

Experiences of Adolescents and Young Adults Living With Advanced Cancer: An Integrative Review

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PROBLEM IDENTIFICATION: Knowledge about the experiences of adolescents and young adults (AYAs) living with advanced cancer may be limited. This review was conducted to examine the literature concerning this subject.

LITERATURE SEARCH: A comprehensive search was conducted using CINAHL®, the Cochrane Library of Systematic Reviews, Embase®, the Joanna Briggs Institute (JBI), and PubMed®.

DATA EVALUATION: Each study was systematically assessed. An evidence table detailing key components was compiled.

SYNTHESIS: There is a growing body of knowledge about the experiences of individuals with advanced cancer. However, insufficient evidence exists regarding the experiences of AYAs with advanced cancer.

IMPLICATIONS FOR RESEARCH: The lack of knowledge about AYAs and how they experience living with advanced cancer requires additional research; this will lead to increased understanding of their challenges and more effective supportive interventions.

KEYWORDS adolescents and young adults; advanced cancer; integrative review; interventions
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Evidence suggests that people are living longer with advanced cancer as a result of improved screening, early detection, and treatment advances (American Cancer Society, 2019; Kamal et al., 2011; Salakari, Surakka, Nurminen, & Pylkkänen, 2015). Most individuals with advanced cancer face psychological, physical, social, emotional, and spiritual issues related to their diagnosis (Kamal et al., 2011; Meier & Beresford, 2008). Some individuals with advanced cancer may experience accumulating symptom burden and deterioration of function, whereas others may remain relatively independent and functional for longer periods of time. In addition, although some individuals living with advanced cancer may experience a steady decline in function, others may retain a moderately high level of performance (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). Studies have described individuals living with advanced cancer as feeling forgotten and alone, with persistent unrecognized and unmet needs (Haylock, 2010a, 2010b; Lynn, 2005; Singer et al., 2015).

The adolescent and young adult (AYA) cohort is made up of individuals aged 15–39 years (National Cancer Institute, 2018). Cancer is the leading cause of death among this age group when accidental deaths are excluded (Siegel, Miller, & Jemal, 2016). Diagnosis occurs at a time when these individuals are developing identities, finding their places in the world, establishing careers, creating relationships, and building families (Chen, Parmar, & Gartshore, 2014; Cleeland et al., 2014; Shaha & Bauer-Wu, 2009). Overall, there is limited understanding of the biologic, genetic, epidemiologic, and psychosocial factors of, as well as the quality-of-life implications for, this group. Physical and functional challenges may exacerbate emotional burdens that accompany the disease and its treatment.

It is well established that more research with this population is needed across all stages of disease (DeRouen et al., 2015; National Cancer Institute,

2018). There also is a need for further differentiation in this group because of the wide physical, emotional, and developmental changes that occur during the AYA age range. It has been recommended that supportive care services be provided to meet the unique challenges of the AYA cohort to better provide guidance in managing physical, family, social, and work-related quality of life (Hamer et al., 2017). In addition, the National Institutes of Health and other entities have identified that data on psychosocial factors specific to the population of AYAs with cancer, including educational needs, social and family issues, and employment, are lacking (DeRouen et al., 2015; National Cancer Institute, 2018).

A systematic review by Bibby, White, Thompson, and Anazodo (2017) highlighted the need for age-appropriate services and education for AYAs with various cancers. This lack of age-appropriate information was identified across the cancer trajectory and not limited to diagnosis or treatment. Another important need identified was age-appropriate emotional support, as well as peer contact and support, to enhance well-being.

Although a significant body of literature describes diagnosis, treatment, and end-of-life concerns in patients with cancer across a wide range of ages, literature focused on AYAs with cancer may be limited. However, many AYAs with cancer face unique psychological, physical, social, emotional, and spiritual challenges related to advanced cancer that may not be adequately supported (Kamal et al., 2011; Meier & Beresford, 2008). Consequently, survivorship domains (physical, psychosocial, and economic) for this population need to be better understood to reflect these multidimensional challenges (National Cancer Institute, 2014). Increased knowledge of AYAs' experiences of living with advanced cancer is essential for the development of effective person-centered survivorship and palliative care interventions. As such, this integrative review was conducted to examine the literature concerning the experience of AYAs living with advanced cancer.

