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Dying concerns in young parents with advanced cancer (PWAC): A scoping review

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Review Article

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Abstract

Background. Advanced cancer in young parents (PWAC) can increase dying concerns, the fluctuating thoughts, or feelings, conscious, or unconscious, about an approaching death by a person facing a terminal illness or a family member coping with the impending death of a loved one. However, limited research has been conducted to identify dying concerns in an ill parent as the research has focused on older adults.

Objective. Our goal was to identify dying concerns that PWAC are expressing and to understand how these concerns affect measurable outcomes.

Method. CINHAL, MEDLINE, PsychARTICLES, PsycINFO, Social Work Abstracts, Health Source: Nursing/Academic Edition, and Psychology and Behavioral Sciences Collection were searched. Articles included were samples of PWAC, peer-reviewed, and published within the last 10 years. Elderly or pediatric populations, PWAC with adult children, and early-stage cancer were excluded. The initial search resulted in 1,526 articles, 18 were identified as potentially relevant. Fourteen articles were identified and reviewed.

Results. PWAC expressed concerns for their children ($n = 11$), concerns for their co-parent ($n = 4$), and personal concerns ($n = 11$). Additionally, PWAC have decreased quality of life, have significant emotional and psychological distress, and have increased family dysfunction in relation to their concerns. Samples limit the generalizability of the findings. Majority of the articles consisted of White, upper, middle-class ($n = 8$) women ($n = 7$) diagnosed with breast cancer ($n = 11$) within nuclear families ($n = 11$).

Significance of results. Dying concerns are described in the literature from a fairly narrow sample of PWAC. Future research should focus on recruiting participants from diverse backgrounds, genders, diagnosis types, and non-nuclear families. Identifying concerns for the co-parent would also add to the understanding of dying concerns.

Introduction

While 80% of all cancers in the United States are diagnosed in people 55 years old or older (American Cancer Society, 2019), half of the population who are in their childbearing years will die from their cancer (National Cancer Institute, 2016). There is no epidemiologic data on what percentage of this population has advanced cancer with a terminal diagnosis and who are living with dependent children (parents with advanced cancer, PWAC). About 14% has been reported, although this percentage involves cancer survivors and not parents with active advanced illness (Weaver et al., 2010). Individuals approaching death have concerns about their future and the future of their remaining family. Yet, the literature on approaching death of PWAC have often been limited to the term “parental concerns” (Muriel et al., 2012; Moore et al., 2015; Park et al., 2016, 2017, 2018) rather than the broader concept of dying concerns. Parental concerns are emotional concerns for the well-being and development of the child (Algarvio and Leal, 2016). They focus on one role of the PWAC: being a parent. It does not capture the additional roles the PWAC may have, such as spouse or co-parent. Yet, when the literature is limited by a single role focus, our professional interventions may also be limited.

Dying concerns are fluctuating thoughts or feelings that are conscious or unconscious about an accepted and approaching death which stems from a palliative/terminal diagnosis by the person facing the terminal illness or by a family member coping with the impending death of a loved one (Dickstein, 1972; Arndt et al., 2006; Kakuta et al., 2015). Dying concerns differ from generalized concerns when the perception changes from personal concerns to concerns for the well-being of another. For the ill patient, this occurs once they have acknowledged their impending death. For example, a financial concern is a generalized concern when the patient is troubled about paying for treatment. It becomes a dying concern when the patient accepts their terminal illness and becomes concerned about the future financial stability of their family once they die.

Dying concerns can only be identified in individuals who have accepted their impending death. An individual’s readiness to discuss end-of-life issues are still being explored

(Bell et al., 2016). Kubler-Ross's (1969) seminal work states, acceptance of death may only happen once an individual proceeds through the stages of grief (e.g., denial, anger, bargaining, depression, and acceptance). However, Kubler-Ross asserts, "it is not in human nature to accept the finality of death without leaving a door open for some hope" (Kubler-Ross, 1969, p. 113); therefore, individuals can have acceptance of death while still being in other stages of grief. Grief is not linear but an active course that has fluctuations over time. Dying concerns are also proposed to fluctuate over time.

Dying concerns for advanced cancer patients may have similarities but also differences based on the age of the patient, the active roles they have in their daily lives, and the developmental stage of the family. For example, an elderly couple married for 35 years is likely to be financially stable and have adult children who can assist with caregiving; therefore, their concerns when faced with death may differ from a young couple who is just starting in married life, working on saving for the future, and have dependent children with ongoing and future financial demands.

Cancer research with young families has focused on parents diagnosed with early-stage cancer (Aamotsmo and Bugge, 2014; Zaider et al., 2015). Limited research has been conducted to identify the dying concerns of PWAC. The extant literature has focused on concerns of parenting with a terminal illness and the challenges the parents face, along with the impact of advanced cancer on the children. The research lacks a comprehensive definition of dying concerns which include concerns beyond the parental role such as their role as a co-parent and the effect on a spouse. Therefore, the aims of this scoping review are to (1) describe the research on the concept of dying concerns of PWAC, (2) examine how these dying concerns impact measurable outcomes, and (3) identify gaps in our knowledge of dying concerns in PWAC.

