

Canadian Oncology Nursing Journal

Revue canadienne de soins infirmiers en oncologie

Volume 33, Issue 1 • Winter 2023
eISSN: 2368-8076



Canadian Association of Nurses in Oncology
Association canadienne des infirmières en oncologie

A cancer survivorship model for holistic cancer care and research

by Sameena F. Sheikh-Wu, Debbie Anglade, Charles A. Downs

ABSTRACT

Advancements in cancer have increased survival rates leading to a paradigm shift such that cancer is considered a chronic disease, necessitating an evaluation of our understanding of cancer survivorship (CS). For this purpose, a comprehensive literature search was performed, using CINAHL, MEDLINE, and PUBMED from 2000–2021. Drawing from the concepts in the literature, salient factors that affect CS across cancer populations were identified and a proposed model was developed. This paper describes the Cancer Survivorship Model (CSM). The CSM represents predisposing factors for survivors and survivorship's acute, extended, and long-term phases, influencing factors: treatment and maintenance (medical/psychosocial care), well-being, influencing aspects (life-changing experience, uncertainty, prioritizing life, wellness management, and collateral damage), and social relationship factors that impact survivors' symptom burdens and overall survivorship experience (health outcomes and quality of life). A case study demonstrates the CSM utility. Future application of the model holds promise for improving the quality of survivorship and informing research and clinical practice to promote and optimize survivors' outcomes throughout the evolving survivorship.

INTRODUCTION

Cancer survivorship (CS) is a complex phenomenon. CS is defined as the time between cancer diagnosis and the end of life that encompasses the totality of medical and psychosocial care, side effects from treatments, development of secondary cancers, remission and, ultimately, death (Doyle, 2008; Farmer & Smith, 2002; Mullan, 1985; National Cancer Institute [NCI], 2018; Oliveira et al., 2018; Wood, 2018). Evidence suggests that cancer diagnoses are not uniform (e.g., cancer type,

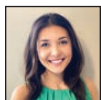
location, treatment, and symptom(s) experiences differ for each person) and may have considerable effects on the CS trajectory (Halpern et al., 2016; Levit, 2013; Paskett et al., 2008). For example, survivors can develop symptoms (e.g., depression, body image disorder, sexual dysfunction, neuropathy of the hands and feet) from cancer and its treatments that may be exacerbated over time (Deshields et al., 2014; Fan et al., 2007; Sheikh-Wu et al., 2020; Sheikh-Wu et al., 2021). If symptoms are left unmanaged, survivors may experience feelings of uncertainty and distress, resulting in poor perceived health status and quality of life and, ultimately, increased mortality (DuMontier et al., 2018; Sheikh-Wu et al., 2020).

In addition to the symptom experience, other salient factors may influence or contribute to the CS trajectory. These salient factors can include predisposing factors (e.g., family history, genetic predisposition, health status, lifestyle behaviours, physical and cognitive function, and socioeconomic, environmental, and cultural status), current health status (e.g., comorbidities), and cancer or disease-related factors (e.g., tumour type, stage, and care or treatment modality). Salient factors may influence and alter how survivors perceive their cancer diagnosis, quality of life, and well-being throughout CS (World Health Organization [WHO], 2020). Evidence suggests that addressing the salient factors of CS through obtaining a thorough understanding of their influence on a personal (persons affected directly/indirectly by cancer), clinical (healthcare teams and services), or research (development of interventions) level can lead to improving survivors' symptoms, quality of life, health outcomes, and social relationships (Halpern et al., 2016).

Much of the prior research related to cancer survivorship has necessarily focused on increasing survival rates. For example, a significant amount of work has been undertaken to create clinical survivorship care plans that are tailored toward enhancing survival, focusing on standardization of treatment follow-up, and improving quality of care (Brennan et al., 2014; Kunthur et al., 2015; Levit, 2013). These efforts have contributed to success, in that overall survival rates have improved and survivors live well beyond 20 years post diagnosis (NCI, 2018; Siegel et al., 2019). Moreover, the number of survivors are expected to increase ~35% over the next decade (Sung et al., 2021). This observation created a paradigm shift where cancer is now considered a chronic disease, allowing for further envisioning of CS. Models are needed that address the chronicity and complexity of CS. Currently, there is a critical gap in understanding cancer survivorship because comprehensive models that encompass the totality of CS are lacking.

