolescents participating in a German family counseling service QualSyst score = 21/22	N = 66 families N = 86 43 adolescents (11–21 years) with parents in palliative care; 43 adolescents (11–21 years) with parents in other disease stages Comparison group—N = 83 adolescents (11–16 years) British community sample			Ill parent M (SD) 48.70 (9.52) 10.23 (5.21) 14.95 (5.35) -Adolescents with parents in palliative care reported significantly higher HRQoL as compared with adolescents with parents in other disease stages. -Older age groups reported significantly lower HRQoL. -Palliative sample showed no significant difference in psychosocial problems as compared with the community sample. Other disease stage sample reported significantly more psychosocial problems when compared with the community sample.
Rainville et al. [21] Canada	Mixed advanced cancer 32% lung, 16% digestive, 21% gynecological, 32% other	Cross-sectional To determine to what extent adolescents who have a parent with advanced cancer experience more psychological distress than adolescents in the general population	IDPSQ-14—(psychological distress) Recent stressing events questionnaire	Community M (SD) 23.19 (7.72)
Psychological distress among adolescents living with a parent with advanced cancer QualSyst score = 21/22	N = 19 families N = 28 adolescents (10 sons, 18 daughters 12–18 years) Comparison group— community sample (ESSEA) N = 2346 adolescents			Ill parent M (SD) 25.36 (5.91)* Sample IDPSQ-14 Distress index Subscales Depressive 9.04 (2.35)* Anxious 5.87 (2.03) Irritability 7.54 (2.15) Cognitive 2.93 (1.36)
*Sheehan & Draucker [27] USA	Mixed advanced cancer Hospice care N = 9 ill parents N = 7 spouses N = 10 adolescent their adolescent children (ages 12–18 years)	Qualitative—cross-sectional To develop an explanatory model that explains interaction patterns between parents with advanced cancer and their adolescent children	Semi-structured interviews with adolescents and parents Constructionist grounded theory	Community M (SD) 23.19 (7.72) 8.11 (3.31) 5.41 (2.17) 6.98 (2.75) 2.76 (1.26)
Interaction patterns between parents with advanced cancer and their adolescent children				Problems *p < 0.05 -Adolescents with an ill parent had significantly higher levels of distress and depressive state compared with adolescents with a healthy parent. -Late adolescents (15–18 years) had significantly higher distress, anxiety, and irritability compared with norms of the same age. -Late adolescents experienced significantly higher distress and anxiety than early adolescents (12–14 years) with an ill parent.
				Time was of great importance to these parents and adolescents; all participants structured their stories in relation to the concept of time. A model was created that reflected the dynamic process by which families adapted their relationships in the face of advanced cancer. Not having enough time together Time with their children was limited because of terminal illness and expressed

<p>QualSyst score = 18/20 *includes adolescent and parenting outcomes</p>	<p>regrets about not spending more quality time before the illness, loss of future time <i>Making the most of the time we have left</i> by coming to know the time we have is limited spending more time together becoming closer extending our time together—finding ways to transcend boundaries of time and death giving up our time together to end suffering</p>	<p>Open communication within the family may lead to more effective coping and a positive experience for children whose parents have advanced cancer. Major themes <i>Response to diagnosis</i> Children described being distressed and having concerns related to their parent's health and their own. <i>Mechanisms of coping</i> Distraction and maintaining normality described as major coping strategies <i>Life changes</i> Increased responsibilities and decreased social activity as most noticeable life changes <i>Positive aspects</i> Strengthening relationships and learning to value family members and the important things in life seen as positive aspects</p>	
<p>*Kennedy & Lloyd-Williams [32] England How children cope when a parent has advanced cancer QualSyst score = 17/20 *includes adolescent and parenting outcomes</p>	<p>Qualitative—cross-sectional Explore the impact of parental advanced cancer on children and how they cope, from the perspectives of children and parents</p>	<p>Semi-structured interviews with parents and children Constructionist, grounded theory</p>	
<p>Beale et al. [40] USA Parents dying of cancer and their children QualSyst score = 10/20</p>	<p>Mixed advanced cancer Palliative care N = 23 children (ages 3–18 years) with an ill parent N = 5 children with an ill sibling</p>	<p>Descriptive (qualitative) To report the experiences of children of parents with terminal cancer</p>	<p>One or more clinical interviews with children</p>
		<p>Child reported emotional domains Seeks reassurance Becomes caretaker Separation ability Anger about abandonment Despair Guilt Discipline problems Aggressive behavior Reliance or denial Blame others</p>	<p>% of children 82 79 79 68 57 54 46 43 39 21</p>