Methods

Literature search

The primary author (CC) reviewed seven databases: CINHAL, MEDLINE, PsychARTICLES, PsycINFO, Social Work Abstracts, Health Source: Nursing/Academic Edition, and Psychology and Behavioral Sciences Collection for English language articles. The following MESH terms were searched: parental concern(s), cancer, advanced cancer, metastatic cancer, terminal cancer, end-of-life cancer, and palliative cancer connected by the Boolean term AND. The term "dying concern(s)" was searched but only yielded articles with an elderly population. The term "parental concerns" was searched to identify research within a younger population. Parental concern will be used interchangeably throughout the rest of the paper to discuss dying concerns of PWAC. Retrieved articles were published between 2008 and 2018. Reference lists of included articles were reviewed to identify additional articles. PRISMA guidelines were utilized for this scoping review (Moher et al., 2015). The information flowchart is depicted in Figure 1.

Study selection

The inclusion criteria were as follows: (1) samples were parents with advanced cancer (Stage III and IV); (2) measured or described parental or dying concerns; (3) peer-reviewed; and (4) published not more than 10 years ago. The exclusion criteria were as follows: (1) samples were dyads of spouse and/or caregiver, parent and children, and/or parents with adult children; (2) early-stage cancer; and (3) pediatric and/or adolescent cancers. Identified abstracts were organized in tables created by the first author.

Data extraction

See Tables 1 and 2 for the extracted data. Data extraction was completed by the first author and verified by the remaining authors. Differences of opinions were resolved through discussion.

Results

The literature search resulted in 1,526 articles. At the abstract level, 1,506 were excluded because they did not meet the aims of this scoping review. The remaining 18 articles were assessed for eligibility by reading the full text. Four were excluded: three articles included participants with early-stage cancer and one article was a commentary on previous research. Fourteen articles were used in the final summary.

Eight articles used quantitative methods (Gazendam-Donofrio et al., 2008; Schmitt et al., 2008; Nilsson et al., 2009; Ernst et al., 2012; Stinesen-Kollberg et al., 2013; Moore et al., 2015; Park et al., 2016, 2018). Four articles were qualitative studies (Lewis et al., 2016; Check et al., 2017; Lundquist, 2017; Park et al., 2017) and two used mixed methods designs (Muriel et al., 2012; Kuhne et al., 2013). Quantitative methodological studies varied between cross-sectional, descriptive, and longitudinal. Cross-sectional designs were commonly utilized ($n = 7$). Qualitative methodologies were qualitative descriptive ($n = 3$) and social constructionists' ($n = 1$) approaches.

Studies were limited to industrialized western countries. Six articles were conducted in Europe ($n = 5$) and Australia ($n = 1$), with the remaining conducted in the United States ($n = 8$). All used a single institution for data collection. Qualitative studies were mostly descriptive in design ($n = 3$) with the aim to describe the experiences of being PWAC. Sample sizes were small to moderate for the quantitative cross-sectional designs ($n = 63 - 381$), were exploratory in nature, and lacked comparison groups.

Limitations were noted in gender and race, cancer type, and the structure of the family unit. The samples consisted primarily of White, upper, middle-class participants ($n = 8$) who were mostly women ($n = 7$). 6 out of 14 studies did not collect data on race (Gazendam-Donofrio et al., 2008; Schmitt et al., 2008; Ernst et al., 2012; Kuhne et al., 2013; Stinesen-Kollberg et al., 2013; Lewis et al., 2016). One study focused solely on White fathers (Lundquist, 2017). Majority of the studies consisted of participants who were married ($n = 10$) (Gazendam-Donofrio et al., 2008; Schmitt et al., 2008; Nilsson et al., 2009; Ernst et al., 2012; Muriel et al., 2012; Park et al., 2016, 2017, 2018; Check et al., 2017; Lundquist, 2017), with one study having more non-married participants (Moore et al., 2015). The remaining studies did not collect marital data.

Fathers had similar concerns as the mothers in the other studies, such as concerns for their children and co-parent and maintaining their role, but the latter two had differences (Lundquist, 2017). Men's concern for their co-parent was on the financial strain that may present itself when they no longer can fulfill their provider role (Lundquist, 2017); whereas, women are concerned about not being able to fulfill their caregiver role.