Much of our current understanding of CS comes from breast, lung, and prostate cancer survivors and focuses on clinical care aspects. However, attention to only clinical care does not address living with cancer as a chronic disease (Halpern

AUTHOR NOTES



Sameena F. Sheikh-Wu*, School of Nursing and Health Studies, University of Miami, Florida



Debbie Anglade, School of Nursing and Health Studies, University of Miami, Florida

Charles A. Downs, School of Nursing and Health Studies, University of Miami, Florida

*Corresponding author: Sameena F. Sheikh-Wu, School of Nursing and Health Studies, University of Miami, 5030 Brunson Dr. Coral Gables, FL 33146.

E-mail: sfs23@miami.edu

DOI:10.5737/236880763314

et al., 2016; Paskett et al., 2008; Rowland et al., 2019). In addition, there is a commonly held misconception that survivorship is solely defined by completion of treatment and/or when one is “cancer-free.” This definition of survivorship is limited in scope and does not account for the dynamic nature and complexities of CS. Specifically, CS encompasses medical and psychosocial care, side-effects from treatments, development of secondary cancers, remission, and ultimately death, beginning from the time a person receives a cancer diagnosis (Doyle, 2008; Farmer & Smith, 2002; Mullan, 1985; NCI, 2018; Oliveira et al., 2018; Wood, 2018). A broader, more inclusive approach in research and care surrounding survivors would allow for greater breadth and depth in understanding survivorship that could improve acute and long-term health outcomes. Thus, a holistic model is warranted to guide understanding and awareness of CS that incorporates the dynamic nature of survivorship and can be individualized.

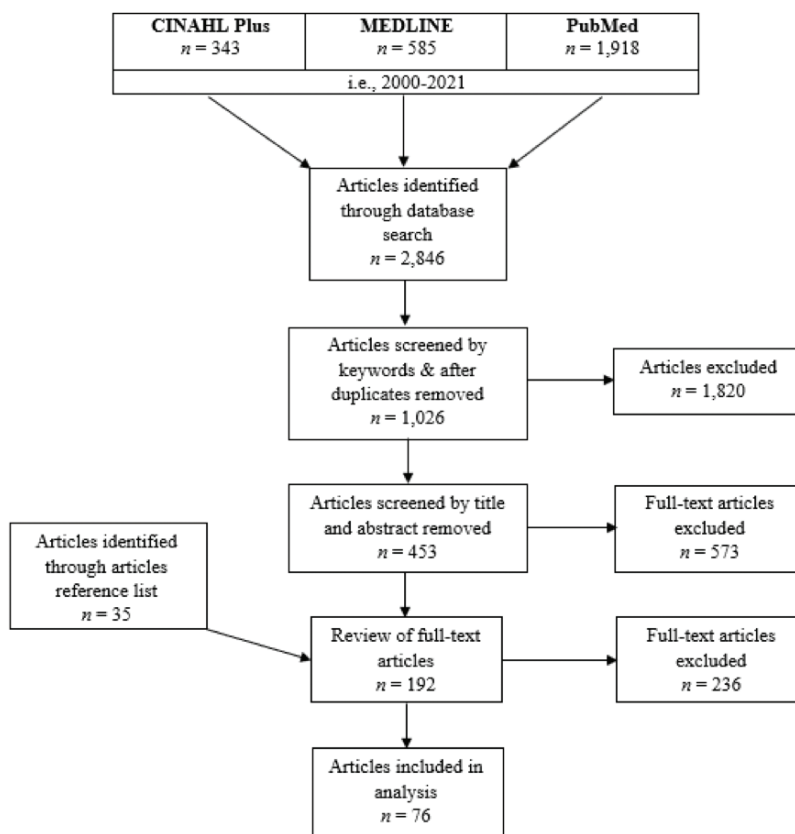
A comprehensive literature review was conducted to identify concepts and salient factors that affect CS across multiple cancer diagnoses. Based on the literature, a proposed model was developed. This paper describes the Cancer Survivorship Model (CSM). First, we define and explain the elements of the CSM. Second, to demonstrate face validity of the model, we illustrate a “real world” application of the CSM through a case study scenario focusing on how the CSM could help improve outcomes by addressing and understanding factors that may impact the quality of survivorship.

