

Quality of Life in Adult Cancer Patients With Underage Children: An Integrative Review

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Authors' disclosures of conflicts of interest are
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Abstract

As many as 24.7% of cancer patients are also parents to children younger than 18 years of age. This population faces unique challenges, and quality of life in parental cancer patients has not been well studied. This integrative review assessed parental cancer patients' quality of life. PubMed and Scopus were searched using the following terms: quality of life, distress, anxiety, coping, emotion, social support, employment, work, psychosocial, physical, function, parental cancer, and parents with cancer. English publications conducted within the past 15 years that used an objective instrument to measure quality of life in adult cancer patients with children 18 years of age or younger were included. Studies with an intervention focus were excluded. After review of 672 articles, nine studies met the criteria for inclusion. Several instruments were utilized to measure quality of life. Some parental cancer patients reported decreased quality of life when compared with other cancer patients and the general population at diagnosis and years after. Parental cancer patients may be at an increased risk of decreased quality of life. With this understanding, health-care providers should complete comprehensive assessments routinely so that these patients' unique needs may be more adequately addressed.

Approximately half of new cancers are diagnosed in adults younger than 65 years of age (National Cancer Institute, 2021). Some of these adults face a cancer diagnosis while parenting children younger than 18 years of age. A recent systematic review estimated that between 14% and 24.7% of cancer patients have dependent children (Inhestern et al., 2021a). Additionally, as cancer screening tests evolve and the average age of first-time mothers rises, it has been theorized that the incidence of adult cancer patients with dependent children may increase in the near future (Inhestern et al., 2021b;

Matthews & Hamilton, 2016). The combination of parenting and cancer presents unique challenges. Assessing the quality of life in the parental cancer population is critical.

Recent systematic reviews have focused primarily on parental cancer in the setting of advanced cancer only, the effect of parental cancer on the children, or resources available for parental cancer patients and their children (Caparso et al., 2021; Faccio et al., 2018; Hauskov Graungaard et al., 2019; Morris et al., 2018; Shah et al., 2017; Weeks et al., 2019; Walczak et al., 2018; Wray et al., 2022). No recent review has focused on quality of life in parental cancer patients.

Healthy People 2020, which was a 10-year plan for addressing the most critical public health priorities and challenges, highlighted the impact of quality of life on overall public health, as the organization identified improving quality of life as a high priority (HealthyPeople.gov, 2022). In oncology patient care specifically, quality of life is a significant factor that should be considered when discussing goals of therapy and treatment options, evaluating response to therapy, and developing clinical trial endpoints. Quality of life at baseline can be used as a predictive factor to determine treatment benefit and overall survival in cancer patients (Trask et al., 2009). With this understanding, it is important for health-care professionals working with the vulnerable oncology population to heed recommendations to regularly assess the quality of life in all cancer patients (National Comprehensive Cancer Network, 2022). Young parents with cancer face unique physical, mental, emotional, and spiritual challenges and are at an increased risk for distress (Caparso et al., 2021; National Comprehensive Cancer Network, 2022). By identifying patients with relatively poor quality of life or at an increased risk for decreased quality of life, health-care providers can best provide patient-centered care and tailor interventions to the patients' specific needs (Centers for Disease Control and Prevention, 2018). This review was conducted to evaluate and synthesize the available data regarding quality of life in the parental cancer population. Specific themes identified were instruments commonly utilized to measure quality of life and quality-of-life results.

METHODS

A search of the literature was conducted using PubMed and Scopus databases. The search terms included: quality of life, distress, anxiety, coping, emotion, social support, employment, work, psychosocial, physical, function, parental cancer, and parents with cancer. The search retrieved 280 articles. After 15 initial duplicates were removed, 263 articles were screened. An additional 394 articles were identified through citation searching.

The inclusion criteria consisted of English language and publications from December 12, 2006, to December 12, 2021. Relevance was determined by the following: focus on parental cancer patients with children 18 years of age or younger, an objective instrument used to measure parental cancer patients' quality of life, and report of the patients' quality-of-life results. Studies were excluded if there was an intervention focus. A total of nine articles met the inclusion and exclusion criteria (see Figure 1).

RESULTS

A description of the studies, the patient population, the instruments utilized to assess quality of life, and parental quality-of-life results are presented in Table 1.

Population Studied

The nine studies reported characteristics of the parental cancer patients or their children (see Table 1). In these nine studies, the total sample consisted of 1,846 parental cancer patients, whose ages ranged from 18 to 63. The number of dependent children in the families ranged from one to four or more, with a mean of two children per family. Children's ages ranged from 0 to 18 years. Most patients were females in partnerships who were employed, educated, or of middle to high socioeconomic status. Breast cancer was the most common diagnosis. Stage I to IV disease and various treatment modalities were represented. Patients' diagnosis time frame ranged from newly diagnosed to 6 years after diagnosis. Studies were primarily conducted across Europe.

Instruments

All articles used a specific quality-of-life instrument. Three articles used the Short Form Health