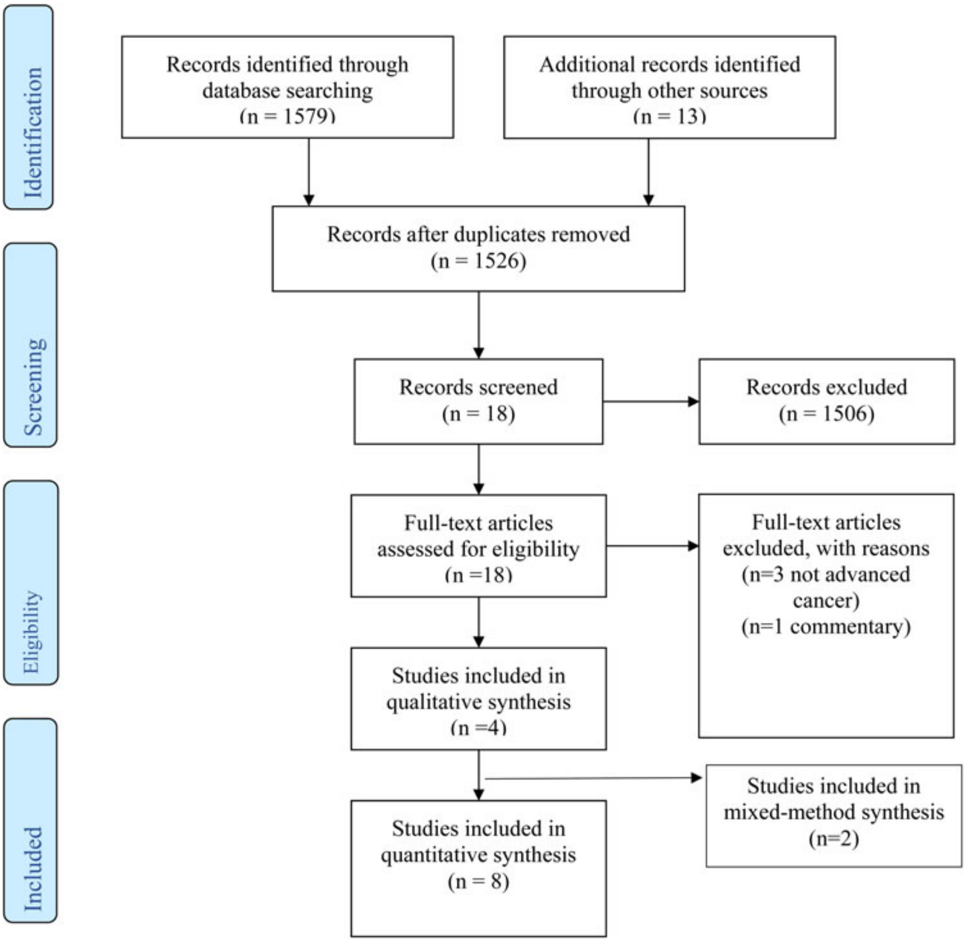

Fig. 1. PRISMA information flowchart.

Since the samples consisted mostly of women, the co-parent was identified as a marital husband ($n = 11$). A co-parent may be the spouse of the individual, but it also may be a significant other, a grandparent, or other close family members (e.g., aunt, uncle, and cousin). As for the children in the family, 10 studies did not collect the mean age of the children, only stating the children were 18 years old or younger.

The samples consisted predominantly of breast cancer ($n = 11$). Cancer type determines the kind of treatment a person receives. Certain treatments are more extensive than others and may affect the functional status of the patient compared to other patients.

Concerns of PWAC

When a parent has a diagnosis of advanced cancer, the major concerns identified are concerns about their children, the co-parent, and personal concerns (i.e., social concerns, psychological well-being, the physical repercussions related to treatment, and spiritual concerns).

All studies included families with children 18 years old or younger with parents having a mean age of 44. Only five studies specified the mean age of the children in the family ($\mu = 11.6$) (Schmitt et al., 2008; Park et al., 2016, 2017, 2018; Check et al., 2017). Open communication about cancer with children was a major concept in quantitative studies for PWAC and was a prominent theme in the qualitative studies. Parents were expected to have difficult conversations about their diagnosis with their children while simultaneously addressing their children's fears that they may die (Muriel et al., 2012; Kuhne et al., 2013; Park et al., 2018). Participants reported these conversations as difficult because they were uncertain about the trajectory of their disease (Lundquist, 2017). In some families, emotional distress was so high parents avoided discussing their illness at home, which was identified under the theme of "uncertainty for the future" (Lewis et al., 2016; Lundquist, 2017; Park et al., 2017). Uncertainty of time of death was the main factor impeding parents from having open communication with their children about their advanced cancer.

Child functioning and disruptions in normal developmental patterns were other major concerns for parents (Gazendam-Donofrio et al., 2008; Park et al., 2017). When the PWAC's parental function decreased, specifically in roles and communication, two studies described parents' perception that adolescent functioning decreased (Gazendam-Donofrio et al., 2008; Schmitt et al., 2008). Furthermore, parents were concerned about their children's development after their death and how their lives will alter growing up without one of their parents (Park et al., 2017).

Participants were concerned about the emotional impact of the illness and the potential emotional distress on their children once they died (Moore et al., 2015; Park et al., 2016, 2017). At the end of life, an increase in anxiety and depression in the parents may