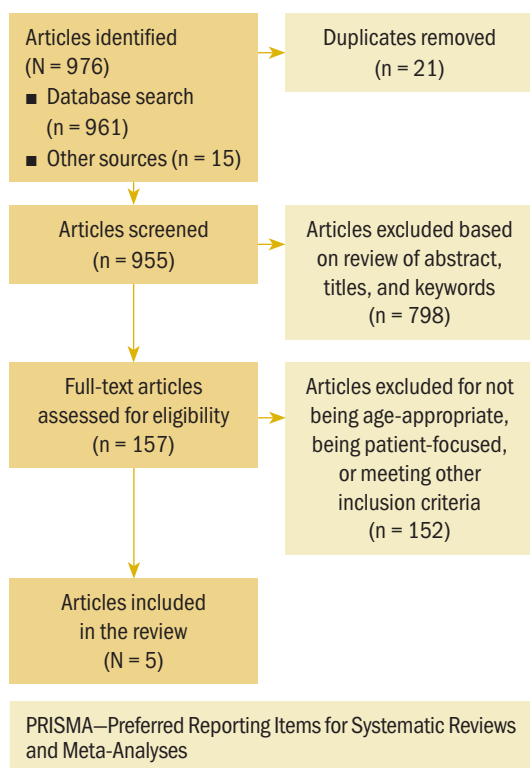
Methods

Strategies by Whittemore and Knafl (2005) were used to appraise the literature. An experienced reference librarian was consulted to discuss search strategies and identify keywords using MeSH (Medical Subject Headings) terms. A comprehensive search was conducted using CINAHL®, the Cochrane Library of Systematic Reviews, Embase®, the Joanna Briggs Institute (JBI), and PubMed®. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were applied (see Figure 1).

The keywords identified to investigate the experiences of AYAs living with advanced cancer were as follows: *advanced cancer*, *cancer metastasis*, *young adults*, *coping*, *quality of life*, and *life experience*. An ancestry search of the reference lists of retrieved articles was also manually conducted for additional articles. For inclusion, each source had to be an empirical study published in English from 2007 to 2017 and involve an individual aged 18–39 years with a metastatic or advanced cancer diagnosis. The following types of sources were excluded: psychometric studies, pharmacologic studies, population-based analyses, review articles, case reports, editorials, and doctoral dissertations. The authors did not expand the date range because of a desire to focus on contemporary literature.

Article titles and abstracts were reviewed to determine whether they met the inclusion criteria, resulting in a list of 976 articles. Articles that appeared relevant were fully reviewed to confirm that they met the inclusion criteria. On closer scrutiny, 798 articles were excluded because their foci

FIGURE 1. PRISMA Flow Chart of Search Strategy and Selection Process



did not match the necessary criteria. Ultimately, the final sample consisted of five articles. Table 1 details key study components that were compiled using the standardized data extraction tools from the JBI Meta Analysis of Statistics Assessment and Review Instrument and the JBI Qualitative Assessment and Review Instrument.

Data Evaluation

Each study was systematically assessed for the following characteristics: country of origin, purpose, study design and instruments, sample size, age, cancer diagnosis, and results. Data were analyzed using the strategies proposed by Whitemore and Knafl (2005) and Garrard (2011) to code, categorize, and summarize findings. Initially, primary sources were categorized by method (quantitative or qualitative). Data from all studies were extracted, organized, and displayed using the matrix method (Garrard, 2011). In addition, the first author assessed the eligibility and methodologic quality of the sources selected prior to inclusion using the appropriate standardized critical appraisal checklists from JBI: the JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies and the JBI Critical Appraisal Checklist for Qualitative Research.

Quantitative and qualitative data were extracted from relevant studies using the appropriate JBI standardized data extraction tool. Six articles were selected; these were then assessed for relevancy. Following further review, five articles that met the inclusion criteria were selected for this review. Extracted data consisted of participant demographics, study methods, and outcomes significant to the objectives of the review. Four of the articles selected for this review employed a quantitative approach, and one article used a qualitative approach.

Data Analysis

This review of the literature that examined the experience of AYAs living with advanced cancer and not receiving hospice care resulted in only five studies.