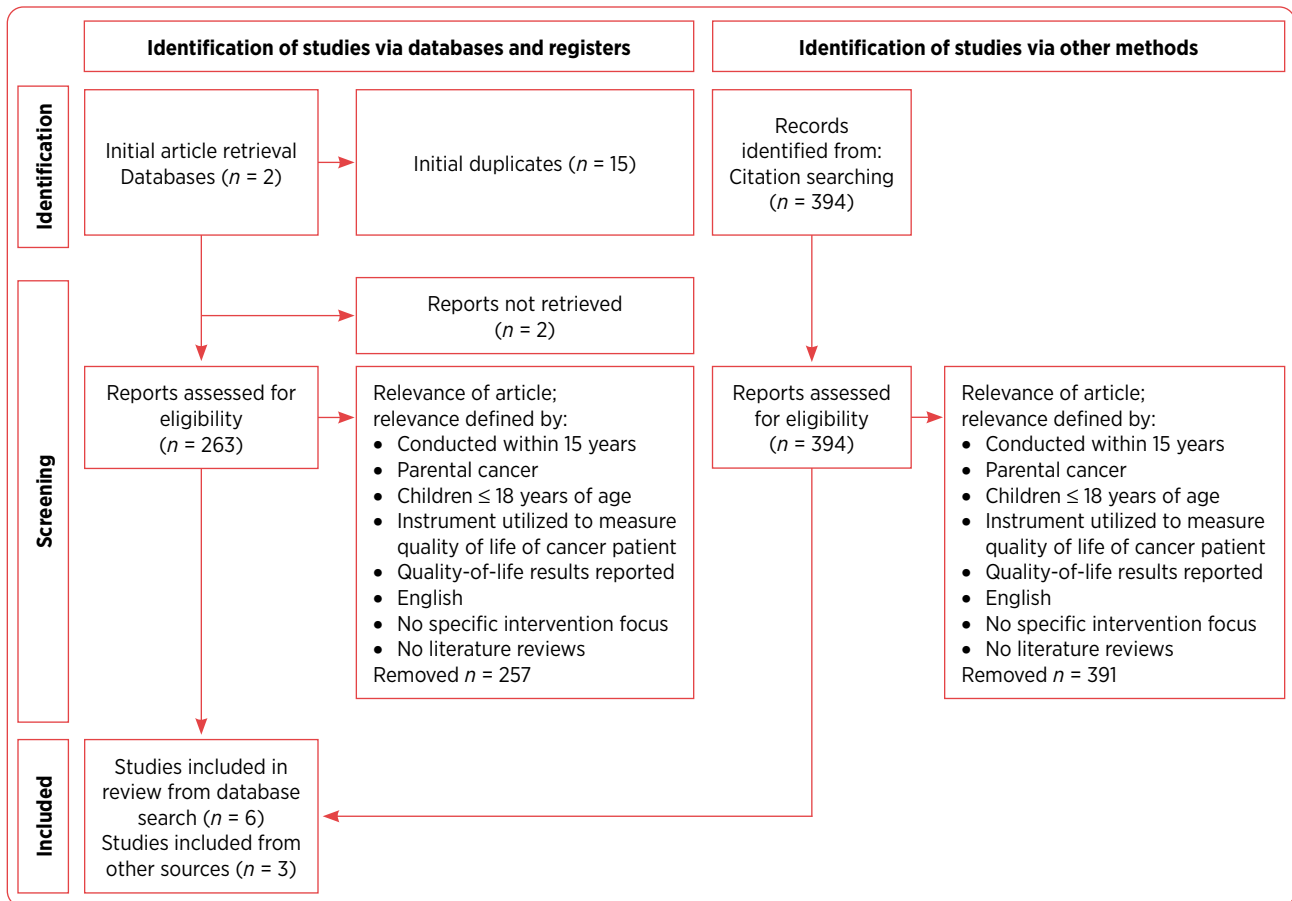


Figure 1. PRISMA flow diagram (Page et al., 2021).

Survey (SF-8; Bultmann et al., 2014; Götze et al., 2015; Krattenmacher et al., 2014). The SF-8 is an abbreviated version of the SF-36 (Bultmann et al., 2014). The questionnaire has been used as a reliable instrument in various studies to measure health-related quality of life among eight domains, as well as provide a summary score for both physical and mental health (Bultmann et al., 2014; Götze et al., 2015; Krattenmacher et al., 2014). Scores range from 0 to 100, with lower values indicating worse quality of life (Bultmann et al., 2014).

The European Organisation for Research and Treatment of Cancer quality of life core questionnaire (EORTC QLQ-C30) was used in three of the studies (Ernst et al., 2012; Götze et al., 2015; Inhestern et al., 2021b). The EORTC QLQ-C30 is a reliable and valid instrument in assessing health-related quality of life in cancer patients (Hjermstad et al., 1995). It is a 30-item self-report questionnaire that evaluates five function scales (physical, social, emotional, cognitive, and role), nine

symptom scales, and global quality of life (Aaronson et al., 1993). After adding the subscale scores, the scores are converted into a result between 0 to 100, with lower scores indicating worse functioning (Ernst et al., 2012).

Two studies used the Dutch RAND-36 Health Survey (Gazendam-Donofrio et al., 2008; Gazendam-Donofrio et al., 2009). Scores range from 0 to 100 on the eight subscales of the survey. Higher scores indicate greater functioning. Psychosocial and physical functioning can be evaluated through two summary scores. Multiple studies have indicated the RAND-36 is a reliable and valid instrument (VanderZee et al., 1996a, 1996b). To further evaluate parents' stress, Gazendam-Donofrio and colleagues (2009) utilized the Dutch Impact of Event Scale (IES) to evaluate patients' cancer-related distress. The IES is a reliable and valid 15-question survey that evaluates stress response after a serious life occurrence (Sundin & Horowitz, 2003; van der Ploeg, et al., 2004). Higher

Table 1. Evidence Table on Quality of Life in Adult Cancer Patients With Underage Children

Author/Title	Study design	Sample	Instrument/Outcomes	Limitations	Evidence level
Bultmann et al. (2014) Parental cancer: Health-related quality of life and current psychosocial support needs of cancer survivors and their children	Cross-sectional population-based	<ul style="list-style-type: none"> Cancer patients diagnosed < 6 years prior with dependent children aged 6-18 n = 976 Germany Average patient age in 5th decade (M = 46.7) Primarily female, early-stage diagnosis, breast cancer, married, and employed Majority of patients underwent surgery (94.4%) Average > 2 years since diagnosis (M = 43.7 mo) 2 children (M) 	<ul style="list-style-type: none"> SF-8 Statistically significant decreased physical and mental health in cancer survivors when compared with the general population 26% survivors report needing psychosocial support 	<ul style="list-style-type: none"> Sample bias (lack of heterogeneity) Excluded cancers with increased mortality rate Static results as this was a cross-sectional study 	Level III
Ernst et al. (2012) Quality of life of parents diagnosed with cancer: Change over time and influencing factors	Longitudinal with questionnaires at diagnosis and starting treatment (T1) and 2 years after (T2)	<ul style="list-style-type: none"> Cancer patients with children < 18 years and cancer patients without children n = 69 Germany Cancer patients with children: <ul style="list-style-type: none"> Average patient age in 5th decade (M = 41.7) Primarily female, with partner, employed, stage I/II, breast or gyn cancer < 2 years since diagnosis 	<ul style="list-style-type: none"> EORTC QLQ-C30 T1 <ul style="list-style-type: none"> Low scores in all EORTC domains Similar impairment in EORTC domains (except for social functioning) among patients with vs. patients without children T2 <ul style="list-style-type: none"> Significant improvement in majority of EORTC domains EORTC scores are lower than general population Higher QOL in patients with children than those without 	<ul style="list-style-type: none"> Sample bias (lack of heterogeneity) Small sample Low response rate at T2 	Level IV
Gazendam-Donofrio et al. (2008) Quality of life of parents with children living at home: When one parent has cancer	Cross-sectional	<ul style="list-style-type: none"> Parental cancer diagnosed 1-5 years prior with children aged 4-18 n = 166 Netherlands Average patient age in 5th decade (M = 44.7) Primarily female, breast cancer Majority underwent intense treatment (86%) Average > 2 years since diagnosis (M = 33.12 mo) 2.3 children (M) 	<ul style="list-style-type: none"> Dutch RAND-36 Health Survey Clinically relevant or statistically significant decreased scores in 3 of 8 QOL domains when compared to the instrument's norm 	<ul style="list-style-type: none"> Sample bias (lack of heterogeneity) Low response rate Static results as this was a cross-sectional study 	Level III