Table 1. Extracted data from qualitative studies

Author and Year	Methodology	Aim of study	Setting, Sample size, and Family unit	Themes	Main findings
Check et al. (2017)	Qualitative descriptive	Explored parents' values and concerns about aggressive treatment and preferences for end-of-life services	**Setting:** Outpatient and Inpatient Oncology Service, North Carolina, USA **Sample size:** $N = 42$ **Family unit:** *Mean age of parent:* 44.2 *Mean age of children:* 11.6 *Marital status:* Married *Majority race:* White *Majority CA type*: Other (did not specify) next highest was Breast	Parental concerns affect preferences for advanced cancer treatment Parental roles affect preferences for hospice and palliative care	Children influenced treatment decisions at the end of life
Lewis et al. (2016)	Grounded theory	Explore how women "live well" with MBC	**Setting:** Oncology clinics and online communities, Australia **Sample size:** $N = 18$ **Family unit:** *Mean age of parent:* Data not collected *Mean age of children:* 18 years of age or younger[a] *Marital status:* Data not collected *Majority race:* Data not collected *Majority CA type:* Breast	Strategies to reestablish a sense of normality Reevaluating and reprioritizing lives Symptoms management	Normality and positive thinking were strategies women used to live well with MBC
Lundquist (2017)	Qualitative descriptive	Describe how men diagnosed with advanced cancer understand their role as a father	**Setting:** Cancer Centers in communities and support groups, Minnesota, USA **Sample size:** $N = 11$ **Family unit:** *Mean age of parent:* Data not collected *Mean age of children:* 18 years of age or younger[a] *Marital status:* Married *Majority race:* White *Majority CA type:* Brain (2); Lymphoma (2); Colon (2); PCA (2); MM(2); MFH (1)	Level of impairment Uncertainty for the future Financial burden	Achieve resiliency (barriers: physical impairments, uncertainty, and financial strain) Flexibility in role (open communication, supportive resources, and finding meaning)
Muriel et al. (2012)	Mixed methods	Higher parenting concerns would be related to increased psychological distress and worst QOL	**Setting:** Cancer Hospital, Massachusetts, USA **Sample size:** $N = 16$ **Family unit:** *Mean age of parent:* 46 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Married *Majority race:* White *Majority CA Type:* Breast	Communicating with children Children's coping or behavior Parenting identity and evaluation of own parenting Partner's ability to support patient and children Changes in parenting	Communication and parental role are common concerns expressed by parents with advanced cancer
Park et al. (2017)	Qualitative descriptive	Describe the experience of being a parent living with advanced cancer	**Setting:** Comprehensive Cancer Center, North Carolina, USA **Sample size:** $N = 42$ **Family unit:** *Mean age of parent:* 44.2 *Mean age of children:* 11.6 *Marital status:* Married *Majority race:* White *Majority CA type:* Breast	Impact of illness and death on children Loss of parental role and responsibilities Maintaining parental responsibilities Parental identity influencing decisions about treatment	Parental identity and parenting concerns impact the patient psychologically and influence decisions about treatment Functional status may impact parenting-related concern in patients

CA, Cancer; MBC, Metastatic Breast Cancer; PA, Prostate Cancer; MM, Multiple Myeloma; MFH, Malignant Fibrous Histiocytoma.

[a] Mean age of children not collected.

Table 2. Extracted data from quantitative studies

Author and Year	Methodology	Aim of study	Setting, Sample size, and Family unit	Variables examined	Measures used	Main findings
Ernst et al. (2012)	Cross-sectional	Examine if gender modifies anxiety and depression in cancer patients with dependent children compared to those without dependent children	**Setting:** University clinic and hospital, Germany **Sample size:** *N* = 253 patients **Family unit:** *Mean age of parent:* 42.1 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Married *Majority race:* Data not collected *Majority CA Type:* Women: Breast; Men: Urological	Anxiety, Depression	HADS-D, German version	Women and men in group with dependent children were more anxious than group without children Depression was not related to parenthood
Gazendam-Donofrio et al. (2008)	Cross-sectional	Assessed QOL of cancer patients between patient and spouse and parents QOL on children's functioning	**Setting:** University Medical Center, Netherlands **Sample size:** *N* = 209 total *N* = 166 patients **Family unit:** *Mean age of parent:* 44.7 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Married *Majority race:* Data not collected *Majority CA type:* Breast	QOL, Child behavior	RAND-36, QOL in patient and spouse, CBCL, YSR, Child QOL	Decreased QOL in the patients Patient's physical and social functioning related to a decrease in child functioning
Kuhne et al. (2013)	Cross-sectional	Assess if parental disease stage and perspective affects family functioning	**Setting:** University Hospitals and Clinics, Germany **Sample size:** *N* = 323 total *N* = 135 patients **Family unit:** *Mean age of parent:* 44.4 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Data not collected *Majority race:* Data not collected *Majority CA type:* Blood or lung	Family functioning	FAD	Increased family dysfunction in parents in relation to roles and in children in relation to communication
Moore et al. (2015)	Cross-sectional	Examine the relations between parental illness, QOL of parent, parenting efficacy and beliefs, and parental concerns about children's emotional distress	**Setting:** Comprehensive Cancer Center, Massachusetts, USA **Sample size:** *N* = 194 patients **Family unit:** *Mean age of parent:* 46 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Data not collected *Majority race:* White *Majority CA type:* Breast	QOL, Depression and Anxiety, Parenting distress and Efficacy beliefs, Parenting concerns	FACT-G, HADS, Distress Thermometer, 5-point Likert Scale for Parenting efficacy, PCQ	Decrease in parenting self-efficacy after diagnosis related to treatment, poorer QOL, and an increase in depression and anxiety Increase in concerns was related to declines in self-efficacy and a decrease in co-parent's efficacy Decrease in parenting efficacy was related to an increase in parental concerns about children
Muriel et al. (2012)	Mixed methods	Higher parenting concerns would be related to increased psychological distress and worst QOL	**Setting:** Cancer Hospital, Massachusetts, USA **Sample size:** *N* = 173 patients **Family unit:** *Mean age of parent:* 46 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Married *Majority race:* White *Majority CA type:* Breast	Parenting concerns, QOL, Anxiety and Depression, Parental distress	PCQ, FACT-G, HADS, Distress Thermometer	Increased parental concerns were related to anxiety, depression, poorer function, and increased distress