Results

Sample Characteristics

Two articles used the same sample (Trevino, Maciejewski, Fasciano, Greer, et al., 2012; Trevino, Maciejewski, Fasciano, & Prigerson, 2012); therefore, the characteristics of four samples will be discussed. The four samples ranged in size from 10 to 93 participants. All participants were described as AYAs aged 18–40 years, with a mean age across the samples of 31.8 years. The samples were heterogeneous in regard

to cancer type, and all participants had advanced disease. Three samples each had more than one-third of participants with breast cancer (34%–40%). Other participant cancers included lung, bone, pancreatic, esophageal, nasopharyngeal, and ovarian cancer; sarcoma; and mediastinal paraganglioma. Across the four samples, participants were mostly female (66%–71%) and White (87%–93%).

Design

Four of the five studies (Trevino et al., 2014; Trevino, Fasciano, Block, & Prigerson, 2013; Trevino, Maciejewski, Fasciano, Greer, et al., 2012; Trevino, Maciejewski, Fasciano, & Prigerson, 2012) were conducted by the same research group, were cross-sectional structured interviews, and were critically appraised using the JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies. The fifth was a qualitative study (Knox et al., 2017) that used a hermeneutic approach; this study was appraised using the JBI Critical Appraisal Checklist for Qualitative Research. This qualitative study was included in the current review because it demonstrated favorable scoring; in particular, there was congruity between the research methodology and the research question, as well as between the methodology and the data collection methods.

Findings

The four cross-sectional structured interview studies focused on coping (Trevino, Maciejewski, Fasciano, Greer, et al., 2012; Trevino, Maciejewski, Fasciano, & Prigerson, 2012) and social support and relationships (Trevino et al., 2013, 2014). Trevino, Maciejewski, Fasciano, and Prigerson (2012) examined the relationship between grief from cancer-related losses and life disruption from cancer-related symptoms, finding that, for this population, grief might add a unique burden to the cancer experience that is more problematic than physical performance status. Study participants were asked to identify coping strategies, and the relationship between these strategies and psychological distress was examined (Trevino, Maciejewski, Fasciano, & Prigerson, 2012). Six coping factors were identified by Trevino, Maciejewski, Fasciano, Greer, et al. (2012): proactive, distancing, negative expression, support-seeking, respite-seeking, and acceptance coping. Trevino, Maciejewski, Fasciano, Greer, et al. (2012) examined the relationship of these coping factors to grief, anxiety, and depression. Acceptance coping and support-seeking were used most often by these

AYAs. Negative expression was a coping style associated with severity of grief. The identification of these coping factors strengthens understanding that coping is multidimensional and is not limited to problem-focused, emotion-focused, and dysfunctional

coping. This research suggests that coping is more complicated than previously identified and is not well described in AYAs. These coping factors were found to be uniquely related to psychological distress in this group of participants (Trevino, Maciejewski, Fasciano,

TABLE 1. Study Characteristics

Study	Aim	Design and Sample	Findings
Trevino, Maciejewski, Fasciano, Greer, et al., 2012 (United States)	To examine the relationship between grief from cancer-related losses and life disruption from cancer symptoms in young adults with cancer	A cross-sectional structured interview study with 53 participants with advanced disease; of these, 35 are women and 18 are men. The mean age is 33.89 years (range = 20–40), and participants are primarily White (93%). 40% of participants have been diagnosed with breast cancer, and 13% have been diagnosed with brain cancer; other cancer diagnoses are lung, bone, pancreatic, stomach, and esophageal cancer.	Young adults with advanced cancer use a wide range of coping responses that are uniquely related to psychological distress.
Trevino, Maciejewski, Fasciano, & Prigerson, 2012 (United States)	To identify coping strategies used by young adults with advanced cancer and to examine the relationship between these coping strategies and psychological distress	A cross-sectional structured interview study with 53 participants with advanced disease; of these, 35 are women and 18 are men. The mean age is 33.89 years (range = 20–40), and participants are primarily White (93%). 40% of participants have been diagnosed with breast cancer, and 13% have been diagnosed with brain cancer; other cancer diagnoses are lung, bone, pancreatic, stomach, and esophageal cancer.	Grief may constitute a unique burden in the cancer experience for young adults with advanced disease.
Trevino et al., 2013 (United States)	To examine the relationship among perceived social support, quality of life, and grief in young adults with advanced cancer	A cross-sectional structured interview study with 71 participants with advanced cancer; of these, 50 are women and 21 are men. The mean age is 34 years (range = 20–40), and participants are primarily White (93%). 39% of participants have been diagnosed with breast cancer; other cancer diagnoses are lung, bone, pancreatic, stomach, and esophageal cancer.	Higher levels of total social support were associated with better psychological and existential quality of life and less severe grief.
Trevino et al., 2014 (United States)	To examine the relationship between the oncologist–patient therapeutic alliance and suicidal ideation in young adults with advanced cancer	A cross-sectional structured interview study with 93 participants with advanced disease; of these, 64 are women and 29 are men. The mean age is 33 years (range = 20–40), and participants are primarily White (87%). 34% of participants have been diagnosed with breast cancer.	Patients with a strong therapeutic alliance were at reduced risk for suicidal ideation after controlling for confounding influences.
Knox et al., 2017 (Canada)	To understand the experience of young adults with advanced cancer	A qualitative, hermeneutic study with 10 patients with advanced disease; of these, 7 are women and 3 are men. The mean age is 26 years (range = 18–35). 3 participants have been diagnosed with sarcoma, and 1 patient has been diagnosed with each of the following diseases: breast cancer, pancreatic cancer, brain cancer, nasopharyngeal cancer, ovarian cancer, lung cancer, and mediastinal paraganglioma.	The experience of advanced cancer is isolating and interferes with developmental tasks.