METHODS

A comprehensive literature search was performed using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, and PUBMED. Only articles published from 2000 to 2021 were included in the review, and search terms included *cancer*, *cancer survivor*, and *cancer survivorship*. Filters were applied in the literature search to include peer-reviewed journals and full-text articles. MEDLINE database had an additional filter that search terms had to be found in a major heading. All cancer populations and study types (reviews, concept-analysis, cross-sectional, and randomized control trials study designs) were included, while articles written in languages other than English were excluded.

Authors examined article titles, abstracts, and full texts for key search terms and categories of interest that included (a) predisposing factors of cancer; (b) cancer diagnosis and associated factors (e.g., psychological, physical, and socio-economic life changes); (c) medical and psychosocial care; (d) symptoms, side effects, and adverse health-related outcomes, such as acute and chronic conditions; (e) well-being and quality of life; (f) health and wellness management; (g) social relationship (e.g., family, friends, and caregivers); and (h) end of life. Figure 1 outlines the search strategy. A total of 2,846 articles were identified from the electronic database search. After removing duplicate articles and reviewing article titles, keywords, and abstracts, full texts for 192 articles were

Figure 1
Search Flowchart



screened for eligibility. A final total of 76 articles published between 1985 and 2021 were included in this analysis. Two authors independently assessed each study to identify salient factors and their associations within cancer survivorship. If the authors disagreed, a third author reviewed the study and the three authors deliberated until there was agreement.

The *a priori* literature synthesis informed the development of the CSM using relevant cancer survivorship literature. Concepts were identified from the literature review and included: predisposing factors of cancer survivors, cancer diagnosis, life-changing experience, uncertainty, phases, medical and psychosocial care, symptoms burden, well-being, quality of life, prioritizing life, wellness management, social relationship, collateral damage, health outcomes, and end of life (Appleton et al., 2013; Drury et al., 2017; Hebdon et al., 2015; Khan et al., 2012; Shockney, 2015; Wood, 2018). These identified concepts were included in the CSM. The model, as it has been designed, will be described below.

CANCER SURVIVORSHIP MODEL

The Cancer Survivorship model presents key concepts, drawn from a comprehensive literature review, which must be considered in caring for cancer survivors to obtain quality survivorship care. The CSM, (see Figure 2), includes the survivors' predisposing factors, cancer diagnosis, and CS phases

(e.g., acute, extended, and long-term), influencing factors of treatment and maintenance (e.g., medical and psychosocial care), well-being domains (e.g., physical, psychological, and social), influencing domains (e.g., life-changing experience, uncertainty, prioritizing life, wellness management, and collateral damage), and social relationships (e.g., family, friends, and caregivers). All of these factors may have an impact on the survivors' experience of survivorship and health outcomes (e.g., symptoms burdens and quality of life). Individuals who acknowledge their cancer are included within the CSM, because these survivors begin to experience many salient factors throughout their CS continuum, whereas individuals without cancer or those either unaware or avoided acknowledgment of their cancer are excluded from the CSM. (Refer to Textbox 1 for a case study scenario demonstrating face validity of the CSM.)