(*Continued*)

Table 2. (*Continued.*)

Author and Year	Methodology	Aim of study	Setting, Sample size, and Family unit	Variables examined	Measures used	Main findings
Nilsson et al. (2009)	Longitudinal perspective	Examine end-of-life outcomes in advanced cancer patients with dependent children	**Setting:** Coping with Cancer study; Massachusetts, USA **Sample size:** *N* = 688 total *N* = 135 with children **Family unit:** *Mean age of parent:* 48.1 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Married *Majority race:* White *Majority CA type:* Other(did not specify other) next highest was Breast	QOL, Psychiatric Disorders, Peacefulness	McGill QOL Questionnaire, SCID, Fetzer Institute/ National Institute on Aging Multidimensional Measure of Religiousness/ Spirituality for Use in Health Research	Increased likelihood to meet panic disorder criteria, were more worried, preferred aggressive treatment over palliative care, and had worse QOL in the last week of life
Park et al. (2018)	Cross-sectional	Explore the relationship between parenting factors and QOL in women with MBC compared with women with no children	**Setting:** Internet-based data collection; geographically diverse **Sample size:** *N* = 224 patients **Family unit:** *Mean age of parent:* 44.2 *Mean age of children:* 11.6 *Marital status:* Married *Majority race:* White *Majority CA type:* Breast	QOL, Parenting concerns, Depression and Anxiety, Functional status	FACT-G, PCQ, PROMIS, Depression and Anxiety, KPS, Functional status	Increase in parenting concerns was related to a decrease in QOL and functional status. A decrease in functional status was associated with depression and anxiety symptoms
Park et al. (2016)	Cross-sectional	Examine association of parenting concerns with QOL, functional status, and symptoms of depression and anxiety	**Setting:** Oncology Clinic, North Carolina, USA **Sample size:** *N* = 63 patients **Family unit:** *Mean age of parent:* 43.6 *Mean age of children:* 11.6 *Marital status:* Married *Majority race:* White *Majority CA type:* Breast	Parenting concerns, Anxiety and Depression, QOL, Performance status, Social support	PCQ, HADS, FACT-G, ECOG, MOS, Social support	Increased parenting concerns were associated with an increase in depression and anxiety and a decrease in QOL Parenting concerns were significantly related to anxiety and QOL even after controlling for ECOG, MOS, and treatment status
Schmitt et al. (2008)	Cross-sectional	Examined factors related to impairment in families that have a parent with cancer	**Setting:** Hospitals in Switzerland, Germany, UK, Finland, Austria, and Denmark **Sample size:** *N* = 381 patients **Family unit:** *Mean age of parent:* Fathers: 44.4; Mothers: 43.4 *Mean age of children:* 11.6 *Marital status:* Married *Majority race:* Data not collected *Majority CA Type:* Breast	Depression, Family functioning	Beck Depression Scale, FAD	Ill parent's depression and poorer physical status was associated with impaired family functioning, specifically roles and communication
Stinesen-Kollberg et al. (2013)	Observational descriptive	Analyze the relation between concerns for children and low psychological well-being	**Setting:** University Hospital, Germany **Sample size:** *N* = 313 patients **Family unit:** *Mean age of parent:* 48.5 *Mean age of children:* 18 years of age or younger[a] *Marital status:* Data not collected *Majority race:* Data not collected *Majority CA type:* Breast	QOL, Anxiety and Depression	QOL Questionnaire on a 7-point Scale, HADS	Increased parental concern for children was related to a decrease in psychological well-being of the parent compared to those who had not worried about their children

N, Number of Patients; HADS, Anxiety and Depression Scale; QOL, Quality of Life; RAND-36, Health-Related QOL; CBCL, Child Behavior Checklist; YSR, Youth Self-Report; FAD, Family Assessment Device; MBC, Metastatic Breast Cancer; PCQ, Parenting Concerns Questionnaire; FACT-G, Functional Assessment of Cancer Therapy-General; SCID, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Axis I Modules; PROMIS, NIH Patient-Reported Outcomes Measurement Information System; KPS, Karnofsky Performance Status Scale; ECOG, Eastern Cooperative Oncology Group; MOS, Medical Outcomes Study Social Support Survey.

[a] Mean age of children not collected.

stem from the fear their children will interpret hospice care as a sign of their parents giving up (Check et al., 2017). The child may think the parent can continue to fight, and they may view the parent's action as selfish. Parents want to ensure the family is happy (Lundquist, 2017). Maintaining normalcy is common strategy parents used to cope with and address this concern (Park et al., 2017). However, as cancer becomes refractory to therapy, this protective strategy stops, and reality is introduced.

Besides the emotional impact and distress of cancer on the children, parents were concerned about how their children would cope with their death (Muriel et al., 2012; Park et al, 2016; Lundquist, 2017). Parents were concerned about the long-term mental health problems their child may develop after the death (Park et al., 2017).

Maintaining normalcy in the household to not change routines for their children was a concern of parents. Yet, routine changes shifted based on the ill parent's moods and physical limitations (Moore et al., 2015; Park et al., 2017). Parents often tried to ensure treatment schedules and managing side effects were not factors that disrupted normal daily activities for their children (Park et al., 2016, 2017).