Greer, et al., 2012). Trevino et al. (2013) examined the relationship existing among perceived social support, quality of life, and grief, finding that higher levels of social support were associated with better quality of life and less grief and concluding that enhanced social support might also improve psychological well-being. Trevino et al. (2014) investigated the therapeutic oncologist–patient relationship and the impact this relationship may have on suicidal ideation, determining that patients with a strong therapeutic alliance with their oncologists had a reduced risk of suicidal ideation.

The one qualitative study examined in this review (Knox et al., 2017) used a hermeneutic approach to understand the experience of living with advanced cancer, with a sample consisting of men and women with various cancers. This study identified themes of feeling “lost and stranded,” including isolation and developmental and existential concerns (Knox et al., 2017), but the heterogeneous nature of the sample makes understanding the experience difficult.

These five studies demonstrated the importance of relationships and their connection to psychological well-being for AYAs living with advanced cancer. Maximizing relationships and promoting social support are important considerations for this population; both actions are connected to better coping abilities and well-being. Grief is a construct that needs to be further explored in this population to better care for this vulnerable group (Trevino, Maciejewski, Fasciano, & Prigerson, 2012). In addition, although many AYAs diagnosed with advanced cancer may experience the disruption of anticipated developmental milestones, these may never be attained (Zebrack & Isaacson, 2012). This reality and its related implications need to be better understood. Overall, the evidence of AYAs living with advanced cancer is scant, highlighting the immature state of the science for this population.

Discussion

This integrative review was conducted to examine the literature concerning the experience of AYAs living with advanced cancer. However, only five studies met the eligibility criteria. Although there is a growing body of knowledge about cancer and the experiences of people with cancer, a lack of understanding exists concerning the experiences and healthcare needs of AYAs with cancer. These AYAs live with the knowledge that the future is uncertain and that they will ultimately die from their disease. Many struggle with physical and emotional challenges while trying to maintain as much normalcy in their lives as possible. The dearth

of knowledge about this age group and how its members experience living with advanced cancer requires additional research for a fuller understanding of their challenges, concerns, and management of daily activities; this will allow for the design of effective supportive interventions (Zebrack, 2009; Zebrack & Isaacson, 2012).

From a clinical perspective, some AYAs with advanced cancer continue to live full lives despite a diagnosis that threatens their lives. They may be busy raising families, working, and juggling many roles and responsibilities while living with advanced cancer (DeSanto-Madeya, Bauer-Wu, & Gross, 2007; Lunquist, Berry, Boltz, DeSanto-Madeya, & Grace, 2019; Zebrack & Isaacson, 2012). The lack of research that explores the quality of life of AYAs with advanced cancer, including their daily challenges, social context (roles and responsibilities), and functional status, suggests that the experience of living with advanced cancer is not valued, or perhaps that the focus during this time is more on curing and surviving the disease.

