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Understanding the Workplace Interactions of Young Adult Cancer Survivors with Occupational and Environmental Health Professionals

A dissertation submitted in partial satisfaction
of the requirements for the degree
Doctor of Philosophy in Nursing

by

Dawn Salpaka Stone

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ABSTRACT OF THE DISSERTATION

Understanding the Workplace Interactions of Young Adult Cancer Survivors with Occupational and Environmental Health Professionals

by

Dawn Salpaka Stone

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2018

Professor Wendie A. Robbins, Chair

This dissertation features the three-manuscript option.

Objective. Work provides personal satisfaction, meaningfulness, and financial stability to adolescent and young adult (AYA) cancer survivors. However, progressive health changes because of cancer and its treatments, may compromise safety and diminish ability to work. Workplace regulations and processes also influence productivity and employment sustainability for AYA cancer survivors. This dissertation explored interactions, and factors influencing interactions, among employed AYA cancer survivors, five years or more after treatment, and occupational and environmental health professionals (OEHPs) within the workplace.

Methods. Data were collected and analyzed using constructivist grounded theory. Individual interviews generated data from twelve AYA cancer survivors (age 15-39 at diagnosis). The sample of AYA cancer survivors ($n = 12$) was obtained from the California

Surveillance Program in Los Angeles. During interviews, AYA cancer survivors identified OEHPs they encountered in the workplace. Then, twelve OEHPs were interviewed based upon the specified professional categories. Qualitative analysis developed theoretical frameworks based upon the narratives of the participants.

Results. Data revealed the complexity of employment issues surrounding AYA cancer survivors during a career. Disclosure of a cancer survivor identity was central to the frameworks. Four processes were identified: Weighing the risks of revealing the survivor-self, sustaining work ability, weighing advocacy, and accessing or providing support. Additionally, employment challenges were organized into themes: Evading the cancer card, working around limitations, and powering-through for AYA survivors. On the other side of legal protection, OEHPs were becoming agents of change by discovering AYA cancer survivors, navigating systems to provide support, and identifying changes needed.

Conclusion. This dissertation illuminated the unique experiences of AYA cancer survivors and OEHPs in the workplace. Availability of services provided by OEHPs facilitated AYA cancer survivors’ work ability if services were available, known to survivors, and if survivors were willing to reveal needs. Education about OEHP services by employers would improve interactivity and provide a supportive work environment for survivors. Education for workers is needed to enhance sensitivity and improve communication with employees who have a history of cancer. Legislation is needed to promote long-term work ability among AYA cancer survivors by protecting confidential communication to promote greater utilization of OEHP services.

The dissertation of Dawn Salpaka Stone is approved.

Jacqueline N. Casillas

Patricia A. Ganz

Carol L. Pavlish

Elizabeth Anne Thomas

Wendie A. Robbins, Committee Chair

University of California, Los Angeles

2018

DEDICATION

To my husband, Richard L. Stone, and my children, Shawna and Zachary, for their love and unwavering support.

To my parents, William and Virginia Salpaka, for a lifetime of encouragement.

To the young adult cancer survivors and occupational and environmental health professionals whose stories made this work meaningful.

TABLE OF CONTENTS

Chapter Two: Manuscript One

Chapter Three: Manuscript Two

Chapter Four: Manuscript Three

LIST OF FIGURES

Chapter Two: Manuscript One

Young Adult Cancer Survivors and Work: A Systematic Review:

Chapter Three: Manuscript Two

Understanding the Workplace Interactions of Young Adult Cancer Survivors with Occupational and Environmental Health Professionals

Chapter Four: Manuscript Three

Employment Challenges for Young Adult Cancer Survivors

LIST OF TABLES

Chapter Two: Manuscript One

Young Adult Cancer Survivors and Work: A Systematic Review:

Chapter Three: Manuscript Two

Understanding the Workplace Interactions of Young Adult Cancer Survivors with Occupational and Environmental Health Professionals

Chapter Four: Manuscript Three

Employment Challenges for Young Adult Cancer Survivors

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Author Contributions

Dawn S. Stone was the Principal Investigator for this research, and Wendie A. Robbins served as the Lead Academic Supervisor. Dissertation committee members credited as authors contributed to the research design, analysis, and interpretation of data, or assisted with revision of draft manuscripts. All authors approved final versions of the manuscripts listed below and provided consent for publication.

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VITA/BIOGRAPHICAL SKETCH

Master of Nursing Degree
Adult Nurse Practitioner Certification
University of California, Los Angeles, School of Nursing

Bachelor of Science in Nursing
California State University, Los Angeles

Associate of Science Degree in Nursing
Rio Hondo College, Whittier, CA

Experience

Associate Professor
Director, Master of Science in Nursing Program
College of Graduate Nursing
Western University of Health Sciences
Pomona, CA

Nurse Practitioner
University of California Los Angeles: Merck Gardasil 9-Valent Randomized Control Trial
Northrop Medical Department

License and Certifications

Registered Nurse, State of California
Nurse Practitioner, State of California
Public Health Nurse, State of California
Adult Nurse Practitioner, American Nurses Credentialing Center
Occupational Health Nurse Specialist, American Board of Occupational Health Nursing

Publications

Stone, D.S., Ganz, P.A., Pavlish, C., & Robbins, W. (2017). Young adult cancer survivors and work: A systematic review. *Journal of Cancer Survivorship*, *11*(6), 765-781. Doi: 10.1007/s11764-017-0614-3

Robbins, W., Berman, B., & Stone, D. S. (2015). Health effects of vanpooling to work. *Workplace Health and Safety*, *63*(12), 554-63. Doi: 10.1177/2165079915607870

Stone, D. (2015). Integrating inter-professional quality and safety education into academic, clinical and community settings: Human diversity: Improving sensitivity through self-reflective practice in G. D. Sherwood & S. Horton-Deutsch (Eds.), *Reflective Organizations: On the Front Lines of QSEN & Reflective Practice Implementation*. Indianapolis (pp. 321-324), IN: Sigma Theta Tau International.

Presentations

Orange County Chapter of the American Association of Occupational Health Nurses
Invitational Podium Presentation: Successful Leadership Strategies in Occupational and Environmental Health Nursing
Santa Ana, CA, September 10, 2016

University of California, Los Angeles
School of Nursing Research Days
Poster: Understanding the Interactions Between Young Adult Cancer Survivors and Occupational Safety and Health Professionals
Los Angeles, CA, May 25, 2016

American Association of Occupational Health Nurses 2016 National Conference: Leading the Future
Poster: Understanding the Interactions Between Young Adult Cancer Survivors and Occupational Safety and Health Professionals
Jacksonville, FL, April 11-14, 2016

Western Institute of Nursing 49th Annual Communicating Nursing Research Conference
Podium: Understanding Interactions between Young Adult Cancer Survivors and Occupational Health Providers
Anaheim, CA, April 7, 2016

National Institute for Occupational Safety and Health (NIOSH) Southern California Education and Research Center
Interdisciplinary Workshop Presentation:
Young Adult Cancer Survivors and Work: Implications for Occupational Health and Safety Professionals
University of California, Los Angeles
Los Angeles, CA, September 16, 2015

Global Summit, American Association of Occupational Health Nurses
Podium: Vulnerable populations: Health and safety strategies for a global workforce
Dallas, TX, May 5, 2014

Awards and Honors

1998-Present: Sigma Theta Tau International Fraternity for Nursing Scholarship
2016: AAOHN Golden Pen Award
2016: AAOHN Foundation United Postal Service (UPS) Scholarship
2016: Shapiro Scholarship
2014: CSAOHN Moore Excellence Award
2011: Southern CA NIOSH ERC Research Training Pilot Project Award Recipient

INTRODUCTION TO DISSERTATION

More than 70,000 adolescents and young adults (AYA) between the ages of 15 and 39 are diagnosed with cancer each year in the United States (NCIa, 2018). The five-year relative survival at the time of diagnosis has been estimated at greater than 80% combining variations in cancer site and stage of disease (Keegan, et al., 2016). Since the majority of AYAs cancer diagnosed and treated for cancer are expected to become long-term survivors, there is a critical need for research to inform survivorship care for AYAs throughout life (Anderson, Smitherman, & Nichols, 2018).

Recent clinical and population studies indicate that people between the ages of 18 and 40 are the most underserved and understudied age group in oncology (Fidler et al., 2017; Keegan, et al., 2012; Liu et al., 2017). However, cancer has generally received substantial attention from national organizations with notable calls for research. The National Occupational Research Agenda supported the importance of cancer in worker populations when a cross-sector council (NORA CRC, 2017) was developed to focus on cancer and chronic disease in the workplace. Additionally, the American Association of Occupational Health Nurses (AAOHN) Research Priorities (2011) promotes evaluation of critical pathways to improve worker health and safety and to enhance optimal recovery and safe return to work. Similarly, the 2014-2018 Oncology Nursing Society Research Agenda encourages interventions that address work reintegration during and after cancer treatment (Cox, Arber, Gallagher, MacKenzie & Ream, 2017; Knobf et al., 2015). This research specifically addressed the aims of these organizations with emphasis on working AYA cancer survivors five years or more into survivorship, in view of their potential longevity and contributions to society through gainful employment.

Cancer Survivorship

Cancer survivors refer to persons with a history of cancer, from the time of diagnosis through the remainder of life (ACS, 2016). Cancer survivorship focuses on the health and life of a person with cancer post treatment until the end of life (NCCS, 2014). Definitions of survivorship also specify the physical, psychosocial, and economic issues of cancer, as well as impact on quality of life (NCIb, 2018). Therefore, AYA cancer survivors consider employment to be more than earning a living; it is important for self-esteem, social contacts, identity, and health insurance, and for many it provides meaning and significance to life (Katz, 2015; Veenstra, Wallner, Bradley & Hawley, 2016). Essentially, work improves quality of life which is an integral part of survivorship (Parsons et al., 2012).

The Concept of Work

Work is a complex concept and a process of social interaction that is defined as an effort or productive activity by an individual performed for providing goods or services of value to others; it is also considered to be work if the individual involved receives financial compensation (Barofsky, 1989; Hall, 1986). Work includes three independent states (working, unemployment, retirement), transitional processes (job establishment, job termination) and relates to pathological conditions (work-induced illness, occupational hazards, impact of illness on work) (Barofsky). Work is a major covariate of general well-being and life satisfaction for the general population. Important attributes of work are experiencing positive emotions, deriving purpose and goals which contributes towards a meaningful existence (Lee, 2015). Work is commonly referred to as an occupation, vocation, trade, profession or calling. AYA cancer survivors and Occupational and Environmental Health Professionals (OEHPs) who participated in this study used all these terms interchangeably as synonyms for work.

Work remains a central determinant of well-being until illness (Barofsky) occurs or interferes. The observed reductions in employment and work hours among cancer survivors are speculated to be prompted by lingering physical and mental health effects of cancer and its treatment, changing preferences for work in the aftermath of serious illness, or discrimination on the part of employers (Moran & Short, 2014). Long-term late effects of cancer or its treatment have also been linked to poor work retention among cancer survivors (Carter, 2017; Pransky et al., 2016). Functional impairment is a strong predictor of work ability underpinning the importance of assessing cancer survivors' abilities in relation to employment demands (Moskowitz, Todd, Chen, & Feuerstein, 2014).

The Occupational and Environmental Health Team

Knowledge about workplace accommodations for people with cancer is critical since millions of people in the workforce have a history of cancer. The long-term complications from cancer treatment, such as recurrence, secondary cancers or late treatment effects, can suddenly emerge, offering a challenging dilemma for employers. AYA cancer survivors may have limitations that fluctuate creating variable health states that require frequent assessments for safety. Understanding the potential for changing health needs is important for planning screening, interventions and support by OEHPs. The workplace team of OEHPs involve several disciplines including, but not limited to the following: Occupational and environmental health nurses who focus on promoting, protecting, restoring and maintaining workers' health within the context of a safe and healthful work environment; occupational physicians who prevent, detect, and treat work-related diseases and injuries; industrial hygienists who identify, evaluate, and control toxic exposures and hazards in the work environment; safety engineers specialize in preventing injuries and maintaining or creating safe workplaces and practices, and human resources specialists who have expertise in employment law, return-to-work policies, benefits, and provide counseling services. Standards mandated by the Occupational Safety and Health Administration (OSHA) determine requirements for occupational health services within work environments (OSHAa, 1999). The goal of the multidisciplinary occupational and environmental health team is achieved through collaboration with an aim to design, implement, and evaluate a comprehensive health and safety program that will maintain and enhance health, improve safety, and increase productivity (OSHAb, 2018). AYA cancer survivor participants in this study worked within a wide range of industry sectors and employers.

Contextual Factors within the Workplace

The health and safety of workers are the result of a confluence of characteristics. These include demographic variables; workplace characteristics, management, processes, products, and laws and regulations that govern work, workplaces and workers (Wachs, 2014). Knowledge about AYA cancer survivors with inherent health risks within a system that can also pose additional risk presented an array of challenges for OEHPs. Little has been known about the impact of health problems on the ability to work successfully throughout an unpredictable course of medical issues and how OEHPs can influence support. The interactions between AYA cancer survivors and OEHPs were also found to be confusing within the context of a workplace. Privacy laws provide protection from discrimination in that revealing medical issues is optional for AYA cancer survivors while simultaneously prohibiting inquiry by employer representatives (ADA, n.d.). The attitudes of OEHPs concerning cancer survivors needs additional investigation to determine if discrimination is a valid concern.

The perspectives of the AYA cancer survivors and OEHPs are products of a social world, which includes the workplace. The role of each individual and each group, either AYA cancer survivors or OEHPs, offered unique perspectives that have been developed through social interactions within the context of the workplace over time. In this dissertation, the interpretation of these perspectives on reality have revealed a segment of what is true (Charon, 2010).

The Purpose of this Study

The impact of cancer on people's working lives is an increasingly important concern to individuals, employers and wider society but knowledge on this issue is extremely limited. This research provided a useful start in obtaining empirical data from AYA cancer survivors and OEHPs regarding their interactions, or factors influencing interactions, and experiences within the context of the workplace.

Specific Aims/Goal

The following specific aims were investigated using constructivist grounded theory to identify concepts and create frameworks upon which associations about interactions and processes in the workplace can be further assessed and developed quantitatively:

1. To understand the interactions of young adult cancer survivors with occupational and environmental health professionals in the workplace.
2. To understand the contextual factors in the work environment that affect interaction and processes.

The overarching goal of this study was to construct an explanatory framework grounded in data from participants that illustrates processes of interaction between AYA cancer survivors and OEHPs within the context of the workplace.

Research Questions

- What are the interactions between AYA cancer survivors and OEHPs?

- How do interactions between AYA cancer survivors and OEHPs influence survivors' ability to work over time?
- What contextual factors affect interaction and processes between AYA cancer survivors and OEHPs in the workplace?

Content of this Dissertation

Chapter One reviewed the scholarly literature to determine what is known about AYA cancer survivors and work. The implications of the analysis revealed interactions between AYA cancer survivors and OEHPs were not studied in the publications qualified for review. Chapter Two described qualitative examination of interactions between AYA cancer survivors and OEHPs as well as the contextual factors that influenced interactions within the workplace. Chapter Three explored employment challenges for AYA cancer survivors and suggested policy implications. The results of this investigation are reported in the following three manuscripts:

1. A targeted literature review (specific aims 1 & 2): Young adult cancer survivors and work: a systematic review.
2. Data-based paper #1 (specific aims 1 & 2): Understanding the workplace interactions of young adult cancer survivors with occupational and environmental health professionals.
3. Data-based paper #2 (specific aims 1 & 2): Employment challenges for young adult cancer survivors.

The conclusion of the dissertation offers suggestions for further research to provide additional new knowledge to the discipline of nursing, and to guide interventions to improve work ability among AYA cancer survivors over the course of a career.

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Young Adult Cancer Survivors and Work: A Systematic Review

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Dawn S. Stone PhD(c), MN, RN,[a,*], Patricia A. Ganz, MD[b], Carol Pavlish, PhD, RN[a,2],
Wendie Robbins, PhD, RN[c]

[a]University of California Los Angeles, School of Nursing
[b]University of California Los Angeles, David Geffen School of Medicine
[c]University of California Los Angeles, Fielding School of Public Health

*Please address correspondence to Dawn S. Stone: dstone@g.ucla.edu or contact by mobile phone: (714)336-7887

Funding: Dawn S. Stone is a PhD candidate at the University of California, Los Angeles School of Nursing, and a National Institute for Occupational Safety and Health Education and Research Center trainee in southern California.

Young Adult Cancer Survivors and Work: A Systematic Review

Context: Sixty-three percent of cancer survivors continue to work or return to work after treatment. Among this population, work ability and challenges encountered in the workplace by *young* adult cancer survivors have not been well established.

Purpose: The purposes of this review are to describe what is currently known about work-related issues for young adult cancer survivors diagnosed between ages 15and 39, to identify gaps in the research literature, and to suggest interventions or improvements in work processes and occupational settings.

Methods: A systematic review of articles using PubMed, CINAHL, and PsychInfo was conducted without date limitations. Search phrases included young adult cancer survivors, long-term cancer survivors, young adults affected by cancer, further combined with key terms employment, work, and occupationally active. Inclusion criteria for publications were young adult cancer survivors initially diagnosed between the ages of 15 and 39, data about work or employment was presented, and articles written in English.

Results: Twenty-three publications met the inclusion criteria. Work-related issues included the potential for reduced work productivity from cancer-changed physical and cognitive functional ability that affected income and resulted in distress. Coping style, support systems, and changing perspectives about work and life in general were also influential on career decisions among young adult cancer survivors.

Conclusions: More research is needed to study interventions to better manage health changes in young adult cancer survivors within the context of the workplace. Since financial hardship has been shown to be especially high among young cancer survivors, employment is essential to ensure payment of cancer-associated costs and continued medical care.

Implications for Cancer Survivors: While young adult cancer survivors may initially grapple with cancer-related physical and psychosocial changes that impact work productivity or influence choice of occupation, employment appears to enhance overall quality of life.