Continues

Table 2. Continued

Source(year)/country	Subject description/sample (N)	Study design/purpose	Measures/methodology	Results/findings
Siegel et al. [16] USA	Mixed advanced cancer Patient died within 1 year of first measures, post- death measures taken within 7–12 months of the loss N = 70 families N = 97 (60 children ages 7–11 years, 41 ages 12–17 years) *ages pre-death Comparison group— community sample N = 467 families N = 616 children	Longitudinal study sample Cross-sectional Comparison group To compare pre-death and post-death levels of depression and anxiety reported by a sample of children who lost a parent to cancer along with levels reported by community sample	CDI STAI-Y STAI-C CDI Pre-death*** Post-death STAI State Pre-death*** Post-death Trait Pre-death*** Post-death	Community M (SD) 46.0 (10.4) 46.1 (10.5) 52.3 (11.5) 45.9 (10.3) 50.8 (11.5) 45.7 (11.6)
Christ et al. [10] USA	Mixed advanced cancer N = 86 families N = 120 adolescents (ages 11–17 years)	Qualitative—cross-sectional Summary of psychological and emotional responses to a parent's advanced illness as described by adolescents	Assessment interview of adolescents	***p < 0.001 -Children facing the death of a parent reported significantly higher levels of depression and anxiety compared with the community children. -7–12 months after the loss of their parent, the same children reported on average the same levels of depression and anxiety as those reported by the community sample. Compared with younger children the adolescents' greater cognitive and empathic capacities allowed them to be more aware of losses and of the parent's physical and emotional pain. Parental cancer precipitated conflict around issues of developmentally appropriate separation. The capacities to use intellectual defenses, search for meaning, and seek help were powerful coping strategies.
Impact of parental terminal cancer on adolescents QualSyst score = 11/20				Interview responses Emotional control Intensification of typical adolescent themes Problems and concerns Empathy for ill parent Increased involvement with parents Household responsibilities

18

Fear for own health

Influence of parental relationship	Community	Study sample
Guilt	M (SD)	M (SD)
Common ways of coping	6.8 (7.0)	10 (6.5)
Intellectual defenses, the search for understanding, seeking help		
Severe reactions		
CDI*		
STAI-C	27.7 (5.9)	32.8 (6.5)
State*	31.0 (6.6)	37.4 (4.9)
Trait*		
STAI-Y		
State*	36.8 (10.7)	46.8 (12.5)
Trait	40.4 (11.2)	44.6 (9.1)
SEI*	76.8 (19.7)	68.8 (19.4)
CBCL		
Internalizing*	47.1 (8.6)	55 (10.5)
Externalizing*	46.1 (8.2)	52.2 (10.8)
Total Problems*	45.7 (9.6)	54.6 (11.5)

*p < 0.05

CBCL, Child Behavior Checklist; CDI, Child Depression Inventory; FAD, Family Assessment Device; HADS, Hospital Anxiety and Depression Scale; IDPSQ-14, Indice de Detresse psychologique de Sante Quebec (derived from Psychiatric Symptom Index (PSI)); Kidcope, cognitive and behavioral coping; Kidscreen-10, global well-being; SDQ, Strength and Difficulties Questionnaire; SEI, Self-Esteem Inventory; STAI-C, State Trait Anxiety Inventory; STAI-Y, State Trait Anxiety Inventory—children's version.

The analysis was organized around the major themes found in the literature within each category. These themes emerged by reviewing the most common themes found in the collected literature and building on the researcher's conceptual model of factors influencing adolescents' adjustment to parental cancer.

Impact on the family and parenting

Need to maintain normalcy

Parents worked hard to maintain normalcy in their family's lives, especially their children's social activities [25,26,28,29,32]. Yet, severe fatigue and side effects from cancer treatments were described as impediments to maintaining stability, normalcy, and daily routines [26,29]. Mothers in particular described a sense of responsibility to their children to maintain normal household routines despite their side effects [26]. Women felt keeping a routine and structure in their children's lives would make children feel safe and grounded [28]. Some parents believed successfully maintaining normalcy and not communicating about the illness would protect their children from the emotional impact of cancer [32].