Although the limited evidence has identified concerns in broad strokes across different cancer types in the AYA population, the lack of disease- and age-specific research makes knowing the true nature of these AYAs’ everyday experiences challenging. For example, although members of the AYA population may have some similarities to other populations with advanced cancer, there may exist unique concerns related to age, life stage, and family responsibilities that have not yet been identified or addressed. Much more remains to be determined before effective interventions for this population can be designed and tested.

Lam et al. (2014) examined the role of psychological distress following the diagnosis of advanced breast cancer in women, finding that most women did not experience psychological distress in the 12 months following an advanced breast cancer diagnosis; however, the researchers did identify preventive measures to mitigate distress. A similar study involving AYAs with advanced cancer would be informative in understanding whether distress trajectories exist and in identifying strategies targeted at preventing distress.

Zebrack (2009) surveyed the supportive care needs and preferences of 879 AYA cancer survivors and reported that more than 60% expressed a desire for age-appropriate information; also, more than 50% of participants reported that their needs for information and services were unmet. In addition, a review by Ngwenya et al. (2017) examined the qualitative

literature to understand the experiences of and preferences for end-of-life care for AYAs during an 11-year period. Eighteen articles from 12 countries were included in the review, and at least 5% of the samples for each of the 18 articles had to include AYAs aged 16–40 years. The experiences of loneliness and isolation were dominant in this population, and these were coupled with the desire to be treated in the same manner as healthy peers and to maintain interpersonal connections. Ngwenya et al. (2017) identified the need for supportive interventions and education to facilitate open and honest communication that is age-appropriate.

Initial work with the aim of understanding the experiences of this population has begun, but much more is needed. For example, a survey could be constructed to validate whether findings are similar among diverse groups (disease, gender, racial, economic). Better understanding of the experiences of AYAs with advanced cancer who are engaging in activities in their communities is important in developing strategies for outreach and education. In addition, there has been a national response to the challenge of improving the delivery of care to individuals living with advanced cancer. Various entities have developed agendas, position statements, and research initiatives to further improve education for healthcare professionals and patients. For example, the Institute of Medicine (2015) report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* calls for significant changes and offers a roadmap for progress in caring for people living with advanced cancer that should be person-centered, family-oriented, and evidence-based.

Limitations

The studies examined in this review were small in size, had very similar patient characteristics, were conducted in the same geographic area, and used instruments that have not been validated in the AYA population. Researchers acknowledged the limitations of using measurement instruments that have not been validated in this population and suggested that additional work needs to be undertaken to validate use of the instruments in the AYA population.

Implications for Practice

Care that is based on knowledge directly taken from patient experiences is needed. Understanding the needs, challenges, and preferences of patients will provide nurses with the necessary evidence to

KNOWLEDGE TRANSLATION

- The lack of disease- and age-specific research makes knowing the true nature of the everyday experiences of adolescents and young adults living with advanced cancer difficult.
 - Care that will improve the life of the patient with advanced cancer in ways that are meaningful to the patient should be based on knowledge acquired from patient experiences.
 - Interventions could be focused on improving social support to minimize isolation, identifying and accessing supportive care resources, and exploring the experience of loss and grief.
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formulate interventions. Nurses have a unique role in the interprofessional care of this population.

Nurses serve the public good with their knowledge, skills, and expertise (Grace, 2018). Ongoing knowledge development and philosophical inquiry are needed to continue to anticipate and meet the needs of individuals and society. Nurses have a commitment to care that is based on relationships, centered on individuals, and focused on the biophysical, psychosocial, and spiritual needs for all people, particularly those who are vulnerable (American Nurses Association, 2010).

Many with a diagnosis of advanced cancer may continue to live for extended periods of time after curative measures have failed. Some continue to live full lives despite a life-threatening diagnosis. Generation of new knowledge is foundational to additional research, with the ultimate goal of developing person-focused interventions and identifying resources for supportive care.

AYAs living with advanced cancer face challenges that are not well understood. This review has highlighted the need for age-appropriate information, resources, social support, and better understanding of coping resources, including assessment of anxiety, depression, and grief. Assessments should be focused and include questions about daily life, sense of isolation, support systems, and coping strategies. Timely referral to appropriate resources is also an easily implemented intervention.