The co-parent was mainly defined as the spouse of the ill parent; 11 out of 14 articles had PWAC who were married women diagnosed with breast cancer. Concerns for the co-parent can be divided into current parental responsibilities and post-death responsibilities.

Quality of parenting was a current parental concern noted when the ill parent's functional ability decreased leading them to no longer be able to perform their normal parental tasks; therefore, they became concerned about the co-parent's ability to undertake the practical and emotional tasks to support all family members (Muriel et al., 2012; Moore et al. 2015; Park et al., 2017). Parental responsibilities, from the perspective of PWAC, were viewed as irreplaceable (Park et al., 2017). PWAC perceived that they (most as mothers) were the preferred caregiver for their children. Sometime in the cancer trajectory, patients needed additional practical and emotional support to continue in their treatments. When PWAC could no longer provide the practical and emotional support to their children, the children looked to the other parent to fill their needs. Yet, PWAC, overwhelmed by their own emotions, never fully accepted this change in roles.

A concern, post-death, for PWAC was the quality of parenting their children would receive in the event of their death (Park et al., 2017). When the PWAC was a mother, the concern was the male co-parent would not be emotionally supportive of the children during the bereavement process (Park et al., 2017).

Park et al. (2016, 2017) have utilized the Parenting Concern Questionnaire (PCQ) to identify concerns about the emotional impact of the PWAC's illness on the co-parent. The PCQ assesses parenting concerns for use in cancer patients about the emotional and practical impact of cancer on the children and the co-parent (Park et al., 2016). Their findings only assess if the PWAC had emotional concerns for their co-parent but does not address the patient's perception of what specific emotional concerns they had for the co-parent. These were the only studies to measure the emotional impact of cancer on the co-parent.

Co-parents coping with the future trajectory of the illness and the possibility of death were of concern for PWAC (Park et al., 2016). PWAC reported two major coping concerns for their co-parent: their co-parents' ability to cope with losing a partner and living as a single parent (Park et al., 2017). No further discussion was found for these two concerns.

PWAC expressed personal concerns about finances, maintaining parental roles, psychological distress, physical pain related to cancer, and spiritual concerns when faced with their terminal illness. Financial burdens were a major concern expressed by PWAC (Lundquist, 2017; Park et al., 2017, 2018). Parents expressed distress about how the financial burden would impact their children (Lundquist, 2017; Park et al., 2017, 2018). None of the studies elaborated on the specific financial concerns in PWAC.

Maintaining parental roles and responsibilities were common themes noted throughout the qualitative literature (Muriel et al., 2012; Check et al., 2017; Lundquist, 2017; Park et al., 2017). Parents reported how their level of impairment impacted their abilities to maintain their parenting roles and responsibilities (Muriel et al., 2012; Lundquist, 2017; Park et al., 2017). Parental identity was the primary reason for PWAC for pursing life-sustaining cancer treatment and delaying enrollment into hospice/palliative care (Check et al., 2017; Park et al., 2017).

Anxiety and depression were reported by participants and stemmed from feelings of uncertainty related to the trajectory of the disease, fear of the unknown, loss of normalcy, missing out, grief, unhappiness, disappointment, and blame (Lewis et al., 2016; Lundquist, 2017; Park et al., 2017). Physical symptoms related to cancer treatment also played a role in these psychological concerns. Participants reported physical symptoms affected their quality of life (QOL) which left individuals feeling useless and frustrated (Lewis et al., 2016). Pain was the only physical concern reported in two articles. Participants reported intractable pain made them slip into despair and decreased their ability to perform their caregiving responsibilities (Lundquist, 2017; Park et al., 2017).

Remaining hopeful and finding meaning were the spiritual concerns of participants (Lundquist, 2017; Park et al., 2017). Remaining hopeful for a cure and having faith helped to decrease emotional distress and facilitate resiliency (Lundquist, 2017; Park et al., 2017). Finding meaning allowed participants to create resiliency and endure treatment to remain strong for themselves and their families (Lundquist, 2017).

Dying concerns and the measurable outcomes in PWAC

We present how dying concerns impact PWAC's psychological distress level, QOL, family functioning, and their spirituality. The PCQ was the standardized tool to assess the severity of parental concerns on the outcomes.

PWAC have psychological distress related to their worries for their children and their parenting abilities. PWAC who worried about their dependent children are 2.26 (CI = 1.50–3.41) times more likely to have increased psychological distress compared to those who did not worry about their dependent children (Stinesen-Kollberg et al., 2013). PWAC were significantly more worried ($p = 0.006$), depressed ($p < 0.001$), and anxious ($p < 0.001$), and were more likely to meet criteria for clinical panic disorder as compared to cancer patients without dependent children (OR = 5.41; CI = 2.13–13.69) (Nilsson et al., 2009; Stinesen-Kollberg et al., 2013; Park et al. 2018).