Key words: Young adult cancer survivors · Work · Employment · Occupational health

Workplace Health and Safety Considerations for Young Adult Cancer Survivors

Young adults, initially diagnosed with cancer between the ages of 15 and 39 [1], may look forward to a lifetime of opportunities. The number of people living beyond a cancer diagnosis reached nearly 15.5 million in 2014 and is expected to rise to almost 19 million by 2024 [2]. Considering this anticipated increase in cancer survivors, many will be at an age when cancer and its treatments could alter employment opportunities. With earlier cancer diagnoses among younger working-aged persons, job-related accommodations could have far reaching social and economic effects [3]. The ability to work following cancer treatment is important for maintaining self-respect, identity, and living conditions. It is also important for society to keep people employed for economic reasons and to prevent social inequality [4]. Information about adults who continue to work long after a cancer diagnosis is integral to understanding their potential health and safety needs in the workplace [3].

A life course perspective on cancer can advance understanding of the unique ways cancer affects young adults [5]. Cancer survivors encounter a variety of work experiences such as changes in responsibilities, decreased capacity to work, and perhaps job loss. Work ability is a complex concept that changes over time as a new balance between job demands and personal capacity is established [6]. These changes can be associated with cancer or cancer treatment, but survivors may also voluntarily change employment after self-reflection about life's priorities [7]. Based upon issues associated with developmental stages coupled with confronting a serious disease, early questions preliminary to this review pondered how young adult cancer survivors approach and interact with others within the work environment. Disclosure, career choices, impact of cancer treatments on health, and work ability over the course of a career could be influence employment status. We also wondered how occupational and environmental health professionals could support working cancer survivors. Hence, this review provides a comprehensive analysis of what is known about young adult cancer survivors and employment. Young adult survivors are an understudied population compared with other age groups who undergo complicated journeys because of their life stage [8]. Therefore, the purposes of this analysis of scholarly literature are to examine what is currently known about the work-related issues for young adult cancer survivors diagnosed between ages 15-39, to identify gaps in the research literature, and to suggest interventions or improvements in work processes and occupational settings.

Methods

Search Strategy

The first author searched the literature using the following electronic databases: PubMed (United States National Library of Medicine); The Cumulative Index to Nursing and Allied Health Literature (CINAHL); and PsychINFO (American Psychological Association). The search was conducted in English without date restrictions and concluded in January 2016. Search phrases included young adult cancer survivors, long-term cancer survivors, and young adults affected by cancer. Search phrases were combined with key terms employment, work, and occupationally active. Eligible publications were also hand-searched for additional references.

Eligibility Criteria

The following criteria were used to select publications for this review: (1) Inclusion of young adult cancer survivors initially diagnosed between the ages of 15 and 39 [1] at any time during survivorship. The age range during survivorship may vary based on how long after diagnosis the research was conducted. (2) Inclusion of data about work or employment (3) articles written in English.

Review Strategy

One thousand one hundred twenty-seven articles were identified from PubMed, CINAHL and PsychINFO databases using the search terms listed earlier; 53 were duplicates (Fig. 1). Study eligibility included the following: Age of cancer survivors at initial diagnosis as well as length of time since diagnosis or treatment; inclusion of work or employment issues as part of content. Study exclusions: Samples of adults diagnosed with cancer at a mean age of 40 or older; age at diagnosis unknown. Careful consideration was given to investigations listing age categorically to determine if the sample met the eligibility criteria. However, quite often these studies did not align the findings with the age categories. The United States (US) Department of Labor's Fair Labor Standards Act defines worker who are economically dependent on the business of an employer, regardless of skill level, to be considered employees. Whereas, independent contractors are workers with economic independence who are in business for themselves [9]. Number of work hours in any capacity are not part of the US definitions of employment; hence, this review considered all variations in reported employed and self-employed work as determined by the research reviewed.

Quality Assessment

Quality was assessed using the Johns Hopkins Hospital/The Johns Hopkins University Evidence Level and Quality Guide [10]. Articles were scored according to evidence levels based upon type of article or research design. Three of the 23 (13%) publications were at level I: Experimental study, randomized controlled trial (RCT), or systematic review of RCTs with or without meta-analysis [11-13]. Three articles (13%) were at level II: Quasi-experimental studies, systematic review of a combination of randomized controlled trials and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis [14-16]. The remaining 17 publications were level III: Non-experimental studies only, with or without meta-analysis, or qualitative study or systematic review of qualitative studies with or without meta-synthesis [8, 9, 17-31]. Levels IV (opinions of respected authorities, committees, and consensus panels) and V (quality improvement program evaluation, case reports) provided interesting insight and background into young adult cancer survivors and work but were not included in this review.

Quality guides associated with evidence levels 1-3 include high quality: Consistent, generalizable results; sufficient sample size for study design; adequate control; definitive conclusions; consistent recommendations. Good quality: Reasonably consistent results; sufficient sample size for study design; some control; fairly definitive conclusions; reasonably consistent recommendations. Low quality: Little evidence with inconsistent results, insufficient sample size for study design (Table 1).

Results

The 23 eligible publications included young adult cancer survivor populations from the USA, Norway, Sweden, Germany, Canada, Switzerland, The United Kingdom (UK), and Europe. Seven publications were cancer-site specific: Osteosarcomas, colorectal cancer, testicular cancer, Hodgkin’s lymphoma, breast cancer, and cervical cancer [14, 15, 19, 20, 24, 25, 32]. Two of these studies emphasized hematopoietic stem cell transplants [22, 27]. Five articles [16, 21-23, 29] described survivors during the first five years of survivorship while nine publications [11, 14, 15, 17, 19, 25-27, 32] examined survivorship in the long-term, greater than five years after initial diagnosis and treatment. The remainder of articles covered the complete span of young adult cancer survivorship, both short and long-term. Most publications utilized quantitative research methods. Seven [8, 20, 24, 28, 30-32] articles featured qualitative designs.

The final group of articles meeting eligibility criteria were published between 2003 and 2015. The search identified two large cohort studies that led to more than one publication: The Medical Expenditure Panel Survey (MEPS) [11-13, 18] and the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA, HOPE) Study [16, 21]. Publications meeting eligibility criteria from these large databases are included in this review. Each publication was thoroughly reviewed to determine if the study's sample included young adult cancer survivors diagnosed between the ages of 15 and 39, and the length of time since cancer diagnosis. Additionally, inclusion of employment, or work, with related findings was abstracted.

This review revealed that young adult cancer survivors ultimately return to work (Table 1). However, it may not be the same work if physical or cognitive changes occurred because of cancer treatments. Work from a psychological perspective is viewed as mental exertion that is difficult, exhausting, or entails creative effort [32]. Only publications conceptualizing work as a synonym for paid employment were considered. Articles describing factors that influence work or employment were included in this analysis to provide a comprehensive appraisal of the work-related issues for young adult cancer survivors. Distress often results from economic challenges presented by costs associated with cancer care along with ability to the work and earn wages. Health insurance provided by employers remains an important decision as young adult cancer survivors seek to obtain employment or return to work after treatments to ensure lifetime access to healthcare. The distress of financial burdens can also affect intimate relationships and overall quality of life.

Two primary themes emerged from this review, work ability and distress. Subcategories within each theme provided a clearer understanding about the influences and impact of physical and cognitive changes from cancer or its treatments on work ability. Coping style, support systems, and changing perspectives about work and life underpinned survivors' actions and reactions to cancer-associated distress (Fig. 2).

Work Ability

Dieluweit and investigators [17] surveyed 820 survivors during adolescence (Mean age at diagnosis 15.8 years of age). Survivors were found to be significantly older at commencement of their first employment (M=21.8, SD=3.6) in comparison to the *German Socio-Economic Panel Study* participants (M=19.9, SD=2.4; t[1,167]=10.9, P<0.001). However, ultimately survivors were as likely to graduate from university or to be employed as controls without a history of cancer.

The Medical Expenditure Panel Survey with Cancer Survivorship Supplement by Yabroff and colleagues [11] is a nationally representative survey detailing the burden of cancer, including access to healthcare, employment patterns in survivors, lost productivity, financial issues and the psychosocial impact on survivors and their families. The supplement indicated that cancer care is typically more aggressive in younger than older cancer patients, potentially resulting in greater medical cost, productivity loss, late and long-term effects. Working young adults with a cancer history may spend more years living with lasting effects of cancer or its treatment and experience different types of late effects than survivors diagnosed with cancer at older ages. Similarly, Guy et al., [18] also studied *The Medical Expenditure Panel Survey* data to understand the economic impact of cancer on young adult cancer survivors. The researchers found that surviving cancer during young adulthood is associated with substantial economic burden. Young adult cancer survivors had an excess annual medical expenditure of $3,170/person and excess annual productivity losses of $2,250/person. The conclusion from this investigation stressed the need to ensure access to lifelong risk-based follow-up care.

The Centers for Disease Control and Prevention agrees with the above findings in their report *Medical Costs and Productivity Losses of Cancer Survivors – United States, 2008-2011* by Ekweme, et al.[12]. Cancer survivors in this study were stratified into two large age groups, 18 to 64 years, and 65+ years. The researchers noted that many cancer survivors (*n*=676; 58.3%) return to work and remain productive. However, for cancer survivors who were employed at any time since diagnosis, cancer and its treatment interfered with physical tasks (*n*=168; 25.1%) and mental tasks (*n*=103; 14.4%) required by the job, with 24.7% (169) of cancer survivors feeling less productive at work. Other investigations support this statement as shown in the work ability subcategories: physical and cognitive functional ability.

Physical Functional Ability

McCorkle and colleagues [19] used a quality of life framework to conduct a population-based survey of women identified via a state tumor registry in southern New England to describe the prevalence and correlates of depressive symptoms among women who survived cervical cancer from 5 to 25 years (*N*=25). Self-reported impact of cervical cancer on ability to work was included in the survey tool. Median age at diagnosis was 39 years; median age at time of survey was 54 years. Difficulty in ability to work increased the odds of depressive symptoms (4.46, 95%CI: 1.44-13.76). Results indicated that pain and post-radiation diarrhea predispose a sub-group of cervical cancer survivors to lingering problems that interfere with their ability to work. Researchers reported that this finding highlights the importance of adequate and appropriate management of cancer treatment-related symptoms during the extended or permanent survival stage.

Rozmovits and Ziebland [20] used a qualitative approach to explore relationships between *The Civilizing Process* by theorist and author Elias [33] with the experiences of colorectal cancer survivors in the UK. A sense of adulthood in relation to employability and professionalism was part of this alignment between the Elias's work and survivors' narratives. The researchers noted according to Elias, for individuals to be considered civilized, they need to exercise control over bodily impulses. Twenty men and 19 women were interviewed who were initially diagnosed at ages ranging from 28 to 68 (33-87 years at time of interview). An overarching theme of the loss of adulthood emerged. Sub-themes included loss of professional identity, loss of ability to socialize, and loss of dignity, privacy, and independence. Control over bowel habits emerged as an important issue for all participants, with or without a stoma. The researchers found that urgent response to sudden bowel evacuation in work-related situations takes a toll on job performance as well as fundamental aspects of adult identity linked to social expectations about professional behavior. The researchers also noted that younger people who had to abandon their careers suddenly were challenged in seeking to fill that void.

Cognitive Functional Ability

Utilizing data from the National Cancer Institute's Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study, Parsons and colleagues [21] examined factors associated with a return to full-time employment or school after cancer diagnosis with a belief that cancer had a negative impact on an individual's work or educational plans. All study participants were between the ages of 15 and 39 at time of cancer diagnosis. The analysis focused on full-time workers/students at time of diagnosis. Of the 463 patients in the AYA HOPE study who completed initial and follow-up surveys, more than 72% of patients who reported working or being in school full time before diagnosis had returned to full-time work 15-35 months' post-diagnosis. More than fifty percent of all patients working or in school full time before diagnosis described problems with cognition at 6-14 months after diagnosis and at 15-35 months after diagnosis. For example, in the follow-up survey, 30% of patients working full time before diagnosis recounted difficulty “paying attention” at work/school. Further, 15-35 months after diagnosis, 53% (*N*=205) of all patients reported “forgetting”, while 28% (*n*=107) had difficulty “keeping up with work or studies”. Similarly, Prasad et al., [34] found in the Childhood Cancer Survivor Study database cognitive and behavioral functional problems in long-term survivors (5+ years since diagnosis) diagnosed during adolescence or early adulthood (*N*=1,334 survivors 15-21 years of age at diagnosis). Self-reported difficulties with task efficiency increased risk for unemployment (OR, 2.93; 95% CI, 2.28 to 3.77), compared to survivors without problems.

Distress

Hamilton and colleagues [22] mailed questionnaires and conducted telephone interviews were utilized to determine associations between economic stress and health-related quality of life in 181 survivors *(M*=640 days’ post-transplant). Seventy-three percent of participants (older than 16 years at time of hematopoietic stem cell transplantation) were working at the time of their diagnosis or transplant, however only 44% were employed during the study. Among the employed survivors, the most common financial problem was a pay cut or lost income due to illness (reported by 67% of participants; 46% found this to be very or extremely upsetting). The next most common problems included going on disability (63%) and needing to take a paid leave of absence (55%). All but one participant had health insurance at the time of transplant. On average, insurance stress experienced during illness or transplant was low as indicated by eight items measured on a five-point scale *(M*=3.43, SD=4.68). The results from this study suggested financial and employment difficulties need to be viewed as sources of chronic stress with implications for survivors’ health long after treatment has ended.

Aksnes, Hall, Jebsen, Fossa, and Dahl [14] examined fatigue, mental distress, and quality of life in extremity bone tumor (EBT) survivors at long-term follow-up compared to gender and age matched control participants with a history of Hodgkin's Disease or testicular cancer in Norway. Normative data was also used for comparison in this study. Mean age at diagnosis ranged from 16-25 among the survivors studied. Findings revealed the EBT survivors did not differ from the other survivor groups as to the level of education and employment status. In the multivariate analyses of the combined survivor and normative data, a low level of education and not being employed were associated with mental distress. Neither age at diagnosis nor time since diagnosis was associated with distress among the survivors.

Coping

Yanez, Garcia, Victorson, and Salsman [23] explored interaction of cancer-related distress with age and interruption of education or work in young adult cancer survivors (Mean age =31.8). The Impact of Event Scale (IES) was used to determine work interruption and interaction between cohort (time post-active treatment: 0-12 months; 13-24 months; 25-60 months) and cancer-related education/work interruption on distress. IES is a 15 item self-report measure of intrusive and avoidant cognitions frequently used in evaluating stress reactions after traumatic experiences. Intrusive cognitions can be ordinary autobiographical memories, or spontaneous flashbacks, whereas, avoidant cognition is a defense mechanism used to avoid coping. Cancer related work interruption was also assessed by a single author-constructed item: 'Did you stop working because of your cancer?' 67.1% of the sample did not stop working because of cancer. Survivors in the 13-24 and 25-60-month cohorts reporting education/work interruption were significantly more distressed than those not reporting education/work interruption ($p<.05$). After adjusting for physical symptom level & gender, a three-way

ANCOVA revealed significant effects: $F(2,310)=9.49$, $p<0.05$, global impact $F(4, 310)=9.95$, $p<.001$, of cancer related education/work interruption $F(1,310)=4.03$, $p<0.05$ on distress. Attending to cancer-related distress beyond the completion of treatment was recommended in the conclusions. Target interventions such as psychosocial services were suggested.

Rutskij, et al [15] conducted a cross-sectional follow-up study of unilateral orchietomized testicular cancer survivors in Norway using the Brief Approach/Avoidance Coping Questionnaire (BACQ) among others. The participants were an average age of 33.3 years at time of diagnosis; mean age at time of survey was 44.7 years. Despite being considered cured of testicular cancer, this sample of survivors continued to demonstrate increased levels of anxiety compared to healthy male controls. Approach and avoidance were the two major coping strategies studied during this investigation. Approach coping implies confronting stressors and making active efforts at management. Alternatively, avoidance coping is characterized by passive, suppressive, and disengaged attitudes toward stressors. The researchers found that survivors who were employed had higher levels of approach coping style, considered a healthier response to stressful situations.

Support

Lewis and colleagues [24] explored psychosocial concerns in semi-structured telephone interviews with 33 African American breast cancer survivors (Mean age at diagnosis 37.39). Almost all women ($n=31$) worked outside the home at diagnosis with nearly half of the participants (46%) reporting that cancer had no impact on their careers. Twenty-four of the participants indicated that employment in a supportive workplace had a positive impact on their careers. Another 18% of women believed, however that cancer had a mild/moderate negative impact on their careers, including two women (6%) who reported job loss due to cancer. The remaining 6% of women were not working outside the home.

In Sweden, Wettergren, et al [25] evaluated individual quality of life in long-term survivors (median time from diagnosis to interview was 14 years; mean age at time of study =47 (11.9) of Hodgkin's Lymphoma (HL) and their views about disease impact. Findings were compared with a randomly selected control group from the Stockholm County Council Database. No significant difference was found between the HL survivors' (5.4, SD: 0.9) and controls' (5.3, SD:0.7) quality of life index scores ranging on a scale from one to seven. The most important areas in life, identified by more than 50% of the participants in both groups, were family, personal health, work and relations to other people. The investigators concluded that special attention should be given to survivors' relationships with family and close friends, work related issues, and late effects from treatment.

Distress may also impact marital relationships. Marriage and divorce among young adult cancer survivors (N=1,198) was investigated by Kirchhoff, et al [26] with comparison to young adult controls without a cancer history. The 2009 Behavioral Risk Factor Surveillance System (BRFSS) dataset was studied to determine how marital status affects young adult cancer survivors diagnosed between ages 18-37 (M = 33.0 (3.8)) with an average time since diagnosis at 7.4 years. Sixty-one percent (731) of survivors were employed (full or part-time status was not given); 19.7% (213) choose not to be in the labor force; 11.1% (125) were out of work or unemployed; 8.2% (127) were unable to work. The investigators found that even with adjustment for education in the regression models, young adult survivors were more likely to divorce or separate than the controls. Financial stressors may contribute to divorce or separation for young adult cancer survivors. The investigators were unable to determine how financial status preceding or during cancer treatment affected martial outcomes. They concluded that many young adult survivors confront economic hardship due to missed work and/or lost income that negatively affect marriage.

Keegan, et al, [16] studied barriers to access of medical care in 465 adolescent and young adult survivors identified through the population-based SEER program cancer registries. Eligible participants were 15-39-year-old residents of eight geographic regions (Detroit; Seattle; Los Angeles; San Francisco; Sacramento; Orange County, CA, Iowa; Louisiana) who were newly diagnosed during 2007-2008. Young adults without insurance were generally less likely to see all types of doctors, particularly oncologists. Among AYAs who did not report a doctor's visit in the past 12 months, the three most common reasons for no care were high cost/no insurance (44%), they felt they did not need follow-up care (40%) or their physician said they did not need follow-up care (28%).