Conclusion

A new population of survivors, AYAs living with advanced cancer, is emerging. Few accounts appear in the literature about their everyday experiences. It is likely that most AYAs with advanced cancer face unique psychological, physical, social, emotional, and spiritual challenges related to advanced disease.

Additional research is needed to better understand this population and, subsequently, to design effective supportive interventions. Without understanding the everyday experiences of members of this population, clinicians have no empirical evidence on which to deliver helpful interventions to improve the lived experience. Consequently, there is a clear need to explore, describe, and interpret the day-to-day experiences of AYAs living with advanced cancer.

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Lundquist completed the data collection and provided statistical support and the analysis. Both authors contributed to the conceptualization and design and the manuscript preparation.

REFERENCES

- American Cancer Society. (2019). *Cancer facts and figures, 2019*. Retrieved from <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2019/cancer-facts-and-figures-2019.pdf>
- American Nurses Association. (2010). *Nursing's social policy statement: The essence of the profession*. Silver Spring, MD: Author.
- Bibby, H., White, V., Thompson, K., & Anazodo, A. (2017). What are the unmet needs and care experiences of adolescents and young adults with cancer? A systematic review. *Journal of Adolescent and Young Adult Oncology*, 6, 6–30. <https://doi.org/10.1089/jayao.2016.0012>
- Chen, B.Q., Parmar, M.P., & Gartshore, K. (2014). Supporting women with advanced breast cancer: The impact of altered functional status on their social roles. *Canadian Oncology Nursing Journal*, 24, 194–203.
- Cleeland, C.S., Mayer, M., Dreyer, N.A., Yim, Y.M., Yu, E., Su, Z., . . . Kaufman, P.A. (2014). Impact of symptom burden on work-related abilities in patients with locally recurrent or metastatic breast cancer: Results from a substudy of the VIRGO observational cohort study. *Breast*, 23, 763–769. <https://doi.org/10.1016/j.breast.2014.08.004>
- DeRouen, M.C., Smith, A.W., Tao, L., Bellizzi, K.M., Lynch, C.F., Parsons, H.M., . . . Keegan, T.H. (2015). Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. *Psycho-Oncology*, 24, 1104–1115. <https://doi.org/10.1002/pon.3730>
- DeSanto-Madeya, S., Bauer-Wu, S., & Gross, A. (2007). Activities of daily living in women with advanced breast cancer. *Oncology Nursing Forum*, 34, 841–846. <https://doi.org/10.1188/07.ONF.841-846>
- Garrard, J. (2011). *Health sciences literature review made easy: The matrix method* (5th ed.). Sudbury, MA: Jones and Bartlett Learning.
- Grace, P.J. (2018). *Nursing ethics and professional responsibility in advanced practice* (3rd ed.). Burlington, MA: Jones and Bartlett Learning.
- Hamer, J., McDonald, R., Zhang, L., Verma, S., Leahey, A., Ecclestone, C., . . . Chow, E. (2017). Quality of life (QOL) and symptom burden (SB) in patients with breast cancer. *Supportive Care in Cancer*, 25, 409–419. <https://doi.org/10.1007/s00520-016-3417-6>
- Haylock, P.J. (2010a). Advanced cancer: A mind-body-spirit approach to life and living. *Seminars in Oncology Nursing*, 26, 183–194. <https://doi.org/10.1016/j.soncn.2010.05.005>
- Haylock, P.J. (2010b). Advanced cancer: Emergence of a new survivor population. *Seminars in Oncology Nursing*, 26, 144–150. <https://doi.org/10.1016/j.soncn.2010.05.008>
- Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: National Academies Press.
- Kamal, A.H., Bull, J., Kavalieratos, D., Taylor, D.H., Jr., Downey, W., & Abernethy, A.P. (2011). Palliative care needs of patients with cancer living in the community. *Journal of Oncology Practice*, 7, 382–388. <https://doi.org/10.1200/JOP.2011.000455>
- Knox, M.K., Hales, S., Nissim, R., Jung, J., Lo, C., Zimmermann, C., & Rodin, G. (2017). Lost and stranded: The experience of younger adults with advanced cancer. *Supportive Care in Cancer*, 25, 399–407. <https://doi.org/10.1007/s00520-016-3415-8>
- Lam, W.W., Tsang, J., Yeo, W., Suen, J., Ho, W.M., Yau, T.K., . . . Fielding, R. (2014). The evolution of supportive care needs trajectories in women with advanced breast cancer during the 12 months following diagnosis. *Supportive Care in Cancer*, 22, 635–644. <https://doi.org/10.1007/s00520-013-2018-x>
- Lundquist, D.M., Berry, D.L., Boltz, M., DeSanto-Madeya, S.A., & Grace, P.J. (2019). Wearing the mask of wellness: The experience of young women living with advanced breast cancer. *Oncology Nursing Forum*, 46, 329–337.
- Lunney, J.R., Lynn, J., Foley, D.J., Lipson, S., & Guralnik, J.M. (2003). Patterns of functional decline at the end of life. *JAMA*, 289, 2387–2392. <https://doi.org/10.1001/jama.289.18.2387>
- Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. *Hastings Center Special Report*, 35, S14–S18.
- Meier, D.E., & Beresford, L. (2008). Outpatient clinics are a new frontier for palliative care. *Journal of Palliative Medicine*, 11, 823–828. <https://doi.org/10.1089/jpm.2008.9886>