Parenting became a priority

The sicker parents became, the more parenting became a chief concern in their lives [23]. As one woman shared, 'I used to want a lot of things. Now, all I want is to see my children grow up' [26]. Whether parents attempted to be better listeners, spend more time with their children, or create memories to sustain long-term attachment, parents with an advanced cancer diagnosis felt compelled to be good parents. Sigal et al. [23] examined the mother-child relationship between women with early-stage breast cancer and women with metastasized breast cancer with surprising results. They found that the sicker mothers and their children were coping better with the illness, with reports of less poor parenting and fewer behavioral problems in their children [23]. The authors suggested that once mothers realize they may die, they begin maximizing the time they have left with their children. Moreover, once children comprehend the seriousness of their parent's condition, they may attempt to protect their parents by controlling any disruptive behavior. They concluded that parents with advanced cancer recognize the life-limiting nature of their illness and in turn make parenting and their relationship with their children a priority in their lives [23].

This idea was also supported by the qualitative studies. Houldin and Lewis [29] interviewed 14 patients with Stage IV colorectal cancer. Parents shared how they were forced to 'rethink their parenting' by not only trying to spend more time with their children but even 'listening to them more'. Sheehan and Draucker [27] created an explanatory model outlining interaction patterns between

Table 3. Intervention studies

		1. Theoretical framework		
		2. Methodology/evaluation method		
Source (year)/study	Subject description/sample	3. Comparison group	Intervention components	Results/findings
Bugge et al. [30] Family support program Norway Parents' experiences of a family support program when a parent has incurable cancer	Metastatic mixed cancer N = 6 ill parents N = 7 spouses Had 12 children ages 6–16 years	<ol style="list-style-type: none"> Based on the coping theory of Libo and Griffith. Family-based approach to reduce risk factors and enhance positive interactions between parent and child Qualitative design: in-depth interviews with ill parents and their spouses up to 6 weeks after completion of the program. phenomenological-hermeneutical perspective No comparison group 	<p>Individual and family/child and parent intervention</p> <p>Five meetings over 4–6 weeks</p> <p>Meeting were as follows: Family meeting to introduce program</p> <p>Parent's meeting to discuss parenting and coping</p> <p>Children's meeting talk about each child's experiences, draw social map, draw feelings, discuss medical treatment, and questions</p> <p>Family meeting to discuss concerns and family strengths assessed</p> <p>Family meeting how to face the future</p>	<p>Parent's experiences of impact on family resilience:</p> <p>Support received</p> <p>Help with talking and telling the children</p> <p>Confirmation of what parents had done well</p> <p>Help dealing with difficult questions and tasks</p> <p>Help dealing with feelings and reactions</p> <p>Reframing the crisis</p> <p>Identifying resources in and out of family</p> <p>Using family strengths to make memories/strengthen relationships</p> <p>Seeking and using help</p> <p>Planning the future and help needed</p>
Bugge et al. [44] Family support program Norway Children's experiences of participation in a family support program when their parent has incurable cancer	Six families with a parent with terminal cancer with 12 children ages 6–16 years	<ol style="list-style-type: none"> Based on the coping theory of Libo and Griffith. Family-based approach to reduce risk factors and enhance positive interactions between parent and child. Qualitative design: In-depth interviews with children up to 6 weeks after completion of the program. Phenomenological-hermeneutical perspective. No comparison group. 	<p>Individual and family/child and parent intervention</p> <p>Five meetings conducted over 4–6 weeks</p> <p>Meeting were as follows: Family meeting to introduce program</p> <p>Parent's meeting to discuss parenting and coping during illness</p> <p>Children's meeting to talk about experiences, draw social map, draw feelings, discuss medical treatment, and questions</p> <p>Family meeting to discuss concerns and family strengths assessed</p> <p>Family meeting to focus on how to face the future</p>	<p>Children's main concerns in relation to the illness situation</p> <p>Fear that parent would die; being unable to talk with parents about illness situation; being sad and frightened, seeing the changes in the parent's condition; and having fantasies and fears about cancer as an illness</p> <p>How children experienced the family support program in relation to coping factor 'belonging'</p> <p>Confidence to talk about the illness situation; predictability about illness situation; talking about family strengths, confirmation, and association within the family; information sharing with social network about illness situation</p> <p>How children experienced the family support program in relation to coping factor 'competence'</p> <p>Increased knowledge about illness and prognosis; being important and valuable</p>

in the family:
 Confronting and coping with their own
 fear and other reactions to the illness situation