Maintaining parental identity and parenting self-efficacy were reported by PWAC. Researchers found that a decrease in parenting identity and parenting self-efficacy were related to an increase in parental concerns (Muriel et al., 2012; Moore et al., 2015). When PWAC could no longer maintain physical and functional capabilities, they perceived their parenting abilities as poor which increased depression and distress scores significantly ($p =$ <0.001) (Moore et al., 2015). Furthermore, PWAC's poor perceptions of the co-parent's parenting ability were also related to the PWAC's depression ($p < 0.001$), anxiety ($p < 0.05$), and distress ($p < 0.01$) (Moore et al., 2015). This finding suggests that a decrease in parenting ability maybe contribute to indignity with the co-parent due to the PWAC's dependency on them (Moore et al., 2015). Muriel et al. (2012) also supported the correlation between parental concern and anxiety ($p < 0.05$) and depression ($p < 0.05$) but also found a significant correlation between parental concerns and patient functioning ($p < 0.05$) and overall distress ($p < 0.05$).

Psychological distress shows differences and similarities by the gender of the PWAC regarding anxiety and depression. Males who had dependent children less than 18 years old were significantly more anxious ($p = 0.02$) compared to men who did not have dependent children (Ernst et al., 2012). Additionally, anxiety in women was not related to having dependent children but related to a diagnosis of advanced cancer ($p = 0.03$) (Ernst et al., 2012). In both genders, increased depression scores were significantly associated with the presence of advanced cancer ($p = 0.04$) (Ernst et al., 2012).

QOL in PWAC is related to their parental concerns about their co-parent and children, their psychological distress, and continuing treatment for extending life over QOL. Increased parental concerns were associated with a decrease in QOL ($p < 0.001$) (Moore et al., 2015; Park et al., 2016). Lower QOL scores were associated with an increase on the PCQ, specifically with financial concerns and communicating with children about cancer ($p = 0.04$) (Park et al., 2018). QOL was also related to how the PWAC perceived their child functioning both physically and emotionally ($p < 0.01$) (Gazendam-Donofrio et al., 2008). Anxiety and depression also explained 50% of the variance of QOL in PWAC (Park et al., 2018). These studies supported how being PWAC impacts the QOL of the patient.

PWAC preferred extending life over QOL. Treatment courses that focus on extending life rather than on treatments that provided relief from pain and discomfort were preferred (OR = 1.77; CI = 1.07–2.93) (Nilsson et al., 2009). Increased parenting concerns were noted in those who preferred life-extending treatments ($p < 0.001$) (Muriel et al., 2012). 27 out of 42 participants in Check's et al. (2017) study preferred treatment that would extend their time with their children. This may explain Nilsson's et al. (2009) finding of worse QOL during the last week of a patient's life when they had dependent children ($p =$ 0.04) compared with those patients who did not have dependent children. Furthermore, 41% of PWAC stated that having children impacted their pursuit of palliative care (Park et al., 2017).

Family functioning assessed how a family communicated and worked together to solve the problem (Schmitt et al., 2008). Physical limitations of cancer on the family and how the family will emotionally cope with the PWAC's death were associated with a poorer perception of family functioning (Park et al., 2016). In families of palliative cancer patients, Kuhne et al. (2013) found that overall family functioning was perceived as functioning well from all family member's perspectives. However, children in the family perceived increased family dysfunction concerning their roles ($p = 0.04$) when their parents did not. Spouses also reported more family dysfunction in problem-solving and general functioning, ($p = 0.04$) and ($p = 0.02$), respectively (Kuhne et al., 2013). Nilsson et al. (2009) and Schmitt et al. (2008) added further support to this disconnect. When family functioning is perceived as low by the patient and the co-parent, the PWAC becomes more depressed ($p < 0.001$) (Schmitt et al., 2008). Also, co-parents were more likely to meet criteria for major depressive disorder (OR = 4.53; CI = 1.47–14.00) and general anxiety disorder (OR = 3.95; CI = 1.29–12.16) due to a decrease in family functioning (Nilsson et al., 2009).

Nilsson et al. (2009) was the only study to find when parenting concerns are increased, PWAC are half as likely to be at peace (OR = 0.53; CI = 0.32–0.87). No other studies were found that explored the association between parenting concerns and spirituality among PWAC.

Discussion

This scoping review is the first in the literature to identify the multiple concerns of PWAC using the broader concept of dying versus parental concerns, specifically about their children, their co-parent, and their health. Of the 14 studies, 11 expressed concerns about their worries and their dependent children, and four expressed concerns about their co-parent. Personal uncertainties included social, psychological, physical, and spiritual apprehensions. PWAC fears for their children included communicating the advanced cancer diagnosis, disruption in normal development, the emotional impact of cancer, coping behaviors, and routine changes. Fears for their co-parent included the emotional impact of cancer, co-parent coping, and quality of parenting. Additionally, these concerns had significant effects on psychological distress, QOL, family functioning, and spirituality of PWAC.

The review provides new information on dying concerns of PWAC and three key points need to be addressed. First, being PWAC impacts the person's abilities to maintain their parental roles and responsibilities which impacts their family lives. Second, PWAC have decreased QOL, specifically at the end of life. Lastly, PWAC have significantly more emotional and psychological distress compared to cancer patients with no dependent children and they have increased family dysfunction.

Qualitative findings found that PWAC expressed concerns about maintaining parenting identity, communicating the advanced cancer diagnosis, and the effects it may have emotionally and practically on their children and co-parent (Muriel et al., 2012; Lewis et al., 2016; Check et al., 2017; Lundquist, 2017; Park et al., 2017). Not being able to maintain parenting roles in the family cause PWAC to feel the loss of normality in the family. When role changes occur in the family, it can cause family chaos and decrease their family's functioning and their parenting self-efficacy.