- National Cancer Institute. (2014). Definitions. Retrieved from <https://cancercontrol.cancer.gov/ocs/statistics/definitions.html>
- National Cancer Institute. (2018). Adolescents and young adults with cancer. Retrieved from <https://www.cancer.gov/types/aya>
- Ngwenya, N., Kenten, C., Jones, L., Gibson, F., Pearce, S., Flatley, M., . . . Whelan, J. (2017). Experiences and preferences for end-of-life care for young adults with cancer and their informal carers: A narrative synthesis. *Journal of Adolescent and Young Adult Oncology*, 6, 200–212. <https://doi.org/10.1089/jayao.2016.0055>
- Salakari, M.R., Surakka, T., Nurminen, R., & Pylkkänen, L. (2015). Effects of rehabilitation among patients with advanced cancer: A systematic review. *Acta Oncologica*, 54, 618–628. <https://doi.org/10.3109/0284186X.2014.996661>
- Shaha, M., & Bauer-Wu, S. (2009). Early adulthood uprooted: Transitoriness in young women with breast cancer. *Cancer Nursing*, 32, 246–255. <https://doi.org/10.1097/NCC.0b013e31819b5b2e>
- Siegel, R.L., Miller, K.D., & Jemal, A. (2016). Cancer statistics, 2016. *CA: A Cancer Journal for Clinicians*, 66, 7–30. <https://doi.org/10.3322/caac.21332>
- Singer, A.E., Meeker, D., Teno, J.M., Lynn, J., Lunney, J.R., & Lorenz, K.A. (2015). Symptom trends in the last year of life from 1998 to 2010: A cohort study. *Annals of Internal Medicine*, 162, 175–183. <https://doi.org/10.7326/M13-1609>
- Trevino, K.M., Abbott, C.H., Fisch, M.J., Friedlander, R.J., Duberstein, P.R., & Prigerson, H.G. (2014). Patient-oncologist alliance as protection against suicidal ideation in young adults with advanced cancer. *Cancer*, 120, 2272–2281. <https://doi.org/10.1002/cncr.28740>
- Trevino, K.M., Fasciano, K., Block, S., & Prigerson, H.G. (2013). Correlates of social support in young adults with advanced cancer. *Supportive Care in Cancer*, 21, 421–429. <https://doi.org/10.1007/s00520-012-1536-2>
- Trevino, K.M., Maciejewski, P.K., Fasciano, K., Greer, J., Partridge, A., Kacel, E.L., . . . Prigerson, H.G. (2012). Coping and psychological distress in young adults with advanced cancer. *Journal of Supportive Oncology*, 10, 124–130.
- Trevino, K.M., Maciejewski, P.K., Fasciano, K., & Prigerson, H.G. (2012). Grief and life disruption in young adults with advanced cancer. *Journal of Adolescent and Young Adult Oncology*, 1, 168–172. <https://doi.org/10.1089/jayao.2011.0024>
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52, 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Zebrack, B. (2009). Information and service needs for young adult cancer survivors. *Supportive Care in Cancer*, 17, 349–357. <https://doi.org/10.1007/s00520-008-0469-2>
- Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, 30, 1221–1226. <https://doi.org/10.1200/JCO.2011.39.5467>