Themes:

- Thrown into chaos
- Crisis of illness
- Family in turmoil
- Routines abandoned
- Lost in panic
- Kids out of the loop
- No one to turn to
- Crying for help
- Holding them steady
- Family as focus
- Specialist skills
- Working together
- Journeying together
- Preparing to face it
- Traveling together
- Remembering together
- Saying goodbye
- The road ahead
- Riding the storm
- Seeking a balance
- Glimpsing a future
- Securing the legacy

Author provided descriptions of
 children's responses and examples of their coping

Individual and family sessions
 provided pre-death and post
 death with a social worker
 trained in end-of-life care.

1. None noted for intervention.
 Family Systems Theory used
 for data analysis.
2. Qualitative pre-intervention
 and post-intervention evaluation
 design. Case study methods using
 data from in-depth interviews with
 children, parents, stakeholders,
 and staff. Additional data included
 observations, documents, and
 statistical reviews.
3. No comparison group.

Six families with a parent
 with terminal cancer with
 children up to age
 19 years

Kennedy & Lloyd-
 Williams [32]
 Macmillan Cancer
 Support
 Scotland
 Supporting
 children and families
 facing the death of
 a parent

Parent and child intervention
 Collaboration with parents
 and providing them
 psychosocial knowledge
 Provide age-appropriate
 information.
 Arrange hospital visits with
 adequate preparation
 and support
 Help interpret medical status
 for child
 Preparation for death
 of parent

1. Piaget's theory
 of cognitive development
 as a basis for psychosocial
 intervention
2. No formal evaluations
 have been conducted.
3. No comparison group

Toddlers through
 adolescents

Adams-Greenly &
 Moynihan [31]
 Memorial Sloan Kettering
 Cancer Center
 USA
 Helping the children of
 fatally ill parents

parents with advanced cancer and their adolescent children. Using a constructionist grounded theory approach, analysis of their data revealed the core variable, *Making the Most of the Time We Have Left Together*. The study's explanatory model depicts the adolescents and ill parents' responses to the realization that their time together was limited by the parent's impending death. Ultimately, parenting their adolescent well was a critical concern, even for the very ill parent. Their model reflects a dynamic process by which families continuously adjust their relationships in the face of advanced cancer. O'Callaghan and colleagues [33] analyzed the lyrics of songs written by parents with metastatic cancer to their children. They found that parents used these songs as a way to facilitate their child's sense of connectedness to the hospitalized parent and as a way to ensure ongoing attachment to them after death [33].

Drawing on ethnographic fieldwork at a support group for women with metastatic cancer, Bell and Ristovski-Slijepcevic [26] explored the relationship between mothering and living with advanced cancer. Mothering for these women became 'a race against time' as they attempted to 'cram a lifetime worth of parenting into a few short years' by making every effort to create memories [26].

Talking with children about advanced cancer

Parents expressed concerns about ways to talk with their children about their advanced cancer [25,28,29,32]. Communication is an important factor to help children adjust to parental cancer. Yet, parents struggled with the amount of information, timing, and language used to explain an advanced disease [25,28,29]. Mothers wondered if children would understand the implications of a metastatic disease [25] and also felt the need to maintain hope while still being honest with their children [28].

The consensus was that parents did not receive guidance or support from healthcare professionals on how to talk to their children about advanced cancer [25,28,32]. Parents felt their healthcare practitioners avoided discussions about advanced cancer or death [28]. Parents were left to deal with this issue alone. Therefore, many failed to initiate discussions about cancer with their children [28]. Some parents were reluctant to discuss the illness with their children, believing that telling too many details about their cancer would negatively affect their children [29,32].

When women did find parenting resources for cancer, they reported that the materials were mostly aimed at early-stage cancer. Women reported depending on personal experiences or experiences of people they knew for ideas on how best to communicate about cancer to their children [26,28]. When recounting these experiences, women commented on the negative emotions they or their friends felt when their own parents' cancer was not disclosed to them or was purposely obscured. These

findings suggest that parents need help in communicating with their children about advanced cancer in order to maintain trust in the parent-child relationship.