PWAC expressed issues with open communication with their immediate family. Communication problems about advanced cancer caused issues in maintaining family normality. When death was not discussed openly, PWAC became concerned about their family's psychological and physical well-being while they contemplate their deaths. Maintaining a parental identity while coping with an advanced cancer diagnosis can cause patients to feel torn between their responsibilities in parenting and what they are functionally capable of doing during their cancer trajectory. While parental identity and self-efficacy were something PWAC tried to maintain, they did express how their functional status from treatment altered their roles which also impacted their treatment decisions. Qualitative results suggest being PWAC affects the preference for choosing palliative or hospice care, preferring extending time with their children instead of QOL. PWAC maybe misjudging the value behind palliative care, which is to assist patients to increase their QOL while continuing life-prolonging treatment, not ending treatments to shorten their lifespan.

The quantitative findings support PWAC have decreased QOL when compared to patients who do not have dependent children at home which was related to having increased parental concerns (Gazendam-Donofrio et al., 2008; Nilsson et al., 2009; Moore et al., 2015; Park et al., 2016, 2018). Two interesting findings from this review was at the end of life, PWAC had worse QOL and are less likely to be at peace toward the end of life (Nilsson et al., 2009). Religious beliefs have been found to increase coping, QOL, and feelings of support in the elderly advanced cancer population (Tarakeshwar et al., 2006). However, Nilsson et al. (2009) is the only study to measure the concept of spirituality in PWAC. More research needs to be conducted in this area.

The emotional and psychological distress from PWAC stems from concerns about their family (Schmitt et al., 2008; Nilsson et al., 2009; Ernst et al., 2012; Muriel et al., 2012; Stinesen-Kollberg et al., 2013; Moore et al., 2015; Park et al., 2016, 2018). Anxiety and depression are psychological issues found in cancer patients; however, the prevalence of having anxiety and depression in PWAC is due to their young parental status. Amongst anxiety and depression, this review has found an increase in clinical panic disorder, worry, and distress when compared to those cancer patients who do not have dependent children.

Lastly, PWAC have increased family dysfunction regarding roles and communication with their families (Schmitt et al., 2008; Kuhne et al., 2013; Moore et al., 2015; Park et al., 2018). This review reveals the disconnect concerning family dysfunction between family members. In Kuhne et al. (2013), when families were assessed together, the family perceived family functioning as well, but when measured separately, the children and spouses perceived it as poor. Kuhne and colleagues argued that family members may use protective strategies to keep PWAC positive and free from additional family concerns. More research is needed to support the findings, but family therapy research would support the results (Lewis et al., 2016; Park et al., 2017). This review also supports the lack of research in understanding dying concerns when the PWAC is the husband, in different family dynamics, and the age range of the children included in the study all of which may have different findings. For instance, what PWAC are concerned about for their children may vary depending on the developmental age of their children. Families with adolescents may have different concerns compared to families with preschoolers.

Although data are limited, the review suggests that race, culture, and socioeconomic status may affect areas of concern in young families with PWAC. In an interventional pilot study of African American families with a parent with cancer, Davey et al. (2013) found that the communication intervention increased conversations between parents and children ($p = 0.05$) but did not decrease anxiety or depression in these families. In contrast, two communication interventions with White families found that their interventions improved the communication between parents and children ($t = 3.18$) and decreased psychological distress of parents ($p < 0.005$) (Thastum et al., 2006; Kobayashi et al., 2017). More research with diverse families is needed to support this research.

Implications for further research

This review indicates the need for more research in identifying the broader "dying concerns" in PWAC rather than the limited "parental concerns" concept. Future research should also include a more diverse sample relative to the gender of the ill parent, race/ethnicity of the PWAC and family, the cancer type, and family units. Furthermore, an understanding of dying concerns from the perspective of the co-parent and children needs to be identified.

There is still much to be studied in dying concerns research in PWAC. Most important, the research needs to understand the term "dying concern" regarding PWAC and the family. The term "parental concern" was used in place of dying concern, but this does not encapsulate the full meaning of the term. Although the studies focused on parental concerns and measuring these concerns using the PCQ, it does not capture the broader term of dying concerns. The PCQ only focuses on the role of being a parent (Muriel et al., 2012). Questions for the co-parent assess the emotional and practical support of the PWAC during treatment, plus, the emotional and practical support for the children in the event of the PWAC's death. It does not assess concerns for the co-parent themselves. Dying concerns may impact parental concerns, but PWAC are more than just parents; therefore, the concept of dying concerns needs to be further defined.

Future research should identify dying concerns for the co-parent, from the PWAC's perspective. Therefore, the research can start understanding the concerns from the co-parent's perspective. Communication interventions can then be developed to assist PWAC and the co-parent to increase family functioning, feel more at peace, and increase the likelihood of enrolling in palliative/hospice care to increase QOL.

A long-term research goal would be to identify concerns from the co-parent's and the children's perspective. Researchers can then develop a holistic view of dying concerns of PWAC and their families from a family perspective. A holistic approach may assist researchers in developing family interventions to decrease distress noted by families. Identifying dying concerns from all family members may enhance provider-initiated communications between family members and health care providers to improve psychological distress, QOL, family functioning, and spirituality of all family members.

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