Davidoff, Hill, Bernard and Yabroff [13] examined potential improvements in access to insurance for cancer survivors through adult Medicaid expansions and premium tax credits in the new insurance marketplaces under the Affordable Care Act (ACA). The Medical Expenditure Panel Survey Household Component (2008-2010) was used to sample 2527 cancer survivors; 24.4 percent of the sample was in the young adult age category 18-44. Overall, 18% of cancer survivors reported financial hardship and 37% of the uninsured reported financial destitution. The experience of cancer survivors prior to the ACA indicates that many faced substantial out-of- pocket burdens even with insurance. Given the heavy personal financial burden and access barriers faced by cancer survivors, it is expected that many of those without current employment-related insurance would participate in Medicaid or the marketplaces. Plans purchased through the marketplace are required to provide adequate networks but may limit the number of providers to maintain affordability, which may impede cancer survivors' access to oncology specialists. The researchers note the importance of monitoring the changing landscape of insurance coverage, access to care, and uncovered medical expenses for cancer survivors as healthcare access continues to be revamped in the USA.

Changing Perspectives

Bieri and colleagues [27] studied young adult cancer survivors after allogeneic hematopoietic Stem Cell Transplant (SCT) (N=124) in Switzerland using the *European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30* and *the Functional Assessment of Cancer Therapy-Bone Marrow Transplant* tools. Survivors' median age at diagnosis was 34; with median time since treatment of 7 years. A control group of healthy participants was not recruited or sampled for comparison in this study. The researchers found that age and employment status were significantly associated with global quality of life. Among survivors employed full-time, 73% reported good quality of life as opposed to 28% working part-time, and 22% of those on disability insurance (HR 0.35 (95% CI 0.22-0.58) p <0.0001). Younger than 25 years of age at hematopoietic SCT and return to full-time employment were the only parameters in this study that were significantly associated with a better perception of health-related quality of life in comparison to other patient characteristics, such as age or gender.

Using qualitative methods Parsons, et al [32] studied young adult primary bone cancer survivors in Toronto, Canada. The eligible participants were diagnosed at ages 22, 25 and 30 and interviewed at 27, 31, and 35 respectively. The researchers prompted participants to reflect about returning to work. Respondents recounted being engaged in three kinds of work: Illness work, identity work, and vocational work. All three types of work were intricately interwoven with illness work occurring during active cancer treatments, which was described as a transformative experience. Participants felt changed from who they were prior to cancer and when they returned to their respective vocations, they reported a changed relationship to work with a different sense of themselves from when they had left the workplace. Transformation of identity repositioned survivors differently socially, psychologically, and physically. The researchers recommended clinicians adopt a sophisticated approach when discussing plans for returning to work with survivors. Improvement of programs within the workplace that are tailored to meet individual needs were also encouraged.

Hammond, Reese, and Teucher [28] used a qualitative approach to produce an accurate accounting of relationships between personal stories of cancer and cultural understanding of illness. Twenty-one young adults were individually interviewed using a semi-structured guide. Uncertainty and possibility were two themes that emerged from this study. Participants expressed uncertainty in relationship to cancer diagnosis, treatment, and prognosis, but also maintained uncertainty when discussing the future beyond treatment. However, possibility was the theme linked most strongly with work among survivors whose career perspectives and life priorities had changed due to cancer experiences. Alternative career or employment opportunities for future endeavors fit well into the possibility theme.

Bellizzi, et al., [29] studied the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) data to identify the negative and positive impact of cancer on AYA cancer survivors in three age categories: 15-20 years (33.8%), 21-29 (39.9%), and 30-39 year-olds (38.2%). The most prevalent negative life domains Young adults with cancer reported were specific to future plans (financial situation, plans for having children, plans for working) as well as body appearance and sense of control over life. Regarding future plans, all three age categories reported that cancer had similar level (~46% of the sample) of positive impact for the future and goal setting.

Generating Supportive Relationships

Psychosocial concerns were explored in semi-structured telephone interviews with 33 African American breast cancer survivors (Mean age at diagnosis 37.39) by Lewis and colleagues [24] using a 49-question tool containing demographic information including profession and working status outside the home. Several questions inquired about support received during treatments with reflection about support that was missing. Impact of the cancer experience on sexuality and fertility was also included. The majority (64%) of participants were self-identified as being in a white collar occupational category. Twenty-four percent of women reported that cancer had a positive impact on their work life and that co-workers were supportive during cancer treatment, however, one third wished for more emotional support from family or intimate partners, and that need did not diminish over time. The researchers had partnered with a national advocacy organization *Sisters Network Inc.* to create a peer counseling program *SPIRIT* (Sisters Peer Counseling in Reproductive Issues after Treatment) and concluded that psychosocial interventions from such an organization, or a patient navigator model, may provide support to young African-American breast cancer survivors. Mental health care or counseling seemed to be especially needed by this young survivor group, which could potentially be provided at the worksite, but was not suggested by the investigators.

Rabin, Simpson, Morrow and Pinto [30] sought to obtain an in-depth understanding of the preferred content and format of psychosocial and behavioral programs for those diagnosed with cancer during young adulthood. The researchers conducted semi-structured individual interviews with 20 young adult cancer survivors (5 men; 15 women) between 18-39 years of age

(Mean = 33.5 years). Eighty-five percent of the participants were employed during the study. About half of the survivors reported that interventions delivered via the internet have the potential to maximize convenience. Over half (percentage not given) of the participants advocated for using an online forum, chat room, or social networking site to communicate with, and receive support from, other young survivors and behavioral counselors. Most participants felt that a behavior change intervention delivered via telephone would provide an enhanced degree of support and social connection.

Love, et al. [31] studied 350 randomly selected messages, or speech events, related to the psychosocial needs of young adult cancer survivors in an online environment hosted by the University of Texas, Austin. The forum is open to any young adult affected by cancer across the treatment spectrum. It was expressed by members that once treatment ends, survivors struggle with depression, strained relationships, and maladjustment to work, although others describe a more meaningful outlook. The researchers concluded that promotion of online support through care providers could attract more individuals in need of assistance or counseling.

In a qualitative study by Kim and colleagues [8], 164 blogs submitted to the *Planet Cancer* website by 46 young adult cancer survivors were examined. Several major themes were reported with connections between cancer survivorship and work, for example: Life being affected by physical burdens, prospects and uncertainty, creating a positive attitude, and the paradoxical nature of cancer survivorship. Loss of control experienced by the young adult cancer survivors studied was found to be related to external factors such as career, education, and family planning. Internet-based cancer support services, specific to young adult cancer survivors was viewed as being a familiar mode of support with those who are of similar age and in similar situations.

Discussion

By examining the effects of cancer and its treatments on work, this review fills an important gap in knowledge about young adults diagnosed with cancer between 15 and 39 years of age. This systematic review revealed that the cycle of functional ability impacting work productivity on employment is a strong source of stress affecting not only acquiring and maintaining a job, but also financial security, access to health care, relationships, and quality of life. The work-related issues for young adult cancer survivors during a career trajectory are complex with physical and psychosocial implications. In the review provided, survivors initially experienced delays in obtaining education and employment due to cancer diagnosis and treatment. However, the related studies found that many survivors become equal to healthy controls overall in achieving a successful career. Many young adult cancer survivors continue working throughout the treatment phase, although some found treatment schedules and side-effects interfered with productivity. The reviewed literature also indicated that physical or cognitive consequences occasionally prompted a change in occupation. Alternately, while some survivors find work to be a return of normalcy, others describe a changed perspective that redefined future goals. The length of survivorship ranged from 1 year to 20 years or more, post cancer diagnosis or treatment in the literature reviewed. However, with limited research focusing on a very small component of the career development process, significant knowledge gaps related to the impact of cancer and associated treatments on career development still exist [35].

Considering comparability of cancer with non-cancer samples, as well as the effects of cancer on young adult survivors with older adult survivors from investigations not eligible for this review, we found contrasting results that are also optimistic. For example, in a Canadian study for Jeon [36], effects of cancer on work status and earnings in survivors aged 25-61 revealed smaller negative long-term effects on the work status of survivors diagnosed at 48 years of age and younger than the effect for the full cancer group. In an investigation comparing cancer survivors 28-54 years of age (*N* = 676) 2-6 years after diagnosis with non-cancer controls in Pennsylvania, Moran, Short, and Hollenbeak [37] found the extent of cancer's long-term effects on employment unclear, a contradiction that could be explained by survivors who continue to work despite impairments and disabilities. Additionally, according to a meta-analysis by de Boer [38] and colleagues, cancer survivors in general are 1.37 times more likely to be unemployed than healthy control participants although age did not have a clear association with unemployment risk. These variations in results may be explained in a systematic review by Duijts et al [39], who found that cancer survivors require a period of adjustment to cope with work demands again upon return.

The limitations of the publications reviewed limit generalizability of findings for several reasons. Labor laws, national insurance programs, and benefits differ between the countries and states within the USA. In addition, several studies seemed to emphasize whether young adult cancer survivors with specific diagnoses were working rather than how they were functional and productive at work. The studies presenting changes in physical functioning were specific to types of cancer or treatments and described well consequences while neglecting to provide content about accommodations that will be needed for work. Since half of the publications were at evidence level 3, experimental are especially need to strength the body of knowledge about young adult cancer survivors in the workplace. Five of the 23 publications [8, 12, 13, 28, 31] did not reveal the length of time after cancer diagnosis or treatment, an important marker to determine long-term effects on work ability. However, strengths of the publications reviewed highlighted work as central to quality of life since it is pivotal to financial stability and quite often, access to health insurance and ultimately continued health care. Young adult cancer survivors can now ponder the complexity of health insurance systems in the USA, as access to healthcare is important to consider during times of employment transition.

Conclusion

From this review, the resounding message for clinicians in the publications reviewed largely relate to the need for close monitoring of young adult cancer survivors to determine the presence of distress and/or depression. The aftermath of emotions following treatment is a particularly vulnerable time that may require addition time or services. It is also important to assess the interests of young adult cancer patients as well as their dreams and career aspirations. Inter-disciplinary collaboration is critical to understanding the process of returning to work in view of symptomology, and the potential need for accommodation (Table 2).

Implications

To the best of our knowledge, no studies explored the interactions between young adult cancer survivors and occupational and environmental health professionals in the workplace. Research is needed to investigate young adult cancer survivors regardless of cancer site to determine specific challenges encountered in the workplace over the course of a career, along with evidence-based strategies that contribute to success. Additionally, important to explore are support services available within the work arena, and if employed survivors are aware of the support available. Since technology was shown to be a flexible and convenient mode of communication for young adult cancer survivors, the use of online forums could be a feasible and effective method of providing support. Clearly, young adult cancer survivors are an integral part of the workforce. Determining physical and cognitive functioning and changes in needs over time are important directions for future research, formulation of workplace policies, and maintenance of a robust labor market.

Compliance with Ethical Standards

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Figure I: PRISMA (2009) Flow Diagram

PRISMA 2009 Flow Diagram

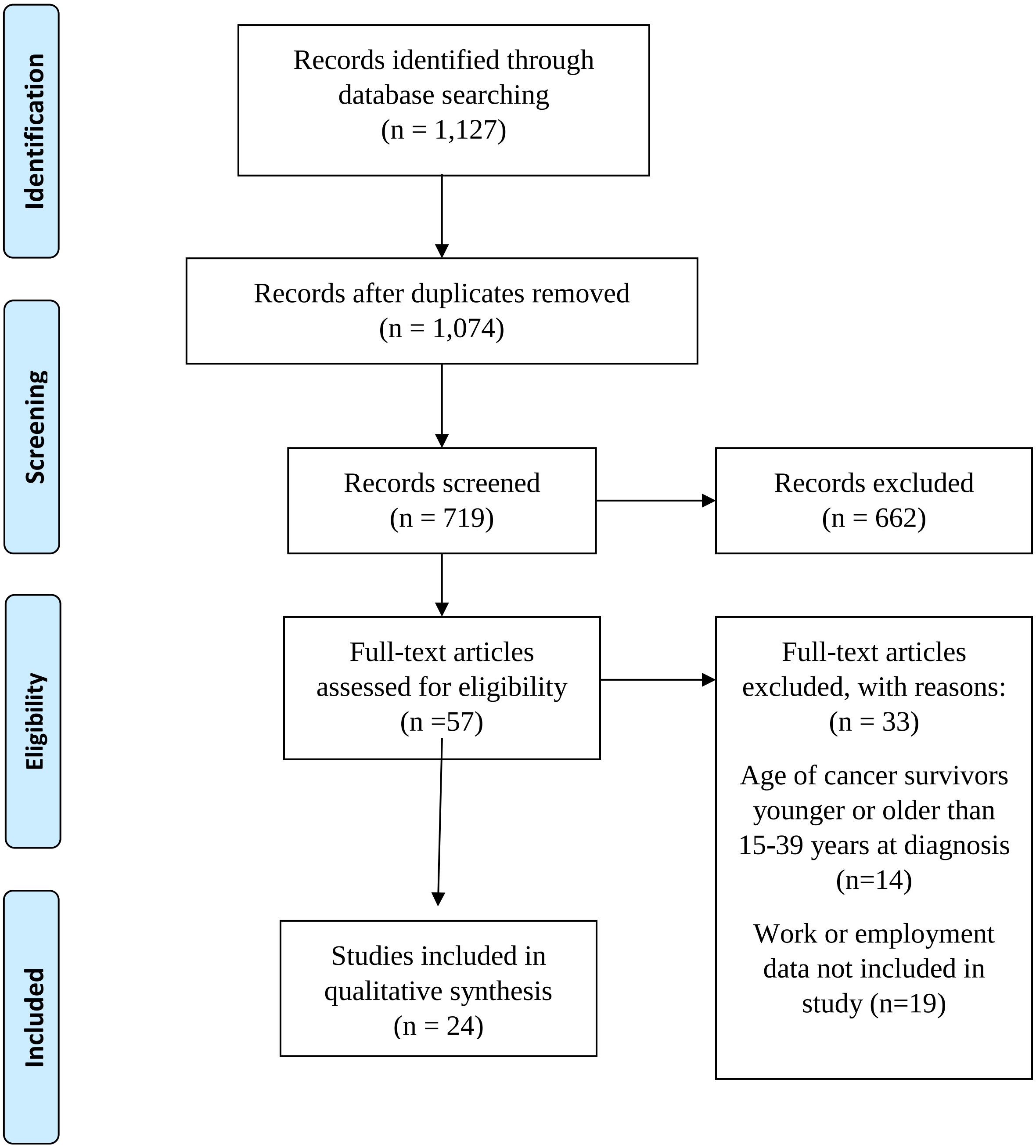

Table 1: Publications meeting eligibility criteria concerning Young Adult Cancer Survivors (aged 15-39 at diagnosis) and Work (paid employment)

First Author Year Evid-ence Level and Quality Rating[a]	Population and Eligibility	Study Design Purpose, aims, or objectives	Participant Characteristics	Relevant Measures	Outcomes Related to Work
Aksnes 2007 Level II - A	Scandinavian Sarcoma Group *N*=75 Eligible 58 responses (77%) 31 male & 27 female Extremity Bone Tumor (EBT) Survivors Mean age at diagnosis: Males 20; Females 16 Age at survey: Males 34 (9.4) Females 27 (4.8) Years since diagnosis: Males 14(4.5); Females 11(4.8) 5 years or more after treatment	Cross-sectional, Comparative Purpose: To compare quality of life, fatigue and mental distress in Extremity Bone Tumor survivors with Hodgkin's Disease survivors, Testicular Cancer survivors, and gender and age matched individuals from the general population.	Cancer Sites: Extremity Bone Tumors (EBT); Hodgkin's Disease (HD); Testicular Cancer (TC) Working Status: Employed 45 Not Employed 12	Fatigue Questionnaire Hospital Anxiety and Depression Scale SF-36 to measure Quality of Life SF-36 Physical Component Summary Scale & Mental Component Summary Scale	EBT survivors did not differ from the other survivor groups as to education & employment status. EBT survivors had lower scores on all physical dimensions of the Short Form-36 compared to other survivors and the normative samples. (p <0.5) In multivariate analyses of the combined survivor and normative data, a low level of education and not being employed were associated with mental distress (OR 2.28; CI 1.26-4.14; p=0.01).

					EBT survivors had higher mean fatigue scores than the normative samples (p <0.5) but about the same levels as other survivor groups. Clinical Implications: Eventually prepare for reduced physical functioning.
Bellizzi 2012 Level III - B	National Cancer Institute Surveillance, Epidemiology and End Results Program Adolescent and Young Adult Health Outcomes and Patient Experience Study *N*=523 Mean age 29 +/- 6.7 years 1/3 of AYAs in all 3 age groups: 15-20 years 33.8% 21-29 years 39.9%	Cross-sectional Objectives: To identify the negative and positive impact of cancer on development during adolescence and young adulthood, and to examine impact according to stage of development (age at diagnosis).	Cancer Sites: Germ cell, non-Hodgkin lymphoma, Hodgkin lymphoma, acute lymphocytic leukemia, or sarcoma.	Life Domains: Future Body Appearance Control over Life	The most prevalent negative life domains reported were specific to future plans (financial situation, plans for having children, plans for working) as well as body appearance and sense of control over life. All 3 age groups reported that cancer had a similar level (~46% of the sample) of positive impact on plans for the future and goal setting.