Note. M = mean; QOL = quality of life; HRQOL = health-related quality of life; SF-8 = Short Form Health Survey; EORTC QLQ-C30 = European Organisation for Research and Treatment of Cancer quality of life core questionnaire; FACT-G = Functional Assessment of Cancer Therapy - General.

Table 1. Evidence Table on Quality of Life in Adult Cancer Patients With Underage Children (cont.)

Author/Title	Study design	Sample	Instrument/Outcomes	Limitations	Evidence level
Gazendam-Donofrio et al. (2009) Parent-child communication patterns during the first year after a parent's cancer diagnosis: The effect on parents' functioning	Longitudinal with questionnaires at diagnosis (T1), 6 months (T2), 12 months (T3)	<ul style="list-style-type: none"> Recent parental cancer diagnosis with children 4–18 yo at home n = 70 Netherlands Average patient age in 5th decade (M = 42.5) Primarily female, breast cancer, married, greater than elementary schooling Majority of patients underwent intense treatment at T1 (77%) and T2 (82%) but had completed therapy by T3 (99%) Average < 2 years since diagnosis (M = 2.3 months at T1) 2.2 children (M) 	<ul style="list-style-type: none"> RAND-36 Dutch Impact of Event Scale T1 Low psychosocial functioning and high distress at diagnosis Physical functioning comparable to the norm Worse physical and psychosocial functioning than spouses at diagnosis <p>T2</p> <ul style="list-style-type: none"> Low psychosocial functioning Physical functioning comparable to the norm <p>T3</p> <ul style="list-style-type: none"> Psychosocial functioning clinically significant improvement Distress improved at 1 year 	<ul style="list-style-type: none"> Low response rate Excluded patients that had < 1-year survival 	Level IV
Götze et al. (2015) Predictors of quality of life of cancer patients, their children, and partners	Longitudinal with data collection post treatment (T1), 6 months (T2), 12 months (T3)	<ul style="list-style-type: none"> Cancer patients with children 11–17 yo n = 161 Germany Average patient age in 5th decade (M = 40.4) Primarily female, breast cancer, living with partner < 2 years since diagnosis (majority diagnosed within 1 year of T1) Majority with 1 child 	<ul style="list-style-type: none"> SF-8 EORTC QLQ-C30 <p>T1</p> <ul style="list-style-type: none"> Low QOL in all domains <p>T2</p> <ul style="list-style-type: none"> Improvement in majority of QOL domains <p>T3</p> <ul style="list-style-type: none"> QOL significantly improved in all domains except cognitive functioning 	<ul style="list-style-type: none"> Sample bias (lack of heterogeneity) Excluded palliative care patients 	Level IV
Inhestern et al. (2021b) Families affected by parental cancer: Quality of life, impact on children and psychosocial care needs	Cross-sectional	<ul style="list-style-type: none"> < 55 yo parental cancer patients with children < 18 yo n = 78 Germany Average patient age in 5th decade (M = 42.2) Primarily female, breast cancer, greater than 11 years of schooling, employed, living with partner Majority of patients underwent chemotherapy (98.7%) < 2 years since diagnosis (majority diagnosed within 1 year) Majority with 2 or more children 	<ul style="list-style-type: none"> EORTC QLQ-C30 GOL was lower than general population Greatest functioning was in the physical domain; lowest in the social domain 	<ul style="list-style-type: none"> Small sample Sample bias (lack of heterogeneity) Static results as this was a cross-sectional study 	Level III

Note. M = mean; QOL = quality of life; HRQOL = health-related quality of life; SF-8 = Short Form Health Survey; EORTC QLQ-C30 = European Organisation for Research and Treatment of Cancer quality of life core questionnaire; FACT-G = Functional Assessment of Cancer Therapy - General.

Table 1. Evidence Table on Quality of Life in Adult Cancer Patients With Underage Children (cont.)

Author/Title	Study design	Sample	Instrument/Outcomes	Limitations	Evidence level
Krattenmacher et al. (2014) A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life	Cross-sectional	<ul style="list-style-type: none"> Cancer patients and mentally ill patients with children 0–18 yo n = 136 Germany Average patient age in 5th decade (M = 42.9) Primarily female Single most predominant cancer was breast Average > 2 years since diagnosis (M = 29.8 mo) Majority with 2 or more children 	<ul style="list-style-type: none"> SF-8 Decreased mental and physical HRQOL in parental cancer patients when compared to the norm Parental cancer patients had similar results in physical HRQOL than mentally ill patients Parental cancer patients had greater mental HRQOL than mentally ill patients 	<ul style="list-style-type: none"> Missing data Excluded patients with mental illness and cancer Static results as this was a cross-sectional study 	Level III
Park et al. (2016) Parenting concerns, quality of life, and psychological distress in patients with advanced cancer	Cross-sectional	<ul style="list-style-type: none"> Advanced parental cancer patients ≥ 18 years old with ≥ 1 child under the age of 18 n = 63 Single US center study Average patient age in 5th decade (M = 43.8) Primarily female, stage IV, breast cancer, white, married, with average 15 years of education Majority receiving treatment for metastatic disease (88.9%) Average < 2 years since metastatic diagnosis (M = 17 mos) 2.4 children (M) 	<ul style="list-style-type: none"> FACT-G FACT-G score 65.9 	<ul style="list-style-type: none"> Small sample Sample bias (lack of heterogeneity) Selection bias Static results as this was a cross-sectional study Study completed at a single institution 	Level III
Park et al. (2018) Understanding health-related quality of life in adult women with metastatic cancer who have dependent children	Cross-sectional	<ul style="list-style-type: none"> Mothers with stage IV solid tumor diagnosis with at least 1 child < 18 yo n = 224 40 states and 5 countries (83% participants in the US) Average patient age in 5th decade (M = 44.2) Primarily female, white, stage IV, breast cancer, married, college graduates, employed Average > 2 years since metastatic diagnosis (M = 30 mo) 1.8 children (M) 	<ul style="list-style-type: none"> FACT-G score 65.9 Lower FACT-G score than adult patients with cancer and patients with metastatic cancer Particularly low scores in the Emotional Well-Being category when compared to other adult cancer patients 	<ul style="list-style-type: none"> Sample bias (lack of heterogeneity) Static results as this was a cross-sectional study 	Level III