Worrying about emotional impact on children

Parents were often concerned about the emotional impact cancer had on their children [25,26,28,33]. Some parents worried less about the impact of the disease on themselves, than about its effect on their family and children [29]. One study revealed a consensus upon a 'hierarchy of suffering'. This hierarchy was an oftentimes unspoken agreement that living with advanced cancer was far worse when the women had dependent children [26]. Most parents described their children as being upset by the news of their cancer diagnosis. They described their children's distress such as crying uncontrollably or asking 'how many sleeps' until the parent died. Parents also reported concerns about their family, especially their children, watching their physical deterioration [25,26].

Impact on children and adolescents

Psychosocial impact

Quantitative studies of the impact of parental advanced cancer on adolescents are rare. However, there are several studies that included parents with advanced cancer in their samples. Although the results of these studies are aggregated across all stages of cancer, they have identified factors related to children's adjustment that may be important to consider when examining families dealing with advanced cancer. For instance, recurrence of parental cancer has been associated with high rates of distress and stress response symptoms (SRS) in adolescents [34,35]. Studies have found that the severity of the parent's physical impairment and the child's perception of the illness as serious are both factors strongly related to greater distress in adolescents [36-38]. It can be inferred from these studies that adolescents experiencing a parent with advanced cancer may have similar psychosocial outcomes.

Siegel and colleagues [22] found that children whose parents were receiving treatment for advanced cancer reported significantly higher levels of depression, anxiety, and lower self-esteem than peers. In addition, parents reported higher behavioral problems and lower social competence in the children with a terminal parent [22]. In a follow-up study, Siegel et al. [16] found that children's levels of depression and anxiety prior to their parent's death were significantly higher than it was 7-12 months after the loss of their parent. This suggests that the terminal phase of a parent's illness may in fact be a period of more distress than after the actual loss. A recent study by Rainville et al. [21] found that adolescents living with a parent's advanced cancer showed significantly higher levels of distress and depression compared with the general population. Upon further analysis, they discovered age effects on their

results with early adolescence (12 to 14 years) showing no significant differences in measures when compared with the same age group of peers. However, late adolescents (15 to 18 years) continued to show significant differences in their levels of distress, anxiety, and irritability compared with their peers [21]. This result was reiterated in another study that found older age of adolescent was associated with lower health-related quality of life (HRQoL) [24]. Surprisingly, the same study found that adolescents of parents with advanced cancer reported significantly less behavioral and emotional problems and higher HRQoL when compared with adolescents whose parents were in other disease stages. The authors speculate that these results may be due to the effort made by adolescents to 'ward off potentially overwhelming emotions', conceal their thoughts, and control negative behaviors in order to protect their parents during a distressing period [24].

It has been shown that depressive mood or negative affect in the parent with cancer is associated with emotional and behavioral problems in children [23]. Further findings show that negative parenting behaviors (as assessed by a parenting behaviors questionnaire) are associated with negative child outcomes such as increased externalizing symptoms [23]. Behavioral problems were also reported in children by parents who did not have open communication styles. However, these parents pointed to the adolescents' age and not the cancer as the reason for the behavioral problem [32].

The qualitative studies reviewed provide further insight and context to these results. Adolescents reported the knowledge that their parent's cancer had spread or was incurable as very distressing, upsetting, and heartbreaking [10,32,39]. They reported feelings of intense sadness and guilt accompanied by concerns about impending parental death, as well as concerns for their own health [10,32,39]. These studies bring to light the adolescents' ability to empathize with their ill parent and show a deep level of awareness of the ramifications of advanced cancer.

Parent-child relationships

There is evidence of a relationship between parenting quality and child and adolescent adjustment to a parent's illness [23]. The significance of the adolescents' relationship with their parent was reported by many of the adolescents interviewed. A positive relationship before the diagnosis helped adolescents adapt to the changes brought about by the illness [10]. Open communication between the parent and child led to more effective coping and also seemed to strengthen the parent-child relationship [32]. Children and adolescents often described a consequence of the illness as spending more time with their parent and 'a sense of becoming closer to their family' [10,27,32]. Sheehan and Draucker [27] found that adolescents spent more time together with family and extended their time together by developing strategies to maintain their relationship after the parent's death.