	30-39 years 38.2% <14 months after diagnosis				These findings demonstrate the coexistence (in the aggregate) of negative and positive psychosocial aspects of cancer in adolescents/young adults.
Bieri 2008 Level III - B	University Hospital of Geneva *N* = 124 patients in remission after allogeneic Hemato-poietic Stem Cell Transplant (HSCT). Comparison with health controls. Median age 34 (range 14-65) Median time from HSCT was 7.3 years. Median age at time of answering questionnaire: 42 years.	Cross Sectional Aim: To assess health-related quality of life in comparison with healthy controls.	Cancer Sites: AML ALL CML CLL Myelo-dysplasic syndrome Myeloma Myelo-proliferative syndrome Aplastic anemia	Functional Assessment of Cancer Therapy scale with specific modules for Bone Marrow Transplant and the European Organization for Research and Treatment of Cancer (EORTC QLQ-C30) Questionnaires	In total, 119 (96%) had an occupation or were in school or training before HSCT. After HSCT, 60% of these patients returned to their activities, 29% returned to full-time employment, 21% part time and 10% returned to training or school. In total, 40% of the patients did not return to work and depend on disability insurance (39%) or are retired (1%). Among patients fully employed, 73% reported good quality of life as opposed to 22% of those on disability

					insurance and 28% of those on part-time work (P<0.0001).
David-off, 2015 Level I - A	United States national household survey *N* = 2527 cancer survivors age 18-64 years. 24.4 percent of the sample was in the young adult age category 18-44 Variable length of time since treatment	Descriptive Baseline prior to Affordable Care Act (ACA) for future comparison post implementation ACA Purpose: To characterize coverage options for nonelderly adult cancer survivors and the subset with financial hardship	Cancer Sites: Breast Prostate Colorectal Other male genitourinary Hematologic malignancy Bone, muscle, soft tissue	Medical Expenditure Panel Survey Household Component (MEPS-HC) data from 21008-2010 as a population base for estimates.	Overall, 18% of cancer survivors reported financial hardship and 37% of the uninsured reported financial hardship. Of those, 39% (95% CI = 34%-45%) would be Medicaid eligible under the ACA. It will be important to monitor the effects of the ACA on insurance coverage, access to care and out-of-pocket burdens for cancer survivors as the ACA continues to be implemented.
Dielu-weit, 2011 Level III - B	German Childhood Cancer Registry University Ulm	Cross-sectional Aim: To investigate the educational	Cancer Sites: Leukemia Lymphoma CNS tumors Neuroblast-oma	The German Socio-Economic Panel (G-SOEP) Study provided	Survivors were significantly older at the commencement of their first employment (*M*=21.8,

	Age at diagnosis: 15-18 years Mean age 15.8 (0.9) Age at study: 20-46 years Mean years since diagnosis 13.7 (6.0)	and professional achievements of German long-term survivors of adolescent cancer.	Retino-blastoma Renal tumors Hepatic tumors Malignant bone tumors Soft tissue and other extraosseous sarcomas Germ cell tumors	comparison data to the general population (age-matched controls) GCCR was used to access medical records.	SD=3.6) than the G-SOEP participants (*M*=19.9, SD=2.4; *t*[1,167]=10.9, *P*<0.001). A Cox proportional hazard model analysis also demonstrated significant differences between the survivors and the G-SOEP sample for age at first employment; even after statistical control for high school graduations and achievement of college/university degrees, survivors were significantly older at their first employment compared to the age-matched sample [survivors vs. G-SOEP] OR 1.90, 95% CI 1.67-2.17, *P*<0.001).
Ekwu-eme, 2014	US National Survey *N*=1,202	Cross-sectional Purpose:	Cancer Site: Not given	The Medical Expenditure Panel	Results presented in aggregate:

Level I - A	Age at interview 18-39 years 4.5% (3.3-6.0) Age range 18-80+ years. Cancer survivors who were employed at any time since diagnosis.	To estimate lost productivity by assessing employment disability, health-related missed work days, and days spent in bed because of ill-health.		Experiences with Cancer Survivorship Survey Did cancer interfere with: Daily activities outside work Ability to perform mental tasks Ability to perform physical tasks required by job Ability to perform mental tasks required by job Employment Change in work Ever felt less productive at work	Many cancer survivors (*n*=676; 58.3%) return to work and remain productive. However, for cancer survivors who were employed at any time since diagnosis, cancer and its treatment interfered with physical tasks (*n*=168; 25.1%) and mental tasks (*n*=103; 14.4%) required by the job, with 24.7% (169) of cancer survivors feeling less productive at work.
Guy, 2014 Level III - A	United States national survey *N* = 1,464 adolescent/ young adult cancer survivors 86,864 adults without cancer Young adult cancer survivor age	Cross-sectional Descriptive Objective: To use nationally representative data to estimate direct medical costs and indirect morbidity costs among adolescent and young	Cancer Sites: Not given.	2008-2011 Medical Expenditure Panel Survey Data (MEPS)	Young adult cancer survivors had higher annual per person medical expenditures ($7,417) than adults without a history of cancer ($4,247). Annual excess lost productivity was estimated to be $2,250

	at last interview: 18-29: 11% 30-39: 21% Years since diagnosis: 0-9: 30.5% 10-19: 27.7 % 20+: 41.9%	adult cancer survivors, compared to people without a history of cancer.			per young adult cancer survivor. Identifying ways to reduce disruptions in education and at work as young adult survivors transition out of treatment is important for reducing the excess burden of cancer.
Hamilton 2013 Level III - B	Mount Sinai Medical Ctr New York & Hackensack University Medical Center New Jersey *N* = 181 Men and Women who had undergone HSCT 9-36 months prior to assessment Participants were at least aged 18 years (and older than 16 years) at the time of HSCT. 640 days post-transplant.	Cross Sectional Objective: To examine whether the portion of survivors' transplant paid by health insurance, which varies across individuals, and affects how much of the treatment costs they bear, would moderate the association between economic survivorship stress and health-related quality of life.	Hematologic malignancies	Researchers created own 12 Question tool Employment Stressors in Hematopoietic Stem Cell Transplantation (HSCT) Questionnaire Persistent financial, employment, and insurance stressors.	Financial and employment difficulties need to be viewed as sources of chronic stress with implications for survivors' health long after treatment has ended
Hammond, 2015	Canada	Qualitative Aim:	Cancer Sites: Not given	Performance of tricksterdom	3 Major Themes: Uncertainty,

Level III - B	*N* = 21 young adult: 13 women and 8 men 18-45 years of age Variable length of time since treatment	To investigate the prevalence of three tricksterly themes expressed within young adults' stories of cancer.		in cancer survivors' narratives from a social constructionist perspective. Destabilizing social or cosmic order Challenging dominant expectations for human life Exploring alternate ways of viewing the world	subversion, and possibility.
Keegan 2014 Level II - A	National Cancer Institute Surveillance, Epidemiology and End Results Program Adolescent & Young Adult Health Outcomes and Patient Experience (AYA, HOPE) study *N* = 464 Adolescent/ Young Adult survivors Age at diagnosis: 15-19 years: 62 (13.3%) 20-29 years: 195 (41.9%)	Descriptive Aims: To determine young adult cancer survivors and non-cancer-related medical care in a 12-month period, and to examine sociodemographic and cancer-related factors associated with medical care use among survivors 15-35 months after diagnosis.	Cancer Sites: Germ Cell; Acute-lymphoblastic Leukemia; Non-Hodgkin Lymphoma; Sarcoma	Source of health insurance General Health Date of Last Treatment Quality of Care Financial Support Need for Information	Employment Categories: Unemployed 71 – 15.3% PT Working/ Studying FT 92 - 19.8% Working/ Studying 266 – 57.2% Other/unknown 36- 7.7% Adolescent/young adult cancer survivors with current health insurance were nearly five times more likely to receive cancer-related care than those without health insurance (OR=4.9;95% CI=1.7-13.8)

	30-39 years: 208 (44.7%) 15-35 months after diagnosis.				
Kim, 2013 Level III - C	Online Forum 164 Cancer-related blogs from *Planet Cancer* by 46 young adult cancer survivors. Age of participants at time of diagnosis or research was not given. *N* = 34 females – 136 blogs; 12 males – 28 blogs Length of time since diagnosis was not given.	Qualitative Purpose: To explore the experiences and gain a better understanding of young adult cancer survivors by examining their blogs.	Cancer Sites: Not given	Survivors blogged about career and employment issues	Themes: Life being affected by physical burdens, future prospects and uncertainty, creating a positive attitude, and the paradoxical nature of cancer survivorship. Blogs provide support when survivors are isolated or physically unable to interact.
Kirchhoff 2012 Level III - B	Behavioral Risk Factor Surveillance System (BRFSS) dataset USA, the District of Columbia, Puerto Rico, Guam, and Virgin Islands.	Cross-sectional Aim: To determine how marital status is affected for young adult cancer survivors ages 18-37.	Cancer Sites: Not given.	The Behavioral Risk Factor Surveillance System is an annual, nationally representative random-digit telephone survey of non-institutionalized adults ages 18 or older in the	Young adult cancer survivors were older than controls [33.0 (SD=3.8) vs. 30.0 (SD=4.0); p<0.001). Survivors were employed less often (61% vs. 67.4%; overall p<0.001).

	N = 1,198 young adult cancer survivors between ages 20-39 years of age: 218 (age 20-29 years) 980 (age 30-39) Mean time since dx 7.4 years (SD 3.8)			USA, DC, Puerto Rico, Guam, and Virgin Islands. The CDC-HRQOL-4 “Healthy Days Measure” was also used	Survivors reported being 77% more likely to be divorced or separated among those who had every been married (survivors 18% vs. controls 10%; RR 1.77, 95% CI 1.43-2.19, p<0.001) than controls.
Lewis 2012 Level III - B	MD Anderson Cancer Center and Sisters Network *N* = 33 African-American breast cancer survivors Mean age at diagnosis: 37-39 Age range: 25-45 years of age Variable duration post-diagnosis Participants were at least one year post-diagnosis, off active treatment	Qualitative Objective: To explore the impact of cancer on women’s living situations, employment, relationships, fertility, and sexuality.	Cancer Site: Breast	Semi-structured phone interviews 45-60 minutes. 141 Items focusing on impact of cancer on living situations, employment, relationships, fertility, and sexuality.	26% believed treatment interfered with employment Change in job due to cancer: Lost job 6% Mild/moderate negative impact on job 18% Positive impact/supportive workplace 24% No change 46% Not working outside home 6%

	other than hormonal therapy.				
Love 2012 Level III - B	Online Forum Open to any young adult affected by cancer across the treatment spectrum. (U of Texas, Austin) *N* = 350 randomly sampled posts from 2007-2010 Unknown duration post-diagnosis	Qualitative Research question: What are the types of messages related to psychosocial needs being shared within the community?	Cancer Sites: Not given.	Speech events or types of talk: Exchanging support Coping Describing experiences Enacting identity Communicating membership	After treatment ends, survivors reported struggling with depression, strained relationships, and maladjustment to work, although some described a more meaningful outlook. Promotion of online support by care providers could provide additional support to individuals in-need.
McCorkle 2006 Level III - A	Southern New England tumor board *N* = 208 Median age at diagnosis 39 years (range 29-92 years); Median age at time of survey 54 years (range 29-92 years) The average length of survival post	Cross-sectional Population-based survey Purpose: To describe the prevalence and correlates of depressive symptoms among women who have survived cervical cancer for 5-25 years.	Cancer Site: Cervical 70% employed full-time or functioning as homemakers	The Center for Epidemiological Studies – Depression Scale (CES-D)	Pain and post-radiation diarrhea predispose a sub-group of cervical cancer survivors to lingering problems that interfere with their ability to work. Researchers reported that this finding highlights the importance of adequate and appropriate

	initial diagnosis was 13,9 years (median =13).				management of cancer treatment-related symptoms during the extended or permanent survival stage.
Parsons 2008 Level III - B	Toronto, Canada *N* = 14 bone tumor survivors (8 men; 6 women) Age at diagnosis: 16-35 years 5 years after diagnosis	Qualitative Objective: To characterize the lived experiences of illness of people with osteosarcoma; To characterize the lived experiences of resuming vocational pursuits in the context of osteosarcoma; To understand and explain the relationship between these experiences.	Cancer Site: Bone	In-depth Interviews Topic Areas: Vocational experiences and plans pre-diagnosis and post-treatment; Daily routines 'then' and 'now' Arriving at diagnosis Illness experiences	Respondents recounted being engaged in three kinds of work: illness work, identity work, and vocational work. All three types of work were intricately interwoven with illness work occurring during active cancer treatments, which was described as a transformative experience. Participants felt changed from who they were prior to cancer and when they returned to their respective vocations, they reported a changed relationship to work. Transformation of identity repositioned

					survivors differently socially, psychologically and physically.
Parsons 2012 Level III - A	National Cancer Institute’s Adolescent and Young Adult Health Outcomes and Patient Experience Study (AYA HOPE). *N* = 463 Age at diagnosis (years): 15-19: 16 (31%) 20-24: 17 (25%) 25-29: 28 (29%) 30-34: 24 (27%) 35-39 21 (26%) Within 3 years of diagnosis	Observational Cohort Purpose: To examine the impact of cancer on work and education in a sample of adolescent and young adult patients with cancer.	Cancer Sites: Germ cell Non-Hodgkin’s lymphoma Hodgkin’s lymphoma Acute lymphocytic leukemia Sarcoma	Survey: What is your current school or employment status? Indicate what kind of impact your cancer has had on….plans for education…. for work.	Greater than 50% of survivors working or in school full-time before diagnosis reported a problem with work/school at 6-14 months and at 15-35 months after diagnosis. In the follow-up survey, 30% of survivors working full-time before diagnosis reported problems with “paying attention” at work/school. Further, 15-35 months after diagnosis, 53% (N=205) of all patients reported problems with “forgetting”, while 28% (n=107) reported troubles “keeping up with work or studies.”

Rabin 2013 Level III - B	Hospital-based tumor registry in Rhode Island *N* = 20 young adult cancer survivors between 18-39 years of age. Mean age 33.5 years. Diagnosed within 10 years.	Qualitative Objective: To develop an in-depth understanding of the preferred content and format of psychosocial and behavioral programs for those diagnosed with cancer during young adulthood.	Cancer Sites: Breast (10%) Melanoma (10%) Thyroid (45%) 85% employed.	In-depth, semi-structured individual interviews Topic Areas: Types of programs that might be helpful Delivery of programs Barriers to participation	>50% of participants advocated for using an online forum, chat room, or social networking site to receive support from other young survivors and behavioral counselors.
Roz-movits 2014 Level III - B	United Kingdom *N* = 20 men and 19 women 28-68 years at diagnosis 33-87 years at the time of interview 5-9 years after diagnosis *[For this review, results from the young adult cancer survivor participants, aged 15-39 at the time of diagnosis, were*	Qualitative Aim: To consider aspects of the distress expressed by colorectal cancer patients in their personal narratives of illness and to produce a more detailed account of the illness's impact on their identities and self-understanding.	Cancer Site: Colorectal	Sample was referred for In-depth narrative interviews by Database of Individual Patient's Experiences (DIPEx), an Internet resources based on illness narrative interviews	Major theme: Loss of adulthood Sub-themes: Loss of professional identity; loss of ability to socialize; loss of dignity, privacy, and independence. Management of bowel symptoms interferes with job performance and social expectations about professional behavior.

	exclusively used.]				
Rutskji 2010 Level II - A	Cancer Registry of Norway: Testicular Cancer Survivor (TCS) Controls: Gallup Institute of Norway *N* = 1326 Mean age at survey of TCSs was 44.7 years (range 23-75 years) Mean age at orchidectomy 33.3 years (range 15-64 years) 11.4 years mean time after diagnosis (range 4.3-21.4 years)	Cross-Sectional Objective: To explore approach and avoidance coping strategies in long-term testicular cancer survivors.	Cancer Site: Testes Work status = Paid work & self-employed Vs. unemployed or pensioned	Research Questions: What is the pattern of approach-avoidant coping in testicular cancer survivors, and what are the differences in somatic and mental morbidity between testicular cancer survivors with more avoidance vs. more approach coping? What variables are significantly associated with approach/avoidance coping? Do testicular cancer survivors use more approach coping than a normative sample of men from the general population?	Approach & avoidance are 2 major coping strategies. Approach coping implies facing the stressor and making active efforts to manage it. In contrast, avoidance coping is characterized by passive, suppressive, and disengaged attitudes toward the stress. Paid work, self-employed testicular cancer survivors used more approach coping styles *N*=966 (88)
Wett-ergren 2003	Stockholm County Council's database	Cross-sectional Descriptive Comparative	Cancer Site: Hodgkin's Lymphoma	Extended version of the Schedule for the Evaluation	The most important areas in life, nominated by

Level III - B	*N* = 121 Hodgkin's Lymphoma Survivors Mean age at diagnosis 33 years Mean age at time of study 47 (11.9). Median time from Hodgkin's Lymphoma diagnosis to interview was 14 years (range 6-26 years) .	Aim: To use an individual approach in evaluating quality of life in long-term survivors of Hodgkin's Lymphoma and their view of what impact the disease has had on life.		of the Individual Quality of Life – Direct Weighting (SEIQoL-DW)	more than 50% of the Hodgkin's Lymphoma survivors as well as the control group, were family, personal health, work and relations to other people.
Yabroff 2012 Level I - A	US National Survey *N*= 884 Age category 18-44 (23.7%) Most cancer survivors were diagnosed 6 or more years prior to the survey (52.7% for 18-64 years; 59.7% for 65+ years)	Cross-sectional Aim: To evaluate the association between cancer survivorship and service use frequencies and patient time costs.	Cancer Sites: Not specifically given; included all.	The Medical Expenditure Panel Survey with Cancer Survivorship Supplement	Cancer care was typically more aggressive in younger than older cancer patients, potentially resulting in greater medical cost, productivity loss, late and long-term effects. Working young adults experience different types of late effects than survivors diagnosed with

					cancer at older ages.
Yanez 2013 Level III - B	Tuluna, an online Research Panel *N*=335 Mean age = 31.8 Stratified by cohort/time post-active treatment (months): 0-12 (118) 13-24 (98) 25-60 (106) Within 5 years of diagnosis	Cross-sectional Purpose: To explore whether age and cancer-related education/ work interruption interacted with distress.	Cancer Sites: Breast Cervical Melanoma Lung Colorectal Thyroid Testicular	Impact of Event Scale (IES) Patient-Reported Outcomes Measurement Information System (PROMIS) CR work interruption was assessed by a single author-constructed item: 'did you stop working because of your cancer?' Yes/no	67.1% of the sample did not stop working because of cancer. Highest level of distress -13-24 months Attend to cancer-related distress beyond the completion of treatment; target interventions such as psycho-social services.

[a]Dearholt SL & Dang D. Johns Hopkins Nursing Evidence-Based Practice: Models and Guidelines. 2nd Ed. 2012.