Note. M = mean; QOL = quality of life; HRQOL = health-related quality of life; SF-8 = Short Form Health Survey; EORTC QLQ-C30 = European Organisation for Research and Treatment of Cancer quality of life core questionnaire; FACT-G = Functional Assessment of Cancer Therapy - General.

scores indicate greater distress (Sundin & Horowitz, 2003).

The Functional Assessment of Cancer Therapy - General (FACT-G) was used in two articles (Park et al., 2016; Park et al., 2018). The fourth version of the FACT-G instrument is a 27-item self-report instrument that measures emotional, social/family, physical, and functional health. Scores range from 0 to 108, with higher scores signifying greater quality of life. It is a well-validated tool (Victorson et al., 2008).

Patients' Quality-of-Life Results

All studies evaluated quality of life in patients either across different cancer stages or focused only on patients with metastatic disease. For studies that evaluated patients with various stages of disease, quality-of-life results can be categorized into two subgroups: newly diagnosed patients or long-term survivors. In the newly diagnosed patient group, patients studied were primarily within the first 2 years since diagnosis (Ernst et al., 2012; Gazendam-Donofrio et al., 2009; Götze et al., 2015; Inhestern et al., 2021b). In the long-term survivor group, patients studied had a mean of greater than 2 years since diagnosis and range of up to 6 years post diagnosis (Bultmann et al., 2014; Gazendam-Donofrio et al., 2008; Krattenmacher et al., 2014).

Quality of Life in Newly Diagnosed Patients

Four of the studies focused on quality of life in the first 2 years of diagnosis (Ernst et al., 2012; Gazendam-Donofrio et al., 2009; Götze et al., 2015; Inhestern et al., 2021b). A summary of the studies' quality-of-life results are presented in Table 2. Inhestern and colleagues (2021b) conducted a cross-sectional study of 78 parental cancer patients ($M = 42.2$ years) with at least one child younger than 18 years old ($M = 8.4$ years). Patients were primarily females (91%) with breast cancer (62.8%) who were diagnosed within the past year (75%) and were living with a partner (87.2%). Using the EORTC QLQ-C30, the mean score for patients (55.7) was below the norm (67). Physical functioning scored highest ($M = 75$) but remained below the norm (82.8). The lowest functioning was in the social functioning subscale ($M = 40.7$), which was considerably below the norm (84.8).

Using the EORTC QLQ-C30 but in a longitudinal study, Götze and colleagues (2015) assessed quality of life at the end of treatment, 6 months post treatment, and 1 year post treatment in 161 parental cancer patients. Patients had a mean age of 40.4 years, and children's ages ranged from 11 to 17 years old ($M = 14.3$ years). Most patients were female (77%), living with a partner (88.9%), and had breast cancer (56.9%). Quality of life in parental cancer patients across all EORTC QLQ-C30 scales post therapy (T1) were low, with the following mean scores out of a maximum score of 100: 60.8 in global quality of life, 79.5 in physical function, 60.5 in role function, 61.2 in emotional function, 77.1 in cognitive function, and 63.5 in social function. At 6 months post therapy (T2), improvement was noted across all domains, except for cognitive and emotional functioning, with the following mean scores: 65.4 in global quality of life, 83.4 in physical function, 67 in role function, 61 in emotional function, 76.6 in cognitive function, and 72.2 in social function. At 1 year post therapy (T3), patients' quality of life significantly improved in the global quality-of-life scale ($p = .003$) and all subscales ($p < .001$), except cognitive functioning ($p = .627$). Sleep issues and fatigue continued to be persistent patient-reported issues at T3.

Ernst and colleagues (2012) also used the EORTC QLQ-C30 in a longitudinal study to compare quality of life in parental cancer patients with children younger than 18 years of age ($n = 41$) and cancer patients without children ($n = 28$) during the initial treatment phase (T1) and 2 years after (T2). Parental cancer patients had a mean age of 41.7 years, were predominantly female (65.9%), and had a partner (97.6%). Most patients had breast (26.8%) or gynecological cancers (26.8%). At diagnosis (T1), cancer patients with and without children had similarly low scores in global quality of life, cognitive function, emotional function, role function, and physical function. At 2 years after diagnosis (T2), parental cancer patients' scores significantly improved in all categories except for cognitive and emotional functioning. The social functioning subscale results increased from 49 at T1 to 71 at T2 ($p < .05$). The role functioning subscale score was 36 at T1, which improved to 70 at T2 ($p < .01$). In the physical functioning subscale, scores improved to 83 at T2 from 65 at T1

Table 2. Evidence Table on Quality of Life in Cancer Patients With Underage Children: Newly Diagnosed Patients