These findings imply that warm and supportive parenting may serve as a protective factor for these children and adolescents.

Coping strategies

Lazarus [40] defines coping as 'ongoing cognitive and behavioral efforts to manage specific external demands that are appraised as taxing or exceeding the resources of the person'. Emotion-focused coping is the 'regulation of stressful emotions', and problem-focused coping is 'the management or alteration of the person-environment relationship that is the source of the stress' [40,41]. In other words, emotion-focused coping is when the child attempts to modify their own reactions to their parent's cancer, and problem-focused coping is when the child makes attempts to modify the cancer or stressors related to the experience [42]. The literature shows that children and adolescents who have a parent with advanced cancer utilize one or more of these coping styles.

Two studies specifically looked at children and adolescents' coping styles when faced with a parent's advanced cancer [10,32]. They found that both emotion-focused and problem-focused strategies were employed by adolescents faced with a parent's advanced cancer. Kennedy et al. [32] found that the two most common coping strategies used were an emotion-focused coping strategy, distraction to maintain normalcy in their daily lives, and the problem-focused strategy of talking to someone outside of the family about the cancer. Christ et al. [10] described common ways of coping for adolescents who had a parent with advanced disease including 'intellectual defenses, search for understanding, and ability to seek help'. Adolescents were found to be aggressive in seeking information about the disease from various sources (parent, medical staff, books, etc.). Many adolescents desired more communication about the illness, either factual or emotional [32,39,43]. At times, they expressed a desire to talk to somebody outside of the family about their concerns in order to lessen the burden on their parents [32,43]. Adolescents tried to obtain meaning from the cancer experience and the role it played in their lives and their family [10,27]. Finally, adolescents seemed to cope by eliciting social support from peers, parents, and other adults and professionals [10,32].

Caregiving

Although parents described their efforts to maintain normal daily routines for their children, many adolescents reported increased demands to help with household chores [10,32,39]. A majority of children described becoming a caretaker for their ill parent [39]. Adolescents would run errands and try to take care of family needs in hopes of 'making it better for the ill parent' [27]. For some, the added family demands became stressful because it interfered with their regular activities [10,32], but many adolescents

welcomed the ability to help as a way to feel better about the situation [27,32].

Positive gains

The prevalence of positive well-being is rarely addressed in the literature on parental cancer. But, in the case of advanced cancer, positive aspects of the cancer experience seem to consistently emerge from the findings. Many of these studies have unexpectedly found evidence of resilience or protective factors that have led to positive outcomes for these families [24]. Sheehan and Draucker [27] found that parents and adolescents spent more time together, increased intimacy, and continued to foster a sense of attachment after the parent's death. Kennedy et al. [32] found that parents and children reported a greater sense of appreciation for their family and a sense of 'being grateful for what they have'. As one adolescent shared, '(Cancer) awakens your love for someone' [10]. Many adolescents seemed to search for meaning in the cancer experience as a way to cope and maintain hope [10,27]. Parents also reported witnessing positive outcomes in their children such as increased independence, learning to prioritize, and improvements in relationships with family members [27,32].

Discussion

Methodological and conceptual issues

Quantitative study designs

The majority of these studies were cross-sectional, with only one study using a longitudinal design [16]. Rubin and Babbie [44] explain how cross-sectional designs have an inherent problem. In general, they seek to understand causal relationships that are part of processes that take place over time. However, their findings are determined by an observation made at a single time point [44]. As Lewis [45] argues, 'dynamic change models are needed in future studies to better examine the child or adolescent's response to parental cancer'. Although cross-sectional designs do not allow us to make causal inferences, they do provide valuable insights as to which variables are related to each other and should be examined more closely in further research. Longitudinal research is particularly important in this research area in order to assess which stage of the illness may be most critical for intervention and to examine the long-term consequences of advanced cancer on these emerging adults.

Samples: There are a myriad of sampling issues to consider when reviewing the empirical data on advanced parental cancer. The majority of studies in our review had an extremely small sample sizes with only two studies nearing 100 participants [16,24]. This makes it difficult for most statistical analysis to reach statistical power. Small sample sizes also compound the difficulty in

evaluating differences in child adjustment based on gender, age, and levels of cognitive maturity.