Figure 2: Relationships Among Themes

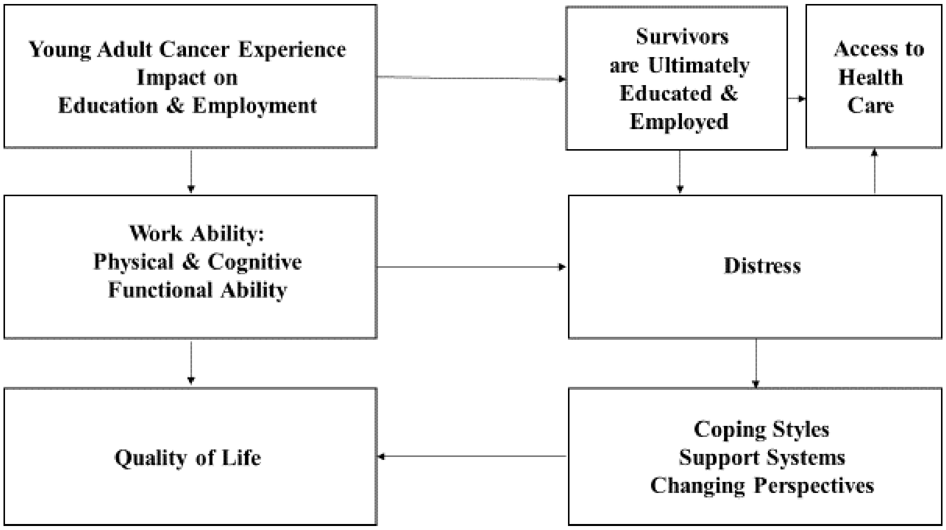

Table 2: Interventions and Improvements for Clinicians and Occupational Settings from Reviewed Publications

Clinicians	Occupational Settings
Discuss plans for returning to work	Discuss plans for returning to work
Discuss alternate careers and employment opportunities if needed	Tailor work to accommodate individual needs
Refer for mental health counseling if needed	Provide Professional Employee Assistance services
Refer to secure online support forums, chat rooms, or social networking	Notify survivors of services available in the workplace

Understanding the Workplace Interactions of Young Adult Cancer Survivors with Occupational and Environmental Health Professionals

[This manuscript (#2) is intended for submission to *Workplace Health and Safety*, the official journal of the American Association of Occupational Health Nurses].

Dawn S. Stone, Carol L. Pavlish, Patricia A. Ganz, Elizabeth Anne Thomas, Jacqueline Casillas, and Wendie A. Robbins

Abstract

Work provides personal satisfaction, meaningfulness, and financial stability to young adult cancer survivors. However, progressive health changes as a consequence of cancer and its treatments, may result in compromised safety and diminished ability to work. The purpose of this study was to explain how young adult cancer survivors, five years or more after treatment, interacted with occupational and environmental health professionals (OEHPs) within the context of the workplace. Data were collected and analyzed using constructivist grounded theory. Four processes were identified: Revealing the survivor-self, sustaining work ability, gatekeeping, and accessing support. Availability of services provided by OEHPs appeared to facilitate survivors' work ability over time if services were available, known to survivors, and survivors were willing to reveal needs. Education about occupational and environmental health services would ultimately improve interactivity and provide a supportive work environment for cancer survivors.

Understanding the Workplace Interactions of Young Adult Cancer Survivors with Occupational and Environmental Health Professionals

Background

Approximately 70,000 young people (ages 15-39) are diagnosed with cancer annually accounting for approximately five percent of cancers diagnosed in the United States (U.S.) (National Cancer Institute [NCI], 2015). Many young people are surviving, living long past the active treatment phase (Bleyer, 2011; Houghton, 2017) and are officially considered cancer survivors, a time frame initiated at diagnosis through the balance of life (NCI, 2014). Adolescent and young adult (AYA) cancer survivors have a range of five-year survival rates dependent upon specific cancer type (American Cancer Society [ACA], 2018). AYA cancer survivors may experience long-term physical and psychological effects from cancer or its treatments during long-term survivorship. The concept of cancer survivorship includes everything in life that changes because of the diagnosis and its aftermath (CISN, 2017), including ability to work.

An individual possesses full work ability if they are occupationally competent within their vocation, while meeting physical, mental, and social health requirements within an acceptable organizational environment (Tengland, 2013). Survivors often resume full-time employment, but this does not always equate to return to full work ability (Tevaarwerk, 2013). Adjusting to the usual routine of work, fitting-in with colleagues, and coping with sequelae related to disease-specific and treatment-related factors are potentially problematic (Katz, 2015; Williams, 2013). AYA cancer survivors may experience long-term continuation of health problems several years after diagnosis and treatment. These could include chronic fatigue, endocrinopathies, cardiovascular and/or respiratory issues, neuropathy (Yi & Syrjala, 2017) and secondary cancers. Treatment and disease-related cognitive impairment can be debilitating and disrupt work ability which poses financial hardships for AYA cancer survivors and their families (Parsons, 2012; Von Ah, 2016). According to the 2008-2011 Medical Expenditure Panel Surveys, working AYA cancer survivors (n=1,464) were shown (20.8%) to experience a loss in productivity as measured by missed work days due to illness, injury, or mental or emotional problems in comparison to research participants who do not have a history of cancer (*n*=86,865) (Guy, Yabroff & Ekwueme, 2014). However, the successful transition back-to-work and maintenance of employment is important for survivors because paid employment provides income, access to health insurance, self-identity, self-esteem, representation of talents and abilities, and is a basis for forming and maintaining social relationships (Moskowitz, 2014; Wells, 2012).

Large numbers of young people are contending with ongoing morbidity while attempting to rebuild lives after a cancer diagnosis (Spathis, et al, 2015). Many studies focus on return-to-work as an outcome, which does not address specific job-related performance challenges during the process of work entry or re-entry for AYA cancer survivors. Additionally, AYA cancer survivors receive little work-related advice from clinicians and variable support from employers (Wells, 2012). Problems in the workplace including discrimination, being passed-over for promotions, and an unwillingness by employers to provide reasonable accommodations were significantly related to both perceived work ability and sustaining work in AYA cancer survivors (Moskowitz, 2014).

The work life of young adult cancer survivors over the course of a career is multi-dimensional and not well understood. The perspectives of under-researched groups (Wells, 2013), such as AYA cancer survivors, provide important considerations for understanding research phenomena such as work-life potential. Hence, the following research questions were investigated using qualitative research methods to identify concepts and create theory explaining interactions between AYA cancer survivors and OEHPs in the workplace:

- What are the interactions between AYA cancer survivors and OEHPs?
- How do interactions between AYA cancer survivors and OEHPs influence survivors' ability to work over time?
- What contextual factors affect interaction and processes between AYA cancer survivors and OEHPs in the workplace?

The overarching goal of this study was to construct a theoretical framework grounded in data from participants that illustrates processes of interaction between AYA cancer survivors and OEHPs within the context of the workplace.

Methods

Research Design

A qualitative study using constructivist grounded theory methodology explored, in depth, the experiences of AYA cancer survivors in the workplace. Grounded theory was originally developed by sociologists, Glaser and Strauss to offer an empirical approach to study social life through qualitative research (Clarke, 2017). Grounded theory methods consist of systematic guidelines for collecting and analyzing qualitative data to construct theories from the data themselves (Charmaz, 2014). Pragmatism-informed symbolic interactionism, a theoretical perspective that assumes society, reality, and self are constructed through interaction, provided a foundation for this qualitative study. Participants who view the world from multiple perspectives interpret meaning in their experiences which is revealed through symbols such as overt behaviors and expressive descriptions of their lived experience. Through these symbols, participants share what they consider important and how they understand information. (Schwandt, 2015).

Grounded Theory methods provide thick descriptions of relevant interactions with a precise accounting of the meaning attributed directly to the experiences of the participants. The assumption that employment situations involve multiple important interactions among AYA cancer survivors and OEHPs influenced by a range of complex work factors underlie this research study. The Conceptual Framework for Occupational Health Programs and Services (Rogers, 2003) supported the assumption by relating physical, psychological, emotional, and social aspects of individual wellbeing within a system where OEHPs aim to improve, protect, maintain, and restore health of the worker/workforce considering external and internal contextual factors. Improved quality of life is an output of the framework.

Recruitment and Eligibility

AYA cancer survivor participants were recruited from the Los Angeles County Cancer Surveillance Program (CSP). CSP is the population-based cancer registry for collecting, storing, and studying data on persons with cancer in Los Angeles County. The CSP is a member of the statewide population-based cancer surveillance system, the California Cancer Registry (CCR) also part of the National Cancer Institute-funded Surveillance, Epidemiology, and End Results (SEER) program. California Health and Safety Code, Section 103885, mandates physicians, hospitals, and other facilities that diagnose and treat cancer patients to report every cancer diagnosed within the state to the California Department of Public Health, manager of the CCR (California Department of Public Health, n.d.). The CCR will only release information to qualified researchers under tightly controlled circumstances where the research has first been approved by the California Committee for the Protection of Human Subjects (12-06-0472). The CSP were queried for an AYA cancer survivor sample diagnosed between 2002-2007.This study was also approved by the University of California, Los Angeles Office of the Human Research Protection Program (11-001999).

AYA cancer survivors were eligible for this study if they were diagnosed with cancer between the ages of 15-39, off-treatment for five years, and were employed during data collection. The AYA cancer survivors were required to speak and understand English well enough to converse with the principal investigator (PI) during semi-structured individual interviews. A total of 343 AYA cancer survivors met eligibility criteria among the Los Angeles County Cancer Surveillance Program. The program provided researchers with a random sample of potential participants. All AYA cancer survivors (N=343) were contacted by mail. Potential participants were sent a packet containing a letter of invitation describing the study, a copy of the interview guide and the PI’s contact information. Sixty letters were not delivered; fifteen AYA cancer survivors responded; 12 were interviewed. AYA cancer survivor sample characteristics are listed in Appendix A. The interested individuals who contacted the PI about the study were rescreened for eligibility including employment status. Purposive sampling (Charmaz, 2014) within the CSP data set was utilized to specifically select potential male participants within the AYA cancer survivor sample.

Twelve OEHPs were recruited from southern California chapters of national organizations for semi-structured interviews. AYA cancer survivor interviewees identified interactions with three OEHP groups and based on the frequency of interactions mentioned, the following were selected for recruitment: Nurses (6), human resources personnel (3) and safety professionals (3). Characteristics of the OEHP sample can be found in Appendix B. Theoretical sampling obtained further selective data to refine major categories (Charmaz, 2014). Nurses were oversampled since they were the most frequently identified profession by AYA cancer survivors as interacting with them within the workplace. Participation in this study was voluntary, thus women and minorities were included as eligible. The principal investigator (PI) obtained written consent from all participants prior to interviews; a copy of the signed consent was given to each participant.

Data Collection

A semi-structured interview guide featured open-ended questions and probes to elicit experiences of interactions between AYA cancer survivors and OEHPs within the workplace. The interview guides were developed from a review of the literature, with evaluation and feedback from content experts (Appendix C & D). Interviews were primarily conducted in the homes of AYA cancer survivors. Most interviews with OEHPs were conducted in person by the PI at each participant's preferred venue on a date/time convenient for them. OEHPs generally preferred to be interviewed in private offices or conference rooms at their workplace. Three professionals required telephone interviews due to security access issues in their respective workplaces, or business travel obligations.

Interviews with OEHPs averaged one hour if conducted in the workplace during lunch breaks. Interviews held in AYA participants' homes ranged from one and a half to two hours in length. All participants were invited to send electronic messages or call with additional comments following interviews. Two participants provided additional insights via e-mail following their interviews.

All interviews were digitally audio-recorded and transcribed verbatim by transcriptionists familiar with qualitative research methods. The PI scrutinized and cleaned all transcripts of identifiers immediately upon receipt from the transcriptionist. Transcripts were organized and stored using Atlas.ti8 (Muhr, 2018). Pseudonyms were assigned to each participant to preserve confidentiality following consent. Recordings of interviews were erased following transcription. In appreciation for participation, a $25.00 gift card was given to each participant.

Analysis

Data were collected and analyzed concurrently by the PI using procedures informed by constructivist grounded theory. A systematic, iterative, line-by-line coding procedure started with attaching labels to depict the meaning of data segments. Analytic techniques included: Initial, focused, axial and theoretical coding procedures as described by Charmaz (2014). Constant comparison between codes was conducted often, during each stage of analysis, and codes were frequently revisited utilizing an iterative process which generated code clusters or categories. Situational analysis and mapping provided additional perspective on the human and nonhuman contextual factors (Clarke, 2009) within the workplace. Trustworthiness of analysis was sought with generation of reflexive, analytical notes and detailed memos. Memo-writing expanded categories, specified their properties, defined relationships between categories, and identified gaps for further data collection using theoretical sampling (Charmaz). AYA cancer survivors and OEHPs codes compared perceptions of interactive experiences within each group. Peer debriefing with expert qualitative researchers, provided consensual validation of codes and analysis.

Findings

Sample Characteristics

Twelve AYA survivors meeting eligibility criteria were individually interviewed using a semi-structured interview guide. The average age of participants at diagnosis was 29 years. The mean age at time of interview was 43.9 years with the length of survivorship averaging 14.8 years. A third (4) of the AYA cancer survivors were diagnosed with breast cancer; another third

(4) had experienced leukemia or lymphoma, and the remaining third (4) had a history of melanoma, testicular, or thyroid cancer. Nine (75%) of the participants were female, and three (12%) were male. Five survivors were married (42%), four (33%) were single, two divorced (17%), and one was widowed. All participants were of Caucasian race with three of Hispanic ethnicity. Occupations of the AYA survivors represented a variety of industries: four (33%) worked in health care, three (25%) were small business owners, two (17%) were engaged in sales. The remaining three participants were employed in education, art, or the beauty industry.

Twelve OEHPs included representation from nursing (50%), 25% safety professionals, and 25% were from human resources. The range of industries is shown in Appendix B.

Twenty-four interviews were sufficient to achieve thematic and theoretical saturation. Saturation of content and theoretical insights occurred when fresh information no longer sparked new data, nor revealed new properties of the core categories (Charmaz, 2014). Six processes emerged, each describing interaction among AYA cancer survivors and OEHPs within the context of the workplace.

The Experiences of AYA Cancer Survivors

The Process of Revealing the Survivor-Self.

The process of revealing the cancer survivor-self is complex within the context of work environments resulting in a variety of contrasting experiences from AYA cancer survivors. One survivor participant found disclosure of a cancer history normalizing, reflecting that when information is shared with peers or colleagues in the workplace, it is news that is no longer shocking or stigmatizing, but relatable since cancer has become a common diagnosis. Two other AYA cancer survivors reported that revealing experiences about their personal cancer journeys could help others who may be going through similar circumstances themselves, co-workers, or with family/close friends. In contrast, one survivor thought she was sharing her medical history confidentially with a supervisor and was astonished to discover the supervisor informed co-workers and others in the workplace. Trust within the relationship was jeopardized by the sequential chain of communication and interactions. Another self-employed AYA survivor reported often telling her cancer story to customers and speculated she ultimately lost business because of her open disclosure which could influence how she interacted with OEHPs.

Half (6) of the AYA cancer survivors-maintained employment in the same workplace before cancer and after treatment. All participants in this situation stated their diagnoses and the seriousness of it were known to others from the beginning and throughout the course of treatment and recovery. All participants, male and female alike, felt “safe” and expressed sentiments about supervisors and colleagues like, “He always had my back.” Early revelations of personal health news often generated support about a known and respected member of the working team who was grappling with a life-changing experience. One AYA cancer survivor shared how often she had taken leaves of absence for various reasons and was always welcomed back to work.

Searching for a new job post-cancer treatment was a quandary for a few AYA cancer survivors. Explaining a gap in employment seemed daunting. For example, questions from Human Resource professionals surprised one survivor who was asked to explain reasons for job interruptions and changes. She said she typically downplayed the cancer part of her life, if it came up, and preferred not to talk about it.

A few AYA cancer survivors found paid employment post-treatment working for agencies or organizations that serve cancer survivors. These AYA cancer survivors reported the open and honest work environment was comfortable and supportive. However, becoming emotionally close to others who experienced cancer recurrence created fear and ultimately resulted in resignation from such emotionally immersive positions. As shown, AYA cancer survivors in this study might opt to reveal a cancer history or choose to keep personal health information private in the workplace. Most AYA cancer survivors reported being “careful” about what to reveal and to whom in the work environment, but also reflected after several years post-treatment, that they had learned how to discuss cancer experiences, without making people feel uncomfortable.

AYA cancer survivors’ perceptions of attitudes about cancer survivors in the workplace affected their process of disclosing diagnosis and accommodation needs. In several interviews, the AYA cancer survivors pondered if cancer is a common diagnosis, or if stigma still exists within the workplace. One survivor wondered if a history of cancer generated sympathy, or if it created fear in employers about potentially high insurance expenditures for someone with a serious pre-existing disease. Another cancer survivor shared it is best to avoid including cancer experiences in a cover letter since it may eliminate an opportunity to be interviewed, or to prove fitness for duty and general overall good health. Some survivors were unaware of the legal boundaries of interview questions in employment situations.

Some AYA cancer survivors experienced job insecurity following a cancer diagnosis and treatment, fearing closer scrutiny of work performance and potential for termination. To avoid revealing the survivor-self to others in administrative or superior positions within the workplace, AYA cancer survivors reported they self-accommodated by informally limiting activities, sometimes aided by trusted peers. Avoiding seeking formal assistance for accommodations, protected the identity of the AYA cancer-survivor self.

The Process of Sustaining Work Ability.

Some survivors experienced uncertainty about health during long-term survivorship that could have impact on work performance. One survivor reported persistent fatigue despite a lengthy interval since diagnosis and treatment. She mused that the fatigue could be related to aging, although she was in her early thirties at the time of interview. Despite the fatigue, she maintained a rigorous work schedule. Panic attacks several years following cancer treatments plagued one AYA cancer survivor, who resolved this issue with counseling and medications. During that time, he did not reveal his continuing fear for cancer recurrence and consequential panic-attacks to coworkers and subordinates; he simply kept working at building his business while maintaining treatment.

Following breast cancer surgery and reconstruction, a survivor utilized the lift team at the healthcare facility where she was employed since it was readily available to all staff. However, the job required occasional sweeping and cleaning which caused arm pain, so a colleague offered to complete these tasks for her. An AYA cancer survivor who worked at an elementary school avoided playground activity during peak sunlight; trusted peers unofficially accommodated her job responsibilities when outdoor activities were required. None of the AYA cancer survivors were given formal work limitations by their health care providers, resulting in AYA cancer survivors navigating the workplace to self-accommodate and sustain long-term ability to work.

Sustaining work ability was driven by determined AYA cancer survivors who had a strong desire to thrive in a workplace where revealing the survivor-self was not comfortable or when job or health insecurity existed. Since formal limitations were not given by health care providers, it is possible symptoms were accepted as a natural consequence of cancer or its treatments. AYA cancer survivors could also fear symptoms indicating potential cancer recurrence and denied their existence. Alternately, if OEHPs were present, sustaining work was enhanced by expertise and support services.