Author/Title	Outcomes
Ernst et al. (2012) Quality of life of parents diagnosed with cancer: Change over time and influencing factors	During treatment <ul style="list-style-type: none"> • Low QOL in all domains • Similar impairment in majority of QOL domains among patients with and patients without children 2 years post treatment <ul style="list-style-type: none"> • QOL significantly improved in all domains except cognitive and emotional functioning • Lower QOL than general population • Higher QOL in patients with children than those without
Gazendam-Donofrio et al. (2009) Parent-child communication patterns during the first year after a parent's cancer diagnosis: The effect on parents' functioning	At diagnosis <ul style="list-style-type: none"> • Lower psychosocial functioning than the norm • High distress • Physical functioning comparable to the norm • Lower physical and psychosocial functioning than spouses 6 months post diagnosis <ul style="list-style-type: none"> • Lower psychosocial functioning than the norm • Physical functioning comparable to the norm 1 year post diagnosis <ul style="list-style-type: none"> • Clinically significant improvement in psychosocial functioning • Statistically significant decrease in distress
Götze et al. (2015) Predictors of quality of life of cancer patients, their children, and partners	End of treatment <ul style="list-style-type: none"> • Low QOL in all domains • Greatest functioning in the physical domain • Lowest functioning in the role domain 6 months post treatment <ul style="list-style-type: none"> • Improvement in majority of QOL domains, except cognitive and emotional functioning • Greatest functioning in the physical domain • Lowest functioning in the emotional domain 1 year post treatment <ul style="list-style-type: none"> • QOL significantly improved in all domains except cognitive functioning
Inhestern et al. (2021b) Families affected by parental cancer: Quality of life, impact on children and psychosocial care needs	Majority of patients within 1 year of diagnosis <ul style="list-style-type: none"> • Lower QOL than the general population • Greatest functioning in the physical domain • Lowest functioning in the social domain

($p < .01$). On the overall global quality-of-life scale, scores significantly improved from 48 at T1 to 70 at T2 ($p < .01$). Although parental cancer patients' quality-of-life scores remained below the general population's, parental cancer patients' scores were moderately to substantially higher than childless patients' scores in all domains except for cognitive functioning (statistical analysis not reported). Parental cancer patients' global quality-of-life score was 70, while childless patients' score was 59 at T2. Interestingly, a subsequent covariance analysis did not identify a significant relationship between parenthood and quality of life.

Gazendam-Donofrio and colleagues (2009) used the Dutch RAND-36 Health Survey and the Dutch IES in a longitudinal study to evaluate par-

ents' quality of life, distress, and parent-child communication patterns at diagnosis (T1), 6 months (T2), and 12 months (T3). 70 parental cancer patients ($M = 42.5$ years) with dependent children aged 4 to 18 ($M = 11.02$ years) were queried. Patients were primarily females (63%) and married (89%). The single most predominant cancer was breast cancer (36%). Using the RAND-36, patients' psychosocial functioning at diagnosis ($T1 = 26.3$) and 6 months later ($T2 = 26.9$) was considerably less than the norm score of 50 and the retrospective group score of 49.2 ($p < .01$). In contrast, physical functioning was comparable to the norm score of 50 at both T1 (48.2) and T2 (51.7). Patients' physical (48.2) and psychosocial (26.3) functioning was worse at diagnosis than that of their spouses, who

had scores of 55.3 and 40.1, respectively ($p < .001$). At 1 year post diagnosis (T3), patients experienced a clinically significant improvement in their psychosocial functioning score to 50.7 and a nonclinically significant decrease in physical functioning to 45.6. Parental cancer patients' total distress decreased significantly over time (statistical analysis not reported), but effect sizes were not significant. At T1, 51% of patients reported clinically elevated distress with a subsequent decrease to 30% at T3.

Quality of Life in Long-Term Survivors

Three of the articles focused on quality of life more than 2 years after diagnosis (Bultmann et al., 2014; Gazendam-Donofrio et al., 2008; Krattenmacher et al., 2014). A summary of the studies' quality-of-life results are presented in Table 3. Krattenmacher and colleagues (2014) completed a cross-sectional study to assess emotional and behavioral problems in underage children of patients with mental illness ($n = 69$) compared with those of cancer patients ($n = 67$), and also assessed health-related quality of life for both patient groups using the SF-8. Most patients were female (67.2%) with a mean age of 42.9 years. The single most predominant cancer was breast (31.3%). Although time since diagnosis ranged from less than 1 year to more than 3 years, the mean was 2.48 years. Parental cancer patients had a significant decrease in mental and physical health-related quality of life than the norm ($p < .001$). When compared with patients with mental illness, parental cancer patients had similar scores in physical health-related quality of life but greater mental health-related quality of life ($p = .014$).

Using the same SF-8 tool and cross-sectional research design, Bultmann and colleagues (2014) assessed health-related quality of life in 976 parental cancer patients ($M = 46.7$ years) diagnosed within the past 6 years and their children aged 6 to 18 years ($M = 9.4$ years at diagnosis). Patients were primarily females (70.6%) in partnerships (88.5%) with breast cancer (56.5%). The mean time since diagnosis was 3.5 years. Both the physical ($p < .05$) and mental health ($p < .01$) of cancer survivors were significantly worse than the general population. Additionally, 26% of cancer survivors indicated a current need for psychosocial support.

Gazendam-Donofrio and colleagues (2008) conducted a cross-sectional study and utilized the Dutch RAND-36 Health Survey to assess the quality of life of 166 parental cancer patients ($M = 44.7$ years) and their spouses. Patients were diagnosed 1 to 5 years prior and had children 4 to 18 years of age. Most patients were females (78%) with breast cancer (52%). With a mean of 2.76 years post diagnosis, patients' mean physical summary score was 46.05 and psychosocial summary score was 47.3. A clinically relevant or statistically significant decrease was identified in three of eight quality-of-life domains in cancer survivors. When compared with the instrument's norm, the domains affected for mothers were social functioning and physical role limitations. For both mothers and fathers, vitality was affected ($p < .0015$).

Quality of Life in the Metastatic Setting

Two studies addressed quality of life of parental cancer patients exclusively in the metastatic setting (Park et al., 2016; Park et al., 2018). A summary of the studies' quality-of-life results are presented in Table 4. Using a cross-sectional research design, Park and colleagues (2016) evaluated parenting concerns, quality of life, depression, and anxiety in 63 parental cancer patients ($M = 43.8$ years) with at least one child younger than 18 years of age ($M = 11.6$ years). Patients were primarily females (67%) and had a partner (66.7%). Breast was the primary cancer reported (30%). The FACT-G tool was utilized to evaluate quality of life in parental cancer patients at an average of 17 months since stage IV diagnosis (Park et al., 2016). With a maximum possible score of 108 and lower scores indicating worse quality of life, parental cancer patients' mean FACT-G score was 65.9 (Park et al., 2016; Victorson et al., 2008). A comparator group was not included in the study (Park et al., 2016).