The preponderance of participants in all the studies reviewed were also Caucasian, educated, and in middle or high socioeconomic class. These homogenous samples diminish the external validity of these studies [44]. Another problem with the sampling methods of these studies is they require voluntary participation from the parents and children. Many of them rely on self-referred families in which the adolescent has been informed of their parent's advanced cancer diagnosis. One study attempted to understand these self-selection effects by using multilevel analysis to compare the SRS of adolescents and ill parents who were self-referred to those recruited by hospital staff [35]. They found that adolescents who self-referred to the study had more emotional problems and higher SRS than those recruited by hospital staff. In addition, self-referred ill parents had higher levels of anxiety. These findings highlight the importance of paying attention to the effects of selection bias when recruiting from different sources and when comparing studies that use different recruitment techniques [44]. Furthermore, ethical and methodological issues prevent researchers from being able to assess the impact of a parent's advanced cancer on adolescents that have not been told about the diagnosis. Therefore, retrospective studies are needed to address such questions.

In addition, many of these studies aggregated various developmental age groups together and defined them as 'children'. Researchers need to distinguish a more restricted conceptualization of children because each period of childhood has its own set of biological, developmental, and psychosocial issues. Research studies should be tailored to each developmental level in order to obtain a clear understanding of the needs of adolescents in each developmental phase. In particular, there are limited studies of the experience of adolescents in this population, although they have been identified as a potentially vulnerable group. More studies should focus on the adolescents' experience by examining differences between early and late adolescents' outcomes.

Measurement: The primary method of data collection in these studies of the effects of advanced parental cancer on children involved parent reports and self-report. Most used preexisting measures that had adequate reliability and validity. But self-report questionnaires can be subject to self-reporting bias and may be unreliable. The best measurement instruments can be hindered by biases such as social desirability, distortions of reality, poor recall, and denial [44]. Few of the studies acknowledged that solely using self-report and parent reports subjected them to self-reporting bias, and none attempted to triangulate their data with more objective measures or examine cross-informant correlations.

Another important limitation to the studies reviewed was that the choice of measures and constructs examined

showed a trend toward using symptom checklists aimed at identifying psychopathology. This focus on adjustment questionnaires lacks the ability to provide a comprehensive view of the adolescents' daily experiences and quality of life [45]. Only one study made an attempt to measure the children's quality of life [24]. This is surprising because of the abundance of quality of life measurements used when studying children with cancer or adult psychosocial oncology. The use of quality of life measures seems to be appropriate for this population because of the normative distress of having a parent with cancer that puts children and adolescents at increased risk of maladjustment but also allows for the possibility of resilient individuals in the samples [46].

Qualitative studies

The concept of quality or rigor in qualitative studies has been an issue of controversy for some time [47]. Armour et al. [48] described rigor as 'the degree to which researchers hold themselves to standards of inquiry that address challenges to the credibility of the studies findings' (p. 102). Therefore, this review evaluated methodological thoroughness as well as strategies used to ensure trustworthiness.

The participants interviewed were overwhelmingly parents (eight studies), and only one study focused solely on the adolescents' experience. This lack of studies focused on the adolescents' perspective means there is still much to learn about the adolescents' experience and how they manage their lives while living with a parent's advanced cancer [45]. The credibility of some of the qualitative studies was also limited by inadequate descriptions of their methods of analysis [10,25,28,39].

Qualitative validity: Lincoln and Guba [49] suggested the concept of trustworthiness as a way to ensure quality in naturalistic research designs. Since then, qualitative researchers have put forth various criteria that can be used to assess a study's authenticity or trustworthiness and strategies that can be used to achieve rigor [47,50]. Creswell [47] recommended researchers employ at least two of these strategies in any given study to achieve adequate trustworthiness of their findings. Seven of the included studies used two or more of these strategies to ensure trustworthiness including use of field notes, clear description of analysis, direct quotations from participants, rich thick descriptions, extended fieldwork, peer review, reflexivity, investigator triangulation, data triangulation, inter-coder reliability, and audit trails [25–33].