The Process of Accessing Support.

Most commonly, AYA cancer survivors sought support from trusted colleagues and superiors within their immediate work environment if their employment continued from before cancer well into long-term survivorship. Social support was more difficult to obtain in new employment situations post-treatment. Work environments that center on services for cancer survivors provided essential support, such as individual and group counseling, in alignment with the mission of their business.

A few AYA cancer survivors proactively recognized their need for occupational interventions in the workplace without formal recommendations from health care professionals and independently accessed support. One young woman sought advice from a safety professional specialized in ergonomics to adjust her workstation following surgery and treatment for cancer. The self-advocated accommodation allowed the AYA cancer survivor to work comfortably and without occurrence of lymphedema in her affected arm. Other AYA survivors needed support from trusted subordinates or family members to manage small business operations. Due to the autonomous nature of small business ownership, these survivors were also able to modify work schedules to enhance energy and efficiency in the presence of work demands.

One AYA cancer survivor desperately needed psychological help to grapple with the magnitude of her cancer experience, but such resources were not readily available to those who are contracted or self-employed. Eventually, she was referred to a counseling service by her health care provider. Similarly, services and resources of OEHPs were noted to be a luxury by an AYA survivor working for a small company. Requirements for OEHP services are related to industry type and company size according to the Occupational Safety and Health Administration (OSHA). Hence, small businesses and entrepreneurial pursuits required AYA cancer survivors to self-accommodate and advocate for self in the workplace. There were also some instances when the AYA cancer survivors were unaware of occupational and environmental health services even in workplaces where they existed.

The Experiences of OEHPs

The Process of Sustaining Survivors' Work Ability.

When AYAs disclosed their cancer survivor-selves to OEHPs, psychological and physical comfort, as well as safety, were the overarching goals identified by Nursing, Human Resources and Safety Professionals. Creating safe, private places for conversation about needs and for assessment was essential to ensure confidential implementation of engineering and/or organizational changes. Occupational and environmental health nurses perceived themselves as trustworthy and expressed that private health information was commonly shared with them. One nurse reported a company requirement for employees to disclose illnesses and injuries due to potential risk for injury post-job offer, or with return-to-work from a medical leave of absence. Nurses also heard about workers' cancer diagnoses from others within the workplace. A network of supervisors or co-workers reported cancer news to the company nurse to be helpful in case of emergent health events, or perhaps because they feared cancer cluster situations from exposures within the workplace. AYA cancer survivor employees who had a reliable and good work history were often returned to work without question.

Safety professionals shared innovative strategies to accommodate AYA cancer survivors in the workplace when AYA cancer survivors' needs were revealed or known. Adaptive equipment for shoulder problems and voice recognition with prolonged computer use were examples given of customized accommodations for survivors' specific needs. Administrative controls were implemented to accommodate issues with fatigue. A flexible work schedule, closer parking or access to building entryways, and working from home to reduce commute time were found to be helpful to AYA cancer survivors. Inter-disciplinary collaboration with other OEHPs facilitated referrals for specialized accommodations in large companies.

The Process of Gatekeeping.

The nurse is typically the OEHP to greet AYA cancer survivors when they return-to-work or are offered employment for the first time within a company. It is the nurse, together with the occupational health team who determine risk associated with job responsibilities and what health conditions are contraindicated to protect health and prevent disease in workers. A nurse revealed if workers are actively receiving treatment for cancer, they are not placed in jobs that expose them to certain chemicals. However, upon return-to-work, cancer survivors typically resume former work responsibilities, even if that means returning to the same exposures. One nurse reported that excellent health was a job requirement for all workers in her industry since positions required a high level of physical rigor. If a medical condition was diagnosed, risk for unemployment was a real possibility. Worker characteristics were also found to influence gatekeeping work processes.

Unfortunately, the process of gatekeeping can also mean closing the gate to employment if AYA cancer survivors were unable to perform essential job functions and accommodation efforts were ineffective or not feasible. One nurse reported that if an employee is unable to return to their previous position, the survivors wondered and worried about their future career prospects considering financial resources and health insurance. Listening, coaching, providing support with exploration of new realities was often a service provided by OEHPs in the workplace during these difficult situations.

The Process of Accessing Support for Survivors.

Nurses most commonly served as sources of information and evaluated usefulness of services available in the workplace or community at large. Employee Assistance Professionals (EAPs) were recognized as being extremely valuable when change of employment status occurred. Interprofessional collaboration was acknowledged by OEHPs to benefit AYA cancer survivors during work transitions.

Some AYA cancer survivors relied on the nurses' expertise to detect changes in health because of exposures while working. One nurse reported routinely evaluating outdoor workers for skin cancer. The same nurse transferred to another department within the company and reflected on how she still heard from former patients; which seems to indicate that positive relationships and trust had developed. All nursing professionals in occupational and environmental health services reported long-term, trusting relationships with workers when interactions were frequent, meaningful, and genuinely caring. Participants' quotations are listed in Appendix E.

Discussion

The focus of this study was to identify and describe interactions of long-term AYA cancer survivors with OEHPs in the workplace. The grounded theory techniques used in this research described complex processes of interaction and a variety of contextual influences within the workplace and facilitated understanding of employment issues grounded by the experiences of AYA cancer survivors and OEHP participants. The primary finding in this study demonstrates that AYA cancer survivors and OEHPs are reaching toward similar goals including support and sustainability of survivors' work ability. The results show that both survivors and OEHPs must navigate challenges to reach these goals. AYA survivors need to weight the risks of revealing their cancer history, while the OEHPs in rather precarious positions between employer and AYA cancer survivors, struggle with advocacy issues. An explanatory framework illustrating the interactive processes found in this study is in Appendix F.

Several major themes add previously undescribed findings within the AYA cancer survivor literature. The interactions between AYA cancer survivors and OEHPs were strongly dependent on AYA cancer survivors' willingness to reveal their survivor-selves within the work environment. The 2010 Equality Act protects all job applicants, regardless of age, against discrimination by disallowing questions about a candidate's health before offering employment. However, once an AYA cancer survivor accepts a position, they may choose to reveal their cancer history to others within the workplace, or not. Anticipating questions and reactions from human resources or department interviewers created fear and mental barriers to potential discovery and prevented early access to OEHPs if available in the setting. Part of the reluctance to reveal the survivor-self may be due to the disruption by cancer during a time when young adults are meeting developmental milestones related to dependence-independence and goal achievement (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). Some AYA cancer survivors could be striving to catch-up with these important markers during times of entry into the workplace.

The "gatekeepers" to returning to work were OEHPs who engaged in a clearance process to allow AYA cancer survivors to resume employment following an extended absence. In return-to-work situations, revelations of the survivor-self were driven by a desire to re-enter the workplace. Work productivity has been reported to be a predictor for successful return-to-work regardless of diagnosis (Cancelliere, 2016) and seemed to influence who could return-to-work. Sustaining work ability in the long-term involved complex processes of accommodation with or without OEHPs. Some AYA cancer survivors chose to self-accommodate workplace needs through their own strategies or accessed supportive others in their immediate work environment. In some situations, AYA cancer survivors had no choice but to create their own safe and healthy workplace, since OEHPs were not present in small businesses. When OEHPs were invited into the process of accommodation, their expertise generated work environment controls that were customized to AYA cancer survivors' specific needs.

Contextual factors that affected interaction and processes between AYA cancer survivors and OEHPs in the workplace included the size of the company, and the type of industry. Federal mandates for the presence of OEHPs currently relate to number of employees exposed to hazardous situations. Laws also protect AYA cancer survivors in situations that create bias or discrimination by controlling questions that can be asked by employers prior to job offers. These legal parameters are not age exclusive but apply to all applicants seeking employment. The knowledge of health care providers about AYA cancer survivor's essential job functions and establishment of temporary or permanent restrictions/limitations were also found to influence interactions between AYA cancer survivors during the process of accommodation. Knowledge too was found to be important to AYA cancer survivors, who were often unaware of OEHP services and expertise within the workplace when available. An explanatory framework illustrating the employment and workplace interactions is in Appendix F.

The strengths of this study include a unique perspective involving interactions between long-term AYA cancer survivors who are gainfully employed, and OEHPs. The random sample of AYA cancer survivors encompassed Los Angeles County was important because it allowed for sampling of a diverse group of survivors. Additionally, utilization of a tumor board for the methodology provided ease of recruitment since AYA cancer survivors commonly relocate at this age. Young adults diagnosed with cancers have received relatively little research attention compared with children and older adults diagnosed with cancer (NCI, 2015). Federal agencies do not recognize 15-39-year-old individuals as a unique population meaning funding, research, and outreach is divided between pediatric and adult oncology specialties resulting in a substantive gap in care and research (Houghton, 2017). Additionally, young adult cancer survivors are not part of the Cancer Moonshot, a federal U.S. program aiming to accelerate cancer research (NCI, 2017). Additionally, AYA Cancer Survivors are part of *Workers with Higher Health Risk*s from a Total Worker Health Perspective (Schill & Chosewood, 2013) supporting the aim of the present research study to assist AYA cancer survivors within the workplace while maintaining their professional and personal autonomy.

AYA cancer survivors clearly strived to be successful and productive in society. OEHPs, if available and known, were shown to be supportive to AYA cancer survivors individually and as a team. However, small business situations and self-employment did not provide such services. Scrutiny of assessment findings and interaction with other health care professionals, when suspicions arose, created a reputation of accurate knowledge and safety when confidential revelations are shared by workers. Sustaining work and maintaining employment improved participants' overall quality of life. This study also highlighted selected OEHP groups as identified by AYA Cancer Survivor participants based upon interactions within varied workplaces. New knowledge of workplace and employment processes has been generated as a result.

A limitation of this qualitative investigation included a lower number of male participants in comparison to female AYA cancer survivor respondents. Additionally, recruitment efforts were influenced by currency of contact information in the CSP data set. Also, due to the nature of semi-structured, in-person interviews, geographic span of sampling was largely limited to southern California.

Applying Research to Occupational and Environmental Health Nursing Practice

Understanding interactions between AYA Cancer Survivors and OEHPs within the context of the workplace has been shown to promote awareness among OEHPs concerning challenges that confront AYA cancer survivors during work processes. Managers, supervisors, and department personnel require education concerning the importance of confidentiality when personal health information is shared. Communication techniques also need to be taught to promote work environments that are supportive and caring of AYA cancer survivors. Because health changes occurred during long-term cancer survivorship, routine safety assessments along with discussion about accommodation strategies could promote work sustainability. AYA cancer survivors also need education about OEHP services. Employers could provide a directory at hire and return-to-work.

Lack of OEHP support in small businesses or industries that do not mandate these roles affected AYA cancer survivors’ ability to obtain supportive interaction and formal improvement of work processes to accommodate needs. Routine and periodic assessments and interventions aimed at decreasing symptoms associated with consequences of cancer need development to promote adaptation to the workplace. Ultimately, workplace strategies aimed to continue work ability among AYA cancer survivors will reduce the state and national fiscal burden of utilizing public funding to support those that are unable to work. The National Cancer Institute can ultimately use this explanatory framework or theory to develop evidence-based guidelines for occupational health and oncology nursing practice.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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Appendix A
Sample Characteristics: Young Adult Cancer Survivors (n=12)

Age at Diagnosis	Age at Interview	Years of Survivorship	Cancer Type	Occupation
18-29	28-59	8 - 35	Melanoma	Speech Pathologist
			Lymphoma	Registered Nurse
			Thyroid	Business Owner
			Leukemia	Business Owner
			Lymphoma	Marketing Director
			Testicular	Art Designer
30-39	44-57	7-25	Leukemia	Cosmetologist
			Breast	Nursing Assistant
			Breast	School Counselor
			Breast	Salesperson
			Testicular	Business Owner
			Breast	Veterinary Technician

Appendix B
Sample Characteristics: Occupational and Environmental Health Professionals (n=12)

Profession	Industry
Nursing	Oil and Gas Extraction
Nursing	Pharmaceutical Manufacturing
Nursing	Air Transportation & Warehousing
Nursing	Ambulatory Health Care Services
Nursing	Business Services
Nursing	Public Administration
Safety	Manufacturing
Safety	Professional, Scientific & Technical Services
Safety	Hospital Health Care
Human Resources	Aerospace
Human Resources	Educational Services
Human Resources	Food Services

Appendix C
Interview Guide for Young Adult Cancer Survivors

Please tell me about your experiences at work following your cancer treatments….

Probe: Did you inform potential employers about your cancer history?
Probe: Needs for accommodation?
Probe: Health changes over time? Work changes over time?

Please tell me about your experiences interacting with OEH professionals….

Probe: Did you meet with an occupational health nurse?
Probe: Did you meet with safety or industrial hygiene professionals?
Probe: Did anyone else help you to ease back into work?

Please tell me about your experiences at work…..

Probe: Support systems…
Probe: Safety issues….
Probe: Accommodation accomplished….

What would make the transition to work easier for cancer survivors?

Probe: In preparation for job search
Probe: During the hiring process
Probe: Once you are on the job

What is life like for you when you are working?

Probe: Health and life insurance
Probe: Fatigue?

What would be helpful to you in the workplace?

Is there anything else that you would like to tell me about your experiences at work?

Appendix D
Interview Guide for Occupational and Environmental Health Professionals

Please tell me how you meet/encounter employees or potential employees in the work environment…

Probe: Do you meet people who are newly hired or for pre-placement PEs?
Probe: Injuries or illnesses?
Probe: Surveillance monitoring?
Probe: Clearance after a medical leave?

Is it possible to identify workers who have had cancer?

Probe: How is this information disclosed?
Probe: Why do you suspect it isn't disclosed?

Have you had any special education or training about cancer survivors in the workplace?

Probe: What did you learn?
Probe: How has this education changed your work?
Probe: Has your approach to survivors changed?
Probe: Do you think you need more education about cancer survivors?

What do you think about late adolescent and young adult survivors of cancer being in the workplace?

Please tell me about the social support systems that exist in your workplace for workers who have a history of cancer?

Is there anything else that influences your work with cancer survivors?

Probe: Safety issues?
Probe: Need for accommodation?
Probe: Policies and/or regulations?

What would be helpful to you in the workplace?

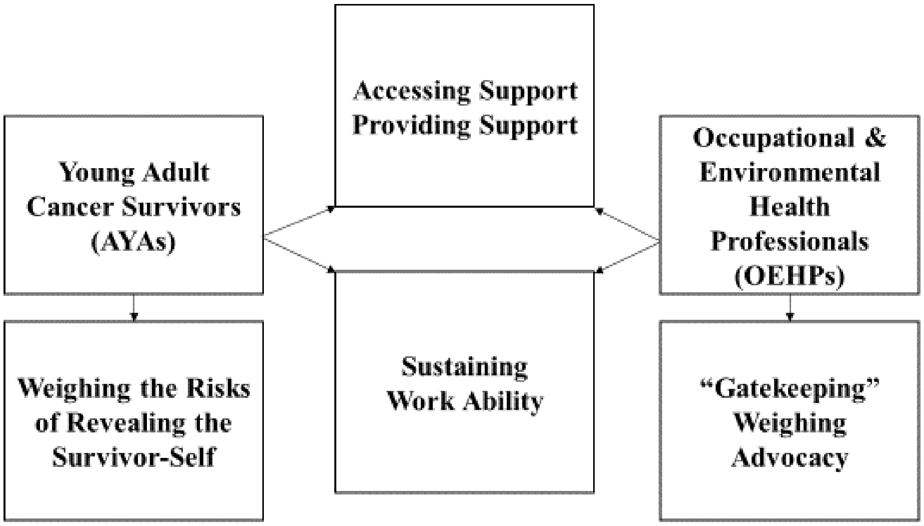
Please tell about an experience you have had with cancer survivors here at work…..

Appendix E
Participant Quotations

Processes	AYAs	OEHPs
Revealing and Listening to the Survivor-Self	I don't talk about it all that much, I guess. If it comes up, I'll talk about it, but I downplay it a lot because other people do. It came up in why are you switching jobs kind of thing. Why did you end at your last job? I just felt weird telling people. I don't want people to feel bad for me or feel sorry for me or feel different around me. I have a really noticeably scar that kind of runs the length of my chest down It's not something I've ever wanted to use to my advantage, even if it is part of who I am and part of my story now. I don't want to use it as a way to get ahead. It wasn't a good experience.	But I've never really had anyone not want to talk about it. I'm sensitive enough to let it come from them or to let them give as much as they want to or as little as they want to as long as I have enough information so that I can really help them. That's the point that I'm trying to get across. "I need to know enough to make sure that I'm not going to do anything to hurt you." …it might be awkward for someone to talk about it or express any feelings about it… They have to disclose to us medical illnesses, injuries, and illnesses for the nature of the jobs that they do. And many of them do open up to us and tell us what's going on - most people aren't ashamed of it.
Sustaining Work Ability	I was back working, you know, full-time, maybe 3 or 4, 5 days later. I got really sick the first treatment and then after that they just figured out what medication regimen worked for me and never got sick again. I worked through the whole time	I had some conversations with the employee and his boss - and the employee said, "No. This is what I want to do. I want to work from home. I want to come in. This is what's really best for me." His boss was like, "Whatever you want to do, I'll accommodate." He said, "If you want to take time off, take time off. Work will always be here. Don't worry about it. We'll get it done, somehow, so don't worry about it."
Gatekeeping: Weighing Advocacy	…they gave me my job back after cancer and everything. Well, there's a competitive factor too, because you know the employer is looking at you and saying, 'Okay, is this	I think a lot of times it does boil down to the philosophy of the company and if the employee was a good worker prior to the onset of disease.

	person really going to be able to handle this for the long term? And how much longer?' And you don't even know.	
Accessing and Providing Support	my arm hurts so I don't have to do it I do need to take care of my arm. I cannot carry my purse for a long time. I cannot lift with it either. We had business that was rolling along, people would ask what I went through, and people understood. Got a lot of support, so yeah. Just kept on going. What sticks out in my mind to me about this experience is that I shiver to think what it is like for people to go through that without support. Family, friends, coworkers, whatever it is, its' that love and support system.	You know, so we deal with the fears of the diagnosis, the uncertainty about the workplace. So, our role is to give them support. Of course, someone like that we'll make sure - we might even extend them to - but our role is to identify and provide resources. Even if they have a good relationship with their manager, sometimes it's just easier to talk to another person. I think that is where we really help them out

Appendix F
Interactions during Employment & Workplace Processes between AYA Cancer Survivors & OEHPs



Employment Challenges for Young Adult Cancer Survivors

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Dawn S. Stone, PhD(c), RN, ANP-BC, COHN-S[a], Carol, L. Pavlish, PhD, RN, FAAN[a], Elizabeth Anne Thomas, PhD, RN[a], COHN-S, FAAOHN, Patricia A. Ganz, MD[b], Jacqueline Casillas, MD[b], Wendie A. Robbins, PhD, RN, FAAN, FAAOHN[c]

[a] School of Nursing, University of California, Los Angeles
[b] David Geffen School of Medicine, University of California, Los Angeles
[c] Fielding School of Public Health, University of California, Los Angeles

Abstract

Background: Challenges to interactions and processes in the workplace for young adult cancer survivors exist in the presence of protective federal and state legislation.