In a later study, Park and colleagues (2018) used the same FACT-G instrument and cross-sectional research design to compare health-related quality of life in mothers with metastatic disease to other adult cancer patients. 224 mothers ($M = 44.2$ years) with stage IV disease and at least one child younger than 18 years of age ($M = 11.3$ years) were evaluated. Most patients were married (80%) and had breast cancer (92%). At an average of 2.5 years since metastatic diagnosis, general FACT-G

Table 3. Evidence Table on Quality of Life in Cancer Patients With Underage Children: Long-Term Survivors

Author/Title	Outcomes
Bultmann et al. (2014) Parental cancer: Health-related quality of life and current psychosocial support needs of cancer survivors and their children	Mean 3.6 years post diagnosis <ul style="list-style-type: none"> • Lower physical and mental QOL than the general population
Gazendam-Donofrio et al. (2008) Quality of life of parents with children living at home: When one parent has cancer	Mean 2.76 years post diagnosis <ul style="list-style-type: none"> • Lower scores in 3 of 8 QOL domains than the instrument's norm
Krattenmacher et al. (2014) A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life	Mean 2.48 years post diagnosis <ul style="list-style-type: none"> • Lower mental and physical QOL than the norm • Similar results in physical QOL than mentally ill • Higher mental QOL than mentally ill

scores for parental cancer patients ($M = 65.5$) were almost a standard deviation lower than those of adult patients with various cancer diagnoses ($M = 79.3$) and more than a standard deviation lower than patients with metastatic breast cancer ($M = 81.9$). Differences were particularly evident in the Emotional Well-Being category, as adults with various cancer diagnoses reported scores a full standard deviation higher than patients with children.

DISCUSSION

In this integrative review, five different reliable and valid instruments were utilized to assess quality of life in parental cancer patients. One tool did not emerge as superior. During the first year of diagnosis and initial treatment phase, parental cancer patients had low global quality of life (Ernst et al., 2012; Götze et al., 2015; Inhestern et al., 2021b). Within the quality-of-life domains, scores were predominantly lowest psychosocially and highest physically (Gazendam-Donofrio et al., 2009; Götze et al., 2015; Inhestern et al., 2021b). Soon after diagnosis, parental cancer patients may

experience more mental than physical distress as the patients and their families aim to adapt to this permanently life-altering diagnosis. Physical symptoms may not be as bothersome as patients have not yet initiated cancer-directed therapy and are not experiencing treatment side effects (Gazendam-Donofrio et al., 2009).

At 1 to 2 years post diagnosis, parental cancer patients reported an improvement in quality of life but continued to face deficits in certain categories, particularly cognitive and emotional functioning (Ernst et al., 2012; Gazendam-Donofrio et al., 2009; Götze et al., 2015). More than 2 years after diagnosis, parental cancer patients continued to experience low mental and physical quality of life (Bultmann et al., 2014; Gazendam-Donofrio et al., 2008; Krattenmacher et al., 2014). These ongoing impairments could be related to many different factors, including continued difficulty adapting to the diagnosis, role changes within the family and societal context, and cancer-related or treatment-related cognitive impairment.

Table 4. Evidence Table on Quality of Life in Cancer Patients With Underage Children: Metastatic Setting

Author/Title	Outcomes
Park et al. (2016) Parenting concerns, quality of life, and psychological distress in patients with advanced cancer	Mean 1.41 years since stage IV diagnosis <ul style="list-style-type: none"> • QOL score 65.9/108
Park et al. (2018) Understanding health-related quality of life in adult women with metastatic cancer who have dependent children	Mean 2.5 years since stage IV diagnosis <ul style="list-style-type: none"> • QOL score 65.9/108 • Lower overall QOL than adults with various cancers and metastatic cancer • Lower QOL in the Emotional Well-Being category than other adult cancer patients

Using the Dutch RAND-36 Health Survey, Gazendam-Donofrio and colleagues (2009) evaluated quality of life in the first year of diagnosis, while an earlier study by Gazendam-Donofrio and colleagues (2008) evaluated quality of life 1 to 5 years after diagnosis. For patients diagnosed within the first year, the mean physical summary score was slightly greater, and the mean psychosocial summary score was considerably lower when compared with patients diagnosed 1 to 5 years previously (Gazendam-Donofrio et al., 2008; Gazendam-Donofrio et al., 2009). These findings indicate that parental cancer patients' psychosocial quality of life can improve dramatically over the years.

When compared with the norm, parental cancer patients had low quality-of-life scores at diagnosis, during initial treatment, and up to 6 years after diagnosis (Bultmann et al., 2014; Ernst et al., 2012; Gazendam-Donofrio et al., 2008; Inhestern et al., 2021b; Krattenmacher et al., 2014). An extensive population-based study conducted in 2012 with more than 26,000 participants had similar findings. Cancer survivors within the following time frame were evaluated: less than 2 years since diagnosis to more than 11 years since diagnosis. In this study, 24.5% of cancer survivors had decreased physical quality of life and 10.1% had decreased mental quality of life when compared with the norm (Weaver et al., 2012).

When comparing parental cancer patients' quality of life with that of childless cancer patients, results were mixed. Ernst and colleagues (2012) reported parental patients' quality-of-life scores were higher than childless patients' 2 years after diagnosis, while Park and colleagues (2018) reported parental patients had lower quality-of-life scores than other adult cancer patients. However, in the Ernst and colleagues (2012) study, most parental cancer patients had stage I to II disease, while all patients in the Park and colleagues (2018) study had metastatic disease. The differences in staging could have influenced the results, especially since multiple studies have reported that patients with advanced disease or recurrence had lower quality of life and were more likely to need psychosocial support (Bultmann et al., 2014; Gazendam-Donofrio et al., 2008; Götze et al., 2015).

Parental cancer patients had improved mental quality of life when compared with patients with mental illness (Krattenmacher et al., 2014). Anxiety and depression have been associated with quality of life (Götze et al., 2015; Park et al., 2016). No studies in this review focused on quality-of-life scores in parents with cancer and mental illness. These patients may have an even lower quality of life.