Intervention studies

The relative absence of intervention studies makes it difficult to draw conclusions about interventions for children and adolescents facing a parent's advanced cancer. The tendency in the literature has been to describe rather than discover

effective methods to intervene [51]. The results of the four intervention studies reviewed may be clinically significant and show promise that providing support for parenthood and children during the terminal phase of illness may provide psychological well-being for families facing parental death from cancer. More importantly, these studies show interventions do not cause harm. Nevertheless, the gains provided by these studies are not convincing from the perspective of intervention research because of study designs and various limitations. One of the primary limitations was the lack of a control group in the studies, greatly decreasing the reliability of the intervention effect. Lack of formal instruments was a significant threat to validity for all studies. Internal validity was compromised in all the studies in varying degrees. Selection was a significant threat in that all the samples were composed of volunteer participants, potentially biasing toward more positive outcomes. Also, future studies are needed using experimental designs that control the independent variable to validate the causal inferences of newly developed interventions and to ensure outcomes are trustworthy. Despite the methodological limitations, the reviewed studies lend support to the benefits of psychosocial programs in helping children adapt to advanced parental cancer: promoting positive parenting, decreasing misconceptions about the illness, providing opportunities for expressing feelings, increasing family communication, and promoting positive coping. Researchers need to continue in their interventional efforts and evaluative research in order to satisfy the current lack of evidence to guide clinical practice.

Conclusion

The results of this analysis of literature must be interpreted cautiously because of the paucity of research on the adolescents' experience when a parent has advanced cancer. Additional limitations include that gray literature was excluded and the quality of each paper was not used as criteria for inclusion.

This review of literature found that adolescents living with a parent's advanced cancer show significantly higher levels of distress, anxiety, and depression, as well as lower self-esteem than their peers [16,21,22]. In addition, parents reported higher behavioral problems and lower social competence in the children with a terminal parent [22,32]. One study found that adolescents of parents in early disease stages reported lower psychosocial well-being when compared with adolescents of parental palliative disease [24]. Results demonstrated worse general family functioning, and older age was more predictive of psychosocial problems and HRQoL than disease stage [24].

Possible factors that impact the adjustment of adolescents to their parent's advanced illness include poor parenting, open communication style, age (early versus late adolescence), and the parent-child relationship [10,21,23,24,32]. Similar to a

previous review of the impact of parental cancer on adolescents [7], these studies showed that adolescents used a variety of coping strategies when faced with a parent's advanced cancer [10,24,32]. The most common included the following: distraction to maintain normalcy, talking about the cancer and not talking about it, reasoning, helping the ill parent, searching for meaning, and seeking social support. In contrast to the previous review by Grabiak and colleagues [7], most studies in this review discovered that families facing advanced cancer employ positive outlook and hope as strategies to overcome the challenges and uncertainties of their experience. As a result, possible resilience or protective factors were identified.

This review found that parents are concerned about the best ways in which to talk about their advanced cancer with their children, try hard to maintain normalcy in their children's lives, strive to be good parents, and are concerned about the emotional impact their cancer has on their children. In light of these results, it would be important for clinicians to encourage parents to communicate openly with their adolescent about the cancer treatment and consequences. In addition, providing parents with the support and resources needed to feel confident in preparing their adolescent is imperative. Several helpful resources for parents and clinical staff include the following:

A brochure developed by Turner and colleagues, "What should I say to the children?: a guide for parents with advanced cancer." Available published in:

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? *Palliative & Supportive Care*, 5(02), 135-145. doi: doi:10.1017/S1478951507070204

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The American Cancer Society website has information on

helping your child deal with a cancer recurrence or progressive illness in the family
<http://www.cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer/dealingwithrecurrenceorprogressiveillness/dealing-with-recurrence-or-progressive-illness-intro>

The National Cancer Institute website has information for parents and caregivers on how to talk to children and adolescents about advanced cancer:

Advanced cancer: living each day
<http://www.cancer.gov/cancertopics/coping/when-some-one-you-love-has-advanced-cancer/page1/AllPages>
<http://www.cancer.gov/cancertopics/coping/advancedcancer/page1/AllPages>

However, there is still much that remains unknown about the experiences of adolescents living with advanced parental cancer. There is a lack of studies that examine the specific concerns parents have about their adolescent children's behavior, an understanding of the adolescent's experience from their own perspective, the difficult situations faced by adolescents in relationship to the parent's advanced cancer, the parent–adolescent relational issues, and what parents tell their adolescents about advanced disease diagnosis. Therefore, more descriptive research focused specifically on adolescents is needed to inform development of effective interventions for this at-risk population.

Conflict of interest

The author has declared no conflicts of interest.

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