Purpose: This study explored interactions, and factors influencing interactions, between young adult cancer survivors and occupational and environmental health professionals.

Method: Constructivist grounded theory methods guided the study. Twelve young adult (AYA) cancer survivors and twelve occupational and environmental health professionals (OEHP) were interviewed. Qualitative analysis developed an explanatory framework based on their narratives.

Results: The model was titled "Challenging Employment Situations for AYA Cancer Survivors." The concept of disclosure was central to the model. AYA processes of powering through, evading the cancer card, and working around limitations interacted with OEHP processes of discovering AYA cancer survivors, navigating systems to provide support, and identifying changes needed.

Conclusions: This research illuminated the unique experiences of AYA cancer survivors and OEHPs who confront challenges in accessing and providing support in the workplace.

Employment challenges for young adult cancer survivors

The AYA population has unique challenges due to their changing life roles including establishing and maintaining independence, developing identity, and setting education and employment goals (Liu et al., 2017). Having cancer at a young age means more decades of living as a cancer survivor, offering a unique set of challenges (Johnson, 2018). Several research studies describe physical, psychosocial and cognitive changes because of cancer or its treatment during late adolescence and early adulthood (Duijts et al., 2013; Parsons et al., 2012); however, the systems within and influencing the workplace also present challenges for AYA cancer survivors including confidentiality, discrimination, and negative beliefs about how cancer affects work performance (Grunfeld, Low, & Cooper, 2010).

In response, the United States (U.S.) federal government initiated several important steps to protect Americans with medical conditions who are attempting to enter the work arena or maintain employment by enacting legislation. For example, the U.S. Equal Employment Opportunity Commission (EEOC, n.d.) enforces the employment provisions of the Americans with Disabilities Act (ADA). The ADA describes in detail when an employer may ask an applicant or employee questions about a cancer diagnosis and how to respond to voluntary disclosures. The ADA also identifies reasonable accommodations employees with cancer may need and how an employer should manage safety concerns for applicants and employees with cancer. However, negotiating the employment and human resource policies of the workplace have been shown to be a challenge for AYA cancer survivors since organizations may lack personnel to manage these aspects (Wells et al., 2012). Emerging research by these researchers suggests different needs exist for AYA cancer survivors, but the ADA does not impose mandates by age categories

Strategies about how an employer can prevent harassment towards cancer survivors is also discussed by the ADA. Additionally, every state regulates disability-based employment discrimination, although they are variable. Some laws clearly prohibit cancer-based discrimination, while others have never been applied specifically to cancer-based discrimination. State laws may also identify the employers (public or private, large or small) that must obey the law (National Coalition for Cancer Survivorship [NCSS], 2018). Employees with cancer often confront discrimination because of misperceptions by others about their work ability following diagnosis and treatment. Some employers anticipate cancer survivors will require frequent and/or long leaves of absence or will be unable to focus on job responsibilities (EEOC, n.d.).

Employed cancer survivors are also protected under the Occupational Safety and Health (OSH) law, which mandates employer responsibility to provide a safe and healthy workplace (OSHAa, n.d.). Hazardous industries are required to provide occupational and environmental health professionals (OEHP) who monitor the work environment for unsafe conditions, provide programs to protect worker health that includes surveillance for health changes because of exposures. Companies without hazardous conditions are not mandated to provide the expertise of OEHPs. The self-employed are not covered under the OSH Act (OSHAb, 2018).

Returning to work and perceived work ability after the diagnosis and treatment of cancer have been identified as important to having meaning and purpose in life for cancer survivors (Husson & Zebrack, 2016). The ability to work also has financial implications and can affect quality of life (Fenn et al., 2014; Meneses, Azeuro, Hassey, McNees, & Pisu, 2012). Positive experiences working through or after cancer have been shown to be dependent upon the provision of good organizational and/or interpersonal support. Organizational support includes work-related support provided by OEHPs and employers' willingness and ability to adjust the workplace and job roles (Wells et al., 2012).

AYA cancer survivors are individuals with chronic health conditions who may be negatively impacted in career development and employment (Strauser, Jones, Chiu, Tansey & Chan, 2015). Survivors relied on guidance of their health care team for making decisions about returning to work, yet such advice was felt to be lacking (Wells et al, 2012). Further research is needed to determine variations in distribution, frequency and importance of employment issues for AYA cancer survivors with differing socio-demographic and clinical characteristics (Spathis et al, 2015). An Additional study has also been suggested to identify barriers to maintaining work, quality of work life, and career progression as important outcomes in young workers (Pransky et al, 2016). Therefore, the purpose of this research was to explore challenges within workplace interactions and processes while suggesting employment and work environment improvements grounded in narratives from AYA cancer survivors and OHPs.

Methods

A qualitative study using constructivist grounded theory methodology explored, in depth, the experiences of AYA cancer survivors and OEHPs in the workplace. Grounded theory methods consisted of systematic guidelines for collecting and analyzing qualitative data to construct theories from the data themselves (Charmaz, 2014). Grounded Theory methods provide thick descriptions of relevant interactions with a precise accounting of the meaning attributed directly to the experiences of the participants. The assumption that employment situations involve multiple important interactions among AYA cancer survivors and OEHPs as influenced by a range of complex work factors underlie this research study.

Sample

AYA cancer survivor participants were recruited from the Los Angeles County Cancer Surveillance Program (CSP). The CSP is a member of the statewide population-based cancer surveillance system, the California Cancer Registry (CCR) also part of the National Cancer Institute-funded Surveillance, Epidemiology, and End Results (SEER) program. California Health and Safety Code, Section 103885, mandates physicians, hospitals, and other facilities that diagnose and treat cancer patients to report every cancer diagnosed within the state to the California Department of Public Health, manager of the CCR (California Department of Public Health, n.d.). The CCR will only release information to qualified researchers under tightly controlled circumstances where the research has first been approved by the California Committee for the Protection of Human Subjects (12-06-0472). The CSP were queried for an AYA cancer survivor sample diagnosed between 2002-2007.This study was also approved by the University of California, Los Angeles Office of the Human Research Protection Program (11-001999).

AYA cancer survivors were eligible for this study if they were diagnosed with cancer between the ages of 15-39, off-treatment for five years, and were employed during data collection. The AYA cancer survivors were required to speak and understand English well enough to converse with the principal investigator (PI) during semi-structured individual interviews. A total of 343 AYA cancer survivors met eligibility criteria among the Los Angeles County Cancer Surveillance Program. The program provided researchers with a random sample of potential participants. All AYA cancer survivors (*N*=343) were contacted by mail. Potential participants were sent a packet containing a letter of invitation describing the study, a copy of the interview guide and the PI’s contact information. Sixty letters were not delivered; fifteen AYA cancer survivors responded; 12 were interviewed. AYA cancer survivor sample characteristics are listed in Appendix A. The interested individuals who contacted the PI about the study were rescreened for eligibility including employment status. Purposive sampling (Charmaz, 2014) was focused within the CSP data set to specifically select potential male participants within the AYA cancer survivor sample to explore interactive experiences from a different perspective.

Twelve OEHPs were recruited for semi-structured interviews. AYA cancer survivor interviewees identified interactions with three OEHP groups and based on the frequency of interactions mentioned, the following were selected for recruitment: Nurses (6), human resources personnel (3) and safety professionals (3). Characteristics of the OEHP sample can be found in Appendix B. Theoretical sampling obtained further selective data to refine major categories (Charmaz, 2014). Nurses were oversampled since they were the most frequently identified profession by AYA cancer survivors as interacting with them within the workplace. Participation in this study was voluntary, thus women and minorities were included as eligible. The principal investigator (PI) obtained written consent from all participants prior to interviews; a copy of the signed consent was given to each participant.

Interviews

A semi-structured interview guide featured open-ended questions to elicit experiences of AYA cancer survivors and OEHPs within the workplace. The interview guides were developed from a review of the literature, with evaluation from content experts (Appendix C & D). Interviews were conducted in person at each participant’s preferred venue on a date/time convenient for them. The interviews lasted between 60 and 120 minutes. All participants were invited to send electronic messages with additional comments. Interviews were digitally audio-recorded and transcribed. The PI removed identifiers on transcripts upon receipt from the transcriptionist. Transcripts were organized and stored using Atlas.ti8 (Muhr, 2018).

Pseudonyms preserved confidentiality. Recordings were erased following transcription. In appreciation for their time, a $25.00 gift card was given to each participant.

Data Analysis

Data were collected and analyzed simultaneously using procedures informed by constructivist grounded theory. Systematic, iterative, analytic techniques included: Initial, focused, axial and theoretical coding as described by Charmaz (2014). Constant comparison between codes was conducted at each stage of analysis, and codes were frequently revisited utilizing an iterative process to generate categories. Situational analysis and mapping provided additional perspectives by constructing workplace situations of inquiry empirically. Situational analysis supplements grounded theory with alternate approaches to gathering, analyzing, and interpreting data (Clarke, 2009). Trustworthiness of analysis was sought with generation of reflexive, analytical notes and detailed memos. Memo-writing expanded categories, defined relationships between categories, and identified gaps for further data collection using theoretical sampling (Charmaz). Peer debriefings with qualitative researchers provided consensual validation of codes and analysis.

Results

Twelve AYA survivors meeting eligibility criteria were individually interviewed using a semi-structured interview guide. The average age of participants at diagnosis was 29 years. The mean age at time of interview was 43.9 years with the length of survivorship averaging 14.8 years. Four of the AYA cancer survivors were diagnosed with breast cancer; another third (4) had experienced leukemia or lymphoma, and the remaining four had a history of melanoma, testicular, or thyroid cancer. Nine (75%) of the participants were female, and three (12%) were male. All participants were of Caucasian race with three of Hispanic ethnicity. Occupations of the AYA survivors represented a variety of industries: four (33%) worked in health care, three (25%) were small business owners, two (17%) were engaged in sales. The remaining three participants were employed in education, art, or the beauty industry.

Twelve OEHPs included representation from nursing (50%), 25% safety professionals, and 25% were from human resources. Occupational and Environmental Health Nurses (OEHNs) are over represented in this research since the OEHN is typically the most knowledgeable person about health, illness, and health promotion (Lukes, 2014). The OEHN is most commonly available in work settings to provide leadership, education, case management, and care coordination within an inter-disciplinary team.

Twenty-four interviews were sufficient to achieve thematic and theoretical saturation. Six challenges emerged, each encountered by AYA cancer survivors and/or OEHPs, during processes involving acquisition of employment, and sustaining work ability over time.

Challenges for AYA Cancer Survivors: Covering-Up and Going-it Alone

Powering Through Work During Treatment.

Some AYA cancer survivors were already gainfully employed when diagnosed with cancer and undergoing treatment. Challenges to maintaining work included recovery from surgery and treatments. However, expressions of determination to continue working productively prevailed in the narratives, “I bounced back pretty quick.” Conquering control of treatment symptoms were also important, “…after they figured out what medication regimen worked for me, I never got sick again. I worked through the whole time.” Another AYA cancer survivor shared her self-talk, “Keep going, don't stop.” A few recognized changes and potential limitations, “fatigue with exercise has been challenging coming out of the gate.” Powering through the cancer experience underpinned the determination to acquire a successful vocation or career, "…when you are growing up, you can do anything and then to have a real moment when someone says I can't tell you if you are going to make it on the other end of treatment. That was definitely the moment when I turned it into 'You bet your booty I am!'" Another AYA cancer survivor lamented, "There are just so many things that people can do and I think spiritually and emotionally having that mentality that you can fight." Not all AYA survivors were able to power through work with a clear direction, one AYA survivor expressed, "But right now I'm lost. I don't know what to do" referring to work.

Evading the Cancer Card.

AYA cancer survivors were challenged by the pros and cons of revealing a cancer history while seeking employment during treatment or survivorship. "I didn't want to explain why I had a gap in my resume because it would either make them feel sorry for me and then I'm sort of playing the cancer card, or it would scare them off for insurance issues." Another participant stated, "It was all just me, you know, spinning my wheels. And I felt very uncomfortable about having to go into the workplace and explain time that was missing." One survivor considered the future implications of sharing news with those in the same line of work, "I do not tell anyone, because I'm going to be looking for employment in that world, and I don't want them to think that I'm frail or weak or that I might get cancer again, even though that's probable for anybody." Open-ended questions posed by hiring officials were another challenge for AYA cancer survivors, "I remember a really tough interview. This guy was a jerk, 'so what makes you special?' On the tip of my tongue I wanted to say I'm a cancer survivor, but then I refrained."

Longer time frames post-cancer made sharing past-medical history easier for some but other AYAs remained cautious once employment was acquired and sustained:

> I did apply and interview for a few jobs. I honestly cannot tell you if I ever talked about cancer with any of them. I don’t even remember. At that point I was several years past treatment. Which means that I’ve learned how to talk about it without making people feel uncomfortable. So, I can mention it and be like, oh, no big deal, so that they don’t react in sort of the cancer card way.

However, various experiences interacting within the workplace provoked cautious reactions, “I'm really careful now. There are people that know, and then there are people that I withhold that from.” Another participant noted, “You just don’t know what kind of response you’re going to get back.”

AYA cancer survivors also recognized heart-felt rewards for revealing their medical history during employment interactions, “I knew people there that had known me for years and knew I had cancer, and so it felt safe there.” Disclosing also meant meaningful interactions with others within the workplace. “I have a level of compassion and empathy and understanding because I went through it myself. I've had patients contact me years after they were better and they just tell me, ‘Oh, I'm so glad I met you - you gave me so much hope when I was first diagnosed.’” Similarly, “I’m definitely concerned about them. When I was teaching…the kids would come in and I would spray them down with sunscreen.” Overall, the AYA cancer survivors desired to maintain an identity unrelated to their cancer history. The AYA cancer survivors interviewed did not want to play the cancer card:

> It’s not something I’ve ever wanted to use to my advantage, even if it is part of who I am and part of my story now. I don’t want to use it as a way to get ahead. It’s not something I see as a card in my pocket to use. It’s the kind of card you want to pack away.

Working Around Limitations.

To avoid disclosing a past medical history of cancer to superiors within the workplace, or when OHPs were not present or available, AYA cancer survivors were challenged to self-accommodate for limitations in activities, sometimes with the assistance of trusted peers. One survivor reported fatigue remained present despite a lengthy interval since diagnosis and treatment. She decided to schedule periodic breaks to combat feelings of fatigue. Panic attacks following the acute phase of cancer treatments were a problem for another cancer survivor, who resolved this issue with counseling and medications. Coworkers and subordinates were unaware of his challenge with panic attacks. Following breast cancer surgery and reconstruction, a survivor reported, "Where I work, they have people who do the lifting. And then, we have to sweep and clean-up…that's when my arm hurts but a friend does it for me…." A melanoma survivor who works with children at a school avoids playground activities during peak sunlight; trusted peers unofficially accommodate for her outdoor job responsibilities or she tries to arrange alternate times of day.

Challenges for OEHPs: Becoming Visible Agents of Change

Discovering AYA Cancer Survivors.

A challenge for OEHPs is waiting for AYA cancer survivors to reveal their survivor-self so support can be provided. An OEHP revealed, "People come to us often with 'I have a health issue. I have cancer. I was just diagnosed. I don't know exactly how to deal with it.'" In contrast, another OHP expressed frustration about not knowing when workers are experiencing health issues:

> We try to build a really tight community, so that people feel like they can approach us. If it is going to affect them, then it might affect their work at the same time…we'd rather

> know about it than to have them struggling and us to be jerks afterwards going, ‘why aren't you meeting your goals?’ And them to be like, ‘Oh, I have cancer, and I'm feeling it today.’

Alternately, an OEHP promotes disclosure by explaining role and responsibilities:

> I let them know what I do and that seems to give them permission to talk about medical information where maybe they wouldn't if they didn't know I had that medical background. I've never really had anyone not want to talk about it.

Some OEHPs work to improve conditions for groups or populations of workers, rather than individuals, “We really don't get involved. It's basically our medical folks and the insurance carrier.”

Navigating Systems to Provide Support.

Interactions between OEHPs and AYA cancer survivors became supportive when concerns were shared. An OHP expressed, “We deal with the fears of the diagnosis, the uncertainty about the workplace. So, our role is to give them support.” Another OEHP promotes a wide range of support during regular meetings of the workforce. “We just openly share - we have a time where we do, we understand that it might be awkward for someone to talk or express any feelings about it, because it might just seem contrived. So, we have this moment where we sort of just silently listen.”

Also, OEHPs recommended services if needed, “We have an advocate for them here, which is amazing. If the claim was wrong, helping them negotiate the health system.” OEHPs also indicated supporting AYA cancer survivors during interactions with management. “If the manager is giving them difficulties about coming back to work or flexible time, we send them to the office of disability and risk management.” Additionally, “Even if they have a good relationship with their manager, sometimes it’s just easier to talk to another person. I think that is where we really help them out.” OEHPs prefer to know about AYA cancer survivors within the workplace:

> I like it when staff tell me what's going on, so that I'm aware; not that I'm going to baby them in anyway, but to be sensitive and make sure we're asking the right questions and they're fit for duty, and we're not putting them in danger.

OEHPs were presented with the challenge of supporting colleagues or peers of AYA cancer survivors. In these instances, OEHPs were approached with needing to help the colleague rather than the survivor, “At times, we also see co-workers who don’t know how to talk to someone who was gone and is coming back to work…’how do I deal with it?’” Conveying support was important to co-workers, “My friend is coming back. Should we talk about it or not?’” Once again, “The employees who don’t know how to have conversations about that often come [to us].” Management or supervision also sought interventions to facilitate workplace improvement for AYA cancer survivors:

> Occasionally a director or something might reach out and say, we have this employee and here's his or her situation, and what can we do? And we try to follow guidelines in general, because not everyone that needs special access has a handicap placard.

The requests were voluntary.

AYA cancer survivors were shown to fear job loss due to cancer-related illness. Overcoming the challenge of disclosure revealed supportive interactions is some situations:

> I had conversations with the employee and his boss - and the employee said, ‘No. This is what I want to do. I want to work from home. I want to come in. This is what’s really best for me.’ His boss was like, ‘Whatever you want to do, I’ll accommodate. If you want

> to take time off, take time off. Work will always be here. Don't worry about it. We'll get it done, somehow, so don't worry about it.'

OEHPs provided methods to accommodate AYA cancer survivor needs that also provoked reassurance of job continuance: "it's just a matter of getting them adaptive equipment. We've used voice recognition. I've had people that are tired trying to come back to work and getting them systems that they can do where they can rest more, showing them how to take breaks, that it's better to take breaks and not just power through and never stop. They feel frustrated because they're getting really tired, so they just keep trying to work instead of saying, 'I'm tired. I'd better just take a little break.' They don't think that they're doing as much as everybody else. Driving in and out of work is a big issue because they just get tired with long drives. So, I've done a lot of car modifications." Similarly, "We try to provide them easy ways in and out of the facility, or maybe we move their work station to a different location temporarily."

An OEHP expressed frustration with processing of equipment.

> You don't get any follow-up if you don't go back and make sure that the supervisor does what you tell him to do. I can't tell you, when I first started, how many reports I wrote for nothing, the supervisor just looked at it and didn't do anything.

Identifying Changes Needed.

OEHPs are also challenged by the physical space needed in the workplace to accommodate AYA cancer survivors. One Occupational Health Nurse reflected:

> This is a good analogy. When women breastfeed, we provide this beautiful little room for them to breastfeed in. And they have a place to wash their hands. But when someone has a cancer problem, we don't talk about that much. We don't really accommodate that

> much. And we should. We should have a medical - I don't know what you would call it but a medical room or a comfort room would be good.

Similarly, “And he tried to work. He worked. I remember him coming in the office and just laying down, ‘Can I take just a quick nap on my lunch hour?’ He was so tired and drained. So yeah.”

Discussion

Several challenges within the workplace were revealed by AYA cancer survivors and OEHPs in this research. As discussed earlier, the ADA protects AYA cancer survivors when seeking employment by prohibiting questions about health and medical conditions. However, AYA cancer survivors were consumed by fear of the open-ended questioning style used by hiring officials and were unaware of how to best explain gaps in employment. When a job had been secured, once again, the AYA cancer survivors hesitated to reveal their past medical history to others, including OEHPs in the workplace. Legislative efforts that included legal assurances of confidentiality did not promote trust among AYA cancer survivors. Conversely, OEHPs were eager to know, and often thought they knew, their worker populations including those who were AYA cancer survivors. OEHPs wanted very much to provide services to AYA cancer survivors to ensure a comfortable environment that will successfully sustain work. However, the OEHPs were unaware of the presence of AYAs since law protects privacy. AYA cancer survivors strongly desired autonomy, by powering through work in the presence of symptoms, and working around informal limitations in the absence of OEHPs, or when job uncertainty existed. “Playing the cancer card” to secure sympathy and favors in the workplace was weighed against potential for discrimination and stigma.

Some OEHPs were more familiar and visible in the workplace, like nurses. As a profession that is well known for being trusted (Brenan, 2017), support was readily available to co-workers and supervisors of AYA cancer survivors as well the to the survivors themselves. Some OEHPs were from professions that were not as visible or known to AYA cancer survivors, such as Safety Engineers, so revealing roles and availability of support systems was essential. Accommodating individual needs provided assurance of job continuance but was occasionally met with system interference to process the needed equipment orders. Changes within the structure of the workplace was also identified by OEHNs as being needed, to support workers not only in healthy situations such as providing lactation rooms, but also to support those who are attempting to manage cancer-related fatigue. For a depiction of the relationships between the categories, please see the explanatory framework in Appendix E.

Recommendations

The findings of the study suggest that organizational strategies are needed to foster a culture of trust that supports the mission of the ADA to preserve and protect health information of applicants and workers (EEOC, n.d.). The ADA needs to consider variations among Americans diagnosed with medical conditions, including cancer survivors, by providing specific mandates based upon age and longevity of needs in the workplace. Self- employed AYA cancer survivors, or those that work for small businesses did not have access to the expertise of OHPs in the workplace. The OSHA consultation services for small businesses needs greater publicity to provide support in these situations (OSHAc, 2016). In larger companies where OHPs are present, the roles and persons fulfilling those roles requires publicity, easy access with or without formal limitations from a health care provider, and respect by administration and managerial staff.
AYA cancer survivors will require accommodation requests to be fulfilled considering

anticipated health changes during a career. Clinicians or their staff in oncology practice also need to inform AYA survivors about legislative support, and the presence of OHPs in large organizations. Education in the form of lunch-time talks, or tool kits, about communication skills to support co-workers experiencing health changes are also needed. The American Cancer Society could also benefit from information about OHP services to share with AYA cancer survivors.

Conclusions

This study used grounded theory to analyze interviews of 12 AYA cancer survivors and 12 OEHP participants to explore challenges experienced during employment and workplace processes. Finding and securing a job is a complex dynamic process situated in the context of legal regulations and personal choices about disclosing a cancer survivor identity. OEHPs, when present in the workplace, were an eager and ready support system waiting to be accessed by AYA cancer survivors through direct contact, referral from supervisors, or other health care providers. New organizational and federal U.S. strategies are needed to enhance communication and trust within the workplace, while making OEHP services available to all workers regardless of company size or working conditions.

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Appendix A
Sample Characteristics: Young Adult Cancer Survivors (n=12)

Age at Diagnosis	Age at Interview	Years of Survivorship	Cancer Type	Occupation
18-29	28-59	8 - 35	Melanoma	Speech Pathologist
			Lymphoma	Registered Nurse
			Thyroid	Business Owner
			Leukemia	Business Owner
			Lymphoma	Marketing Director
			Testicular	Art Designer
30-39	44-57	7-25	Leukemia	Cosmetologist
			Breast	Nursing Assistant
			Breast	School Counselor
			Breast	Salesperson
			Testicular	Business Owner
			Breast	Veterinary Technician

Appendix B
Sample Characteristics: Occupational and Environmental Health Professionals (n=12)

Profession	Industry
Nursing	Oil and Gas Extraction
Nursing	Pharmaceutical Manufacturing
Nursing	Air Transportation & Warehousing
Nursing	Ambulatory Health Care Services
Nursing	Business Services
Nursing	Public Administration
Safety	Manufacturing
Safety	Professional, Scientific & Technical Services
Safety	Hospital Health Care
Human Resources	Aerospace
Human Resources	Educational Services
Human Resources	Food Services

Appendix C
Interview Guide for Young Adult Cancer Survivors

Please tell me about your experiences at work following your cancer treatments….
- Probe: Did you inform potential employers about your cancer history?
- Probe: Needs for accommodation?
- Probe: Health changes over time?
- Probe: Work changes over time?

Please tell me about your experiences interacting with OEHPs….
- Probe: Did you meet with an occupational and environmental health nurse?
- Probe: Did you meet with safety or industrial hygiene professionals?
- Probe: Did anyone else help you to ease back into work?

Please tell me about your experiences at work…..
- Probe: Support systems…
- Probe: Safety issues….
- Probe: Accommodation accomplished….

What would make the transition to work easier for cancer survivors?
- Probe: In preparation for job search
- Probe: During the hiring process
- Probe: Once you are on the job

What is life like for you when you are working?
- Probe: Health and life insurance
- Probe: Fatigue?

What would be helpful to you in the workplace?

Is there anything else that you would like to tell me about your experiences at work?

Appendix D
Interview Guide for Occupational and Environmental Health Professionals

Please tell me how you meet/encounter employees or potential employees in the work environment…

- Probe: Do you meet people who are newly hired or for pre-placement PEs?
- Probe: Injuries or illnesses?
- Probe: Surveillance monitoring?
- Probe: Clearance after a medical leave?

Is it possible to identify workers who have had cancer?

- Probe: How is this information disclosed?
- Probe: Why do you suspect it isn't disclosed?

Have you had any special education or training about cancer survivors in the workplace?

- Probe: What did you learn?
- Probe: How has this education changed your work?
- Probe: Has your approach to survivors changed?
- Probe: Do you think you need more education about cancer survivors?

What do you think about late adolescent and young adult survivors of cancer being in the workplace?

Please tell me about the social support systems that exist in your workplace for workers who have a history of cancer?

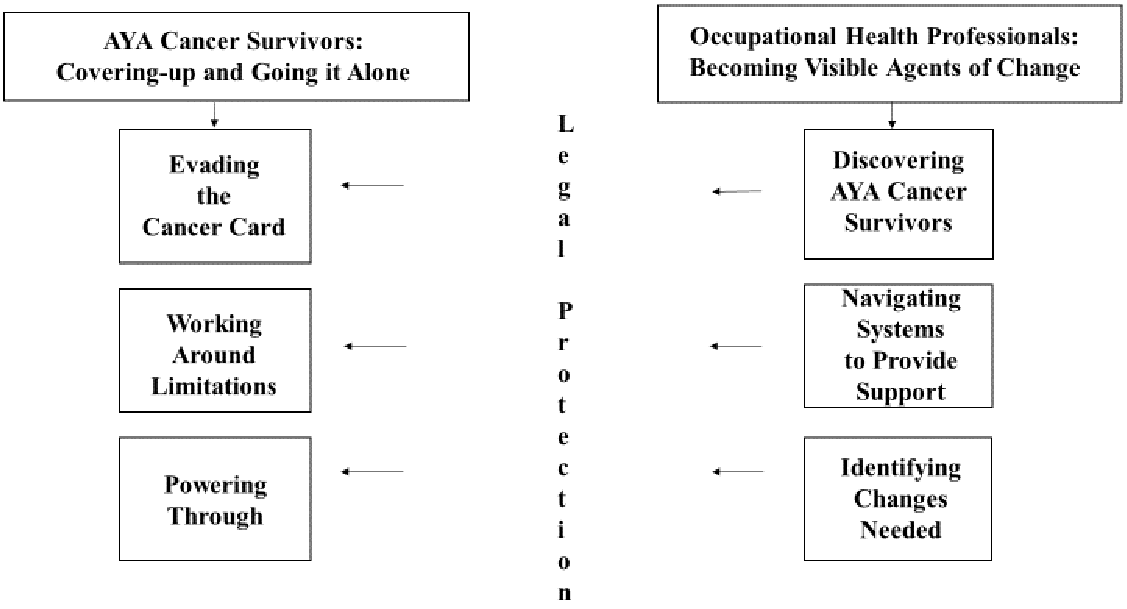
Is there anything else that influences your work with cancer survivors?

- Probe: Safety issues?
- Probe: Need for accommodation?
- Probe: Policies and/or regulations?

What would be helpful to you in the workplace?

Please tell about an experience you have had with cancer survivors here at work…..

Appendix E
Challenging Employment Situations



DISSERTATION CONCLUSION

This dissertation investigated the interactions between young adult cancer survivors and Occupational and Environmental Health Professionals in the workplace. This is the first research study to explore this phenomenon. The study featured two specific aims: To understand the interactions of young adult cancer survivors with occupational and environmental health professionals in the workplace and to understand the contextual factors in the work environment that affect interaction and processes. The answers to the research questions were initially explored through close examination of the scholarly literature. Then the research questions were answered by the qualitative inquiry of perspectives from two groups of participants: Young adult (AYA) cancer survivors and occupational and environmental health professionals (OEHPs) as shown in the three manuscripts provided.

What are the interactions between AYA cancer survivors and OEHPs?

Initially during research design development, it was hypothesized that interactions were occurring in the workplace between AYA cancer survivors and OEHPs. During data collection, it was surprisingly clear that interactions between the two groups could be rare or non-existent. Finding and securing employment is a complex dynamic process involving interaction between AYA cancer survivors and OEHPs, specifically Human Resources professionals. However, OEHPs were unaware that they were interacting with AYA cancer survivors since the Americans with Disabilities Act (EEOC ADA, n.d.) protects persons with pre-existing medical conditions from discrimination in the workplace. Personal choices about disclosing a cancer survivor identity is determined by the survivor. AYA cancer survivors who reported continuous employment with the same employer before and after their cancer diagnoses, discovered sharing confidential cancer news with trusted colleagues and supervisors prompted eager support from co-workers, however lack of knowledge about how to be supportive to those in need was apparent, highlighting an important opportunity for OEHP involvement. AYA cancer survivors who were self-employed or worked under contracts did not have access to OEHPs in any form; and viewed OEHP services as a luxury and benefit. In contrast, there were survivors who were employed in work environments where OEHPs were present but the AYA cancer survivors were unaware of their existence, roles, and responsibilities.

OEHPs, when present in the workplace, were a ready and willing support system waiting to be accessed by AYA cancer survivors through direct contact, referral from supervisors, or other health care providers. The visibility of the OEHPs seemed to be largely known by those who engage in hazardous duties requiring periodic health surveillance and routine safety monitoring, rather than workers who have entered or are present in the workplace with a history of a cancer that could impact physical and/or cognitive functioning and ultimately the ability to perform essential job duties. Since nursing is a well-known profession that can be found in a multitude of settings, the comfort of nursing presence in the workplace was realized by half of the AYA cancer survivor participants. AYA cancer survivors who were unfamiliar with OEHPs' were reluctant to access services due to job insecurity and fear that their cancer history would become known to others within the workplace, jeopardizing future opportunities within a company, industry or profession.

None of the AYA cancer survivors who participated in the study received formal work limitations from any health care provider during their cancer journey. Limitations requiring accommodation by employers are a traditional pathway for interaction with OEHPs. Accommodations require OEHPs to navigate systems to ensure AYA cancer survivors can work effectively without harm or distress. The reasons AYA cancer survivors were not provided with appropriate limitations was not explored in this study but could be investigated in future research endeavors.

How do interactions between AYA cancer survivors and OEHPs influence survivors' ability to work over time?

The systematic review of literature revealed functional ability affecting work productivity was a strong source of distress for AYA cancer survivors due to the impact on financial security, access to health care, and quality of life. More specifically, this research found functional ability diminished progressively as length of survivorship increased. AYA cancer survivors who were working closer to the five-year survivorship mark, were quite often able to self-accommodate to successfully achieve job requirements as mandated by employers. In contrast, survivors approaching end of a career reported experiencing late effects from cancer treatments affecting bone and cardiovascular health resulting in medical or surgical interventions that required time-off from work with impaired functional ability in the aftermath.

Distress was found to manifest in AYA cancer survivors as panic attacks due to profound fear of cancer recurrence, or depression over inability to secure stable employment when fluctuating long-term health effects from cancer or its treatments emerged. The long-term AYA survivors in the study did not contact OEHPs during times of need, largely due to lack of access since this segment of participants was exclusively small business owners or contracted workers. In interviews with OEHPs, accommodations for impairments were sophisticated in function and application requiring a high level of expertise and convenient access to tools, knowledge, and strategic processes to customize interventions to specific workers' needs. OEHPs are well positioned to enhance long-term work ability of AYA cancer survivors but should work to improve their visibility and trustworthiness within the workplace to all employees. Additionally, OEHPs need a formal connection provided by state and national government agencies to offer services to small business owners and those that are self-employed or contracted.

What contextual factors affect interaction and processes between AYA cancer survivors and OEHPs in the workplace?

Contextual factors predominately found to affect interactions between AYA cancer survivors and OEHPs included availability of OEHP services within the workplace, national policies to protect privacy of health information, recommendations about workplace issues given to AYA cancer survivors by health care providers and/or cancer organizations, and creation of alternates to protect health discreetly in work situations as discussed. Self-employment, and employment for small businesses was an especially notable contextual factor that prevented interaction with OEHPs.

Revealing a cancer identity among the survivors was also central to this study. When interactions were possible, legal protections ensuring confidentiality were found to create a protective barrier around AYA cancer survivors who could choose to step over the barrier or stay completely out of view. Perhaps provoking avoidance of interaction is the perspective that OEHPs have unique responsibilities straddling loyalty between employer and workforce, creating an impression of “gatekeeping” to AYA cancer survivors at times when clearance is required to return-to-work. Despite current legislation, AYA cancer survivors are reluctant to reveal their identity to those who are most eager to help facilitate work ability and sustainability.

Significance of the Study

The new knowledge generated from this study will benefit AYA cancer survivors, OEHPs, and the oncology community. Understanding interactions, and factors influencing interactions, between AYA cancer survivors and OEHPs has potential to improve work ability and sustainability for AYAs that will ultimately enhance quality of life. Promoting awareness of AYA cancer survivors to OEHPs was shown to be a challenge, as well as the inverse relationship of creating awareness of OEHPs to AYA cancer survivors. Oncology providers, organizations and support services would benefit from information about OEHPs to inform survivorship care.

Managers, supervisors, and department personnel within the workplace require education concerning the importance of confidentiality when personal health information is shared. Communication techniques also need to be taught to promote work environments that are supportive and caring of AYA cancer survivors. Because health changes occurred during long-term cancer survivorship, routine safety assessments along with discussion about accommodation strategies could further promote work sustainability. Lack of OEHP support in small businesses or industries that do not mandate these roles affected AYA cancer survivors' ability to obtain supportive interaction and formal improvement of work processes to accommodate needs.

Workplace strategies aimed to continue work ability among AYA cancer survivors will reduce the state and national fiscal burden of utilizing public funding to support those that are unable to work. The National Cancer Institute can ultimately use the explanatory frameworks developed from evidence grounded in participants' narratives to create guidelines for occupational and environmental health and oncology nursing practice. Amendments to organizational, state and federal U.S. policies are needed to enhance communication and trust within the workplace, while making OEHP services readily available to all workers regardless of company size, working conditions or sector.

The findings from this study serve as a foundation for future research with generation of a tool based upon the qualitative findings to measure interactivity quantitatively among cancer survivors with OEHPs in companies who employ such roles. Since AYA cancer survivors are a small proportion of working adults who have had a cancer experience, and workplace situations are identical regardless of age, future studies should expand sampling strategies to include all cancer survivor workers. Additional study can also generate assessments and interventions aimed at identifying and decreasing symptoms associated with the consequences of cancer and its treatments while promoting adaptation to the workplace which will enhance quality of life and longevity.

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