Limitations

Additional research evaluating parental cancer patients' quality of life is needed. Most of the studies included in this review were cross sectional. This research design provides quality-of-life results at only one timepoint and limits the ability to draw causative conclusions. In the future, longitudinal studies could provide more dynamic and conclusive data (Gazendam-Donofrio et al., 2008; Inhestern et al., 2021b). The results of this literature review are also limited by the population studied. Patients were predominantly women with breast cancer. Studies targeting fathers and patients with other cancer diagnoses is needed. Additionally, most patients in this literature review had partners and were employed, educated, or with middle to high socioeconomic status. Multiple studies excluded patients with a high mortality rate, those receiving palliative care, or those with a concurrent mental illness. Future research evaluating these potentially more vulnerable populations would be beneficial.

Implications for Practice

The mean age of parental cancer patients in this review was in the fifth decade of life. Therefore, parental cancer patients may be beyond the age limit for adolescent and young adult (AYA) programs, which generally see patients up to age 39, but not yet identify with the older adult or geriatric population (National Cancer Institute, 2020). With this integrative review's findings, advanced practice providers will be well positioned to identify and address quality-of-life deficits in this unique patient population. With an understanding that parental cancer patients may be at an increased risk for decreased quality of life, providers can follow these patients more closely. It is imperative to assess parental cancer

patients' quality of life at diagnosis and at routine timepoints thereafter (Gazendam-Donofrio et al., 2009).

This review highlighted the importance of continuing to assess quality of life years after diagnosis, as patients may have not returned to baseline. With this knowledge, providers will be well equipped to educate others and advocate for patients. Providers can dismantle the incorrect assumption that patients have adequately adapted simply because significant time has passed since diagnosis. Providers can also advocate for quality-of-life assessments to be incorporated in routine appointments in long-term survivorship clinics. This intervention can help identify patients who continue to face impairments. With thorough assessments, providers can recognize quality-of-life deficits and guide patients to appropriate resources.

When evaluating parental cancer patients' quality of life, it is imperative to use a well validated and reliable tool. In the studies included in this review, multiple tools were used to evaluate quality of life. One superior tool did not emerge from the data. Providers should be familiar with several quality-of-life instruments, such as the SF-8, EORTC QLQ-C30, and RAND-36. Several factors should be considered when selecting a quality-of-life instrument, such as tool availability, patients' performance status, and disease specificity (Luckett et al., 2011; Sato et al., 2014).

Future research can focus on identifying specific risk factors associated with decreased quality of life in parental cancer patients. With this analysis, providers would be able to identify which patients may be particularly vulnerable to decreased quality of life and provide education regarding modifiable risk factors (Gazendam-Donofrio et al., 2009). Additionally, studies evaluating family dynamics, how to best evaluate family-specific needs, and effective interventions for decreased quality of life in parental cancer patients would provide valuable guidance for the advanced practice provider caring for this subgroup of patients (Götze et al., 2015; Inhestern et al., 2021b; Park et al., 2016). ●

Disclosure

The authors have no conflicts of interest to disclose.

References

- Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J.,...de Haes, J. C. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute*, 85(5), 365–376. <https://doi.org/10.1093/jnci/85.5.365>
- Bultmann, J. C., Beierlein, V., Romer, G., Möller, B., Koch, U., & Bergelt, C. (2014). Parental cancer: Health-related quality of life and current psychosocial support needs of cancer survivors and their children. *International Journal of Cancer*, 135(11), 2668–2677. <https://doi.org/10.1002/ijc.28905>
- Caparso, C., Appel, J., & Benkert, R. (2021). Dying concerns in young parents with advanced cancer (PWAC): A scoping review. *Palliative & Supportive Care*, 19(1), 93–102. <https://doi.org/10.1017/S1478951520000309>
- Centers for Disease Control and Prevention. (2018). Health-related quality of life (HRQOL). <https://www.cdc.gov/hrqol/concept.htm>
- Ernst, J., Götze, H., Brähler, E., Körner, A., & Hinz, A. (2012). Quality of life of parents diagnosed with cancer: Change over time and influencing factors. *European Journal of Cancer Care*, 21(4), 535–541. <https://doi.org/10.1111/j.1365-2354.2012.01330.x>
- Faccio, F., Ferrari, F., & Pravettoni, G. (2018). When a parent has cancer: How does it impact on children's psychosocial functioning? A systematic review. *European Journal of Cancer Care*, 27(6), Article e12895. <https://doi.org/10.1111/ecc.12895>
- Gazendam-Donofrio, S., Hoekstra, H., van der Graaf, W., van de Wiel, H., Visser, A., Huizinga, G., & Hoekstra-Weebers, J. (2009). Parent-child communication patterns during the first year after a parent's cancer diagnosis: The effect on parents' functioning. *Cancer*, 115(18), 4227–4237. <https://doi.org/10.1002/cncr.24502>
- Gazendam-Donofrio, S. M., Hoekstra, H. J., van der Graaf, W. T., Pras, E., Visser, A., Huizinga, G. A., & Hoekstra-Weebers, J. E. (2008). Quality of life of parents with children living at home: When one parent has cancer. *Supportive Care in Cancer*, 16(2), 133–141. <https://doi.org/10.1007/s00520-007-0299-7>
- Götze, H., Ernst, J., Brähler, E., Romer, G., & von Klitzing, K. (2015). Predictors of quality of life of cancer patients, their children, and partners. *Psycho-Oncology*, 24(7), 787–795. <https://doi.org/10.1002/pon.3725>
- Hauskov Graungaard, A., Roested Bendixen, C., Haavet, O. R., Smith-Sivertsen, T., & Mäkelä, M. (2019). Somatic symptoms in children who have a parent with cancer: A systematic review. *Child: Care, Health and Development*, 45(2), 147–158. <https://doi.org/10.1111/cch.12647>
- HealthyPeople.gov. (2022). Health-related quality of life & well-being. <https://www.healthypeople.gov/2020/topics-objectives/topic/health-related-quality-of-life-well-being>
- Hjermstad, M. J., Fossa, S. D., Bjordal, K., & Kaasa, S. (1995). Test/retest study of the European Organization for Research and Treatment of Cancer Core Quality-of-Life Questionnaire. *Journal of Clinical Oncology*, 13(5), 1249–1254. <https://doi.org/10.1200/JCO.1995.13.5.1249>
- Inhestern, L., Bultmann, J. C., Johannsen, L. M., Beierlein, V., Möller, B., Romer, G.,...Bergelt, C. (2021a). Estimates