Cancer Survivorship Phases

The CS continuum includes positive and negative life-changing events, which occur over three distinct CS phases (e.g., acute, extended, and long-term). (Refer to Table 1 for CS phases definitions and descriptions.) The CS phases are discrete intervals marked by specific circumstances and conditions. Within each phase, survivors experience new events (e.g., remission, recurrence, maintenance chemotherapy) in which they face new challenges to understanding CS, potential

Figure 2

Cancer Survivorship Model

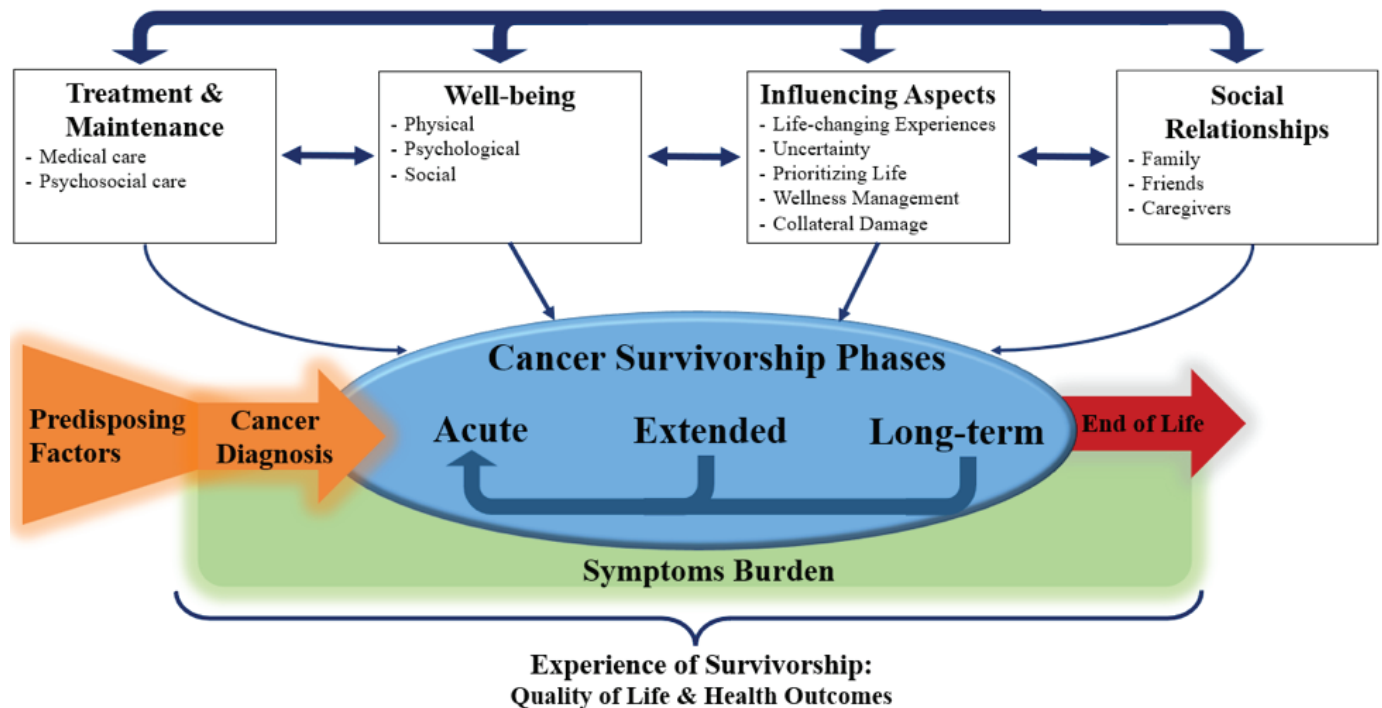


Table 1

Cancer Survivorship Continuum: Phases

Cancer Survivorship Phase	Definition	Description
Acute	The first cancer survivorship phase begins at diagnosis and lasts until the end of primary treatment (Mullan, 1985)	<ul style="list-style-type: none"> • Once diagnosed with cancer, the survivor begins a work-up involving exams and procedures to determine the stage of cancer and treatment options. Survivors may undergo multiple therapies (e.g., surgical interventions, systemic cancer therapy, or radiation; American Cancer Society [ACS], 2018a). • During acute cancer survivorship, the cancer diagnosis, treatment, comorbidities, or a combination may create complications, and survivors experience side-effects and symptoms, up to 13 distinct symptoms at a time (ACS, 2018b; Barsevick, 2016; Deshields et al., 2014; Fan et al., 2007; Sheikh-Wu et al., 2020). • The persistent symptoms reduce survivors' quality of life and health prognosis; the survivors experience a disruption in functional ability, which increases their morbidity and mortality (O'Gorman et al., 2018). • In addition, psychosocial, spiritual, sexuality and intimacy, financial, and intellectual factors also contribute to the survivors' acute survivorship and may positively and/or negatively affect their quality of life and health outcomes along the survivorship continuum.
Extended	The remission or completion of primary treatment lasts until the 5-year post-diagnosis milestone of cancer (Mullan, 1985)	<ul style="list-style-type: none"> • Extended survivorship begins the process of survivors shifting their care from disease treatment to wellness prevention and management even when they may continue to have ongoing medical treatments for stable or slow growth, maintenance, and symptom control (Doyle, 2008). • Cancer survivors may express neglect and uncertainty within the healthcare system when primary treatment is completed (Hebdon et al., 2015; Wood, 2018). • During extended cancer survivorship, survivors primarily begin wellness management and re-prioritizing their new life (e.g., social relationships and activities, exercise programs, occupation involvement, to managing financial strains)*.
Long-term	This phase starts when survivors reach their 5-year post-diagnosis milestone and lasts until the end-of-life (Wood, 2018)	<ul style="list-style-type: none"> • During this phase, cancer is unlikely to recur, and neoplasm activity has decreased or plateaued (Mullan, 1985). • Survivors that remain on maintenance treatment to control their disease or have undergone remission embody the same long-term cancer survivorship qualities. • However, there is still a possibility of disease recurrence and the formation of secondary cancers (ACS, 2018a).

Notes: During extended or long-term cancer survivorship, if a survivor develops another primary cancer diagnosis or has disease reoccurrence, survivors will re-enter into acute cancer survivorship, because they will restart primary care. However, the survivor will continue to embody the extended or long-term cancer survivorship qualities, because they previously experienced and adapted through acute and/or extended cancer survivorship. Nevertheless, a survivor's disease status can become stable or in remission at any phase in cancer survivorship. Survivors will continue to deal with chronic comorbidities, a direct side effect from their cancer, and its treatments. (*) indicates that influencing factors, like wellness management, may be more apparent in a particular phase, but is determined on how a survivor adapts to cancer and survivorship. For example, some survivors may begin wellness management at the beginning of their acute cancer survivorship, whereas other may not, until long-term survivorship.

for new symptoms or unresolved symptoms, and possible effects on their family, friends, and loved ones. Ultimately, these new events may impact the survivors' survivorship experiences and health outcomes.

Influencing Factors

Influencing factors play a significant role in a person's CS continuum. The CSM attributes influence factors, such as treatment and maintenance, well-being, influencing aspects, and social relationships. (Refer to Table 2 for CSs influencing factors definitions and descriptions.)

Treatment and maintenance

Treatment and maintenance consist of survivors' interdisciplinary medical and psychosocial care that may influence their survivorship experience and health outcomes during CS continuum. The survivors' treatment and maintenance care may be altered depending on their predisposed and current health status, such as cancer type, stage, and comorbidities. Symptoms vary considerably based upon the cancer type, location, and treatment and maintenance modalities. Research indicates that cancer care tailored to the whole person will positively increase the survivors' survival and quality of life

Table 2

Cancer Survivorship Continuum: Influencing Factors

Influencing Factor Type	Definition	Description
Treatment & Maintenance:		
Medical care:	Medical care refers to the treatments implemented to restore or maintain homeostasis of the human body and are determined by the severity of cancer (e.g., type and stage) and comorbidities.	<ul style="list-style-type: none"> The cancer stage describes the extent of cancer in the body, factoring in the size, location, and other organs' involvement. A low cancer stage (e.g., I, II) indicates a "lesser degree" of cancer compared to that of a higher stage (e.g., III, IV). The survivors' disease stage (I, II, III, IV) will dictate the type of medical care: curative, maintenance, and palliative (ACS, 2018a).
• Curative care:	Some survivors may