- of prevalence rates of cancer patients with children and well-being in affected children: A systematic review on population-based findings. *Frontiers in Psychiatry*, 12, Article 765314. <https://doi.org/10.3389/fpsy.2021.765314>
- Inhestern, L., Johannsen, L. M., & Bergelt, C. (2021b). Families affected by parental cancer: Quality of life, impact on children and psychosocial care needs. *Frontiers in Psychiatry*, 12, Article 765327. <https://doi.org/10.3389/fpsy.2021.765327>
- Krattenmacher, T., Kühne, F., Halverscheid, S., Wiegand-Grefe, S., Bergelt, C., Romer, G., & Möller, B. (2014). A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life. *Journal of Psychosomatic Research*, 76(3), 213–220. <https://doi.org/10.1016/j.jpsychores.2013.11.020>
- Luckett, T., King, M. T., Butow, P. N., Oguchi, M., Rankin, N., Price, M. A.,...Heading, G. (2011). Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: Issues, evidence and recommendations. *Annals of Oncology*, 22(10), 2179–2190. <https://doi.org/10.1093/annonc/mdq721>
- Matthews, T. J., & Hamilton, B. E. (2016). Mean age of mothers is on the rise: United States, 2000–2014. NCHS data brief. <https://www.cdc.gov/nchs/data/databriefs/db232.pdf>
- Morris, J., Turnbull, D., Preen, D., Zajac, I., & Martini, A. (2018). The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10–24 at time of diagnosis: A systematic review. *Journal of Adolescence*, 65, 61–71. <https://doi.org/10.1016/j.adolescence.2018.03.001>
- National Cancer Institute. (2020). Adolescents and young adults with cancer. <https://www.cancer.gov/types/aya>
- National Cancer Institute. (2021). Age and cancer risk. <https://www.cancer.gov/about-cancer/causes-prevention/risk/age>
- National Comprehensive Cancer Network. (2022). NCCN Clinical Practice Guidelines in Oncology: Distress management. V2.2023. https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D.,...Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, n71. <https://doi.org/10.1136/bmj.n71>
- Park, E. M., Deal, A. M., Check, D. K., Hanson, L. C., Reeder-Hayes, K. E., Mayer, D. K.,...Rosenstein, D. L. (2016). Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psycho-Oncology*, 25(8), 942–948. <https://doi.org/10.1002/pon.3935>
- Park, E. M., Deal, A. M., Yopp, J. M., Edwards, T., Resnick, S. J., Song, M. K.,...Rosenstein, D. L. (2018). Understanding health-related quality of life in adult women with metastatic cancer who have dependent children. *Cancer*, 124(12), 2629–2636. <https://doi.org/10.1002/cncr.31330>
- Sato, K., Shimizu, M., & Miyashita, M. (2014). Which quality of life instruments are preferred by cancer patients in Japan? Comparison of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 and the Functional Assessment of Cancer Therapy-General. *Supportive Care in Cancer*, 22(12), 3135–3141. <https://doi.org/10.1007/s00520-014-2287-z>
- Shah, B. K., Armaly, J., & Swieter, E. (2017). Impact of parental cancer on children. *Anticancer Research*, 37(8), 4025–4028. <https://doi.org/10.21873/anticancer.11787>
- Sundin, E. C., & Horowitz, M. J. (2003). Horowitz's Impact of Event Scale evaluation of 20 years of use. *Psychosomatic Medicine*, 65(5), 870–876. <https://doi.org/10.1097/01.psy.0000084835.46074.f0>
- Trask, P. C., Hsu, M. A., & McQuellon, R. (2009). Other paradigms: Health-related quality of life as a measure in cancer treatment: Its importance and relevance. *The Cancer Journal*, 15(5), 435–440. <https://doi.org/10.1097/PPO.0b013e3181b9c5b9>
- van der Ploeg, E., Mooren, T. T., Kleber, R. J., van der Velden, P. G., & Brom, D. (2004). Construct validation of the Dutch version of the impact of event scale. *Psychological Assessment*, 16(1), 16–26. <https://doi.org/10.1037/1040-3590.16.1.16>
- VanderZee, K. I., Sanderman, R., & Heyink, J. (1996a). A comparison of two multidimensional measures of health status: The Nottingham Health Profile and the RAND 36-Item Health Survey 1.0. *Quality of Life Research*, 5(1), 165–174. <https://doi.org/10.1007/BF00435982>
- VanderZee, K. I., Sanderman, R., Heyink, J. W., & de Haes, H. (1996b). Psychometric qualities of the RAND 36-Item Health Survey 1.0: A multidimensional measure of general health status. *International Journal of Behavioral Medicine*, 3(2), 104–122. https://doi.org/10.1207/s15327558ijbm0302_2
- Victorson, D., Barocas, J., Song, J., & Cella, D. (2008). Reliability across studies from the functional assessment of cancer therapy-general (FACT-G) and its subscales: A reliability generalization. *Quality of Life Research*, 17(9), 1137–1146. <https://doi.org/10.1007/s11136-008-9398-2>
- Walczak, A., McDonald, F., Patterson, P., Dobinson, K., & Allison, K. (2018). How does parental cancer affect adolescent and young adult offspring? A systematic review. *International Journal of Nursing Studies*, 77, 54–80. <https://doi.org/10.1016/j.ijnurstu.2017.08.017>
- Weaver, K. E., Forsythe, L. P., Reeve, B. B., Alfano, C. M., Rodriguez, J. L., Sabatino, S. A.,...Rowland, J. H. (2012). Mental and physical health-related quality of life among U.S. cancer survivors: Population estimates from the 2010 National Health Interview Survey. *Cancer Epidemiology, Biomarkers & Prevention*, 21(11), 2108–2117. <https://doi.org/10.1158/1055-9965.EPI-12-0740>
- Weeks, N., McDonald, F., Patterson, P., Konings, S., & Coad, J. (2019). A summary of high quality online information resources for parents with cancer who have adolescent and young adult children: A scoping review. *Psycho-Oncology*, 28(12), 2323–2335. <https://doi.org/10.1002/pon.5274>
- Wray, A., Seymour, J., Greenley, S., & Boland, J. W. (2022). Parental terminal cancer and dependent children: A systematic review. *BMJ Supportive & Palliative Care*, 1–13. <https://doi.org/10.1136/bmjspcare-2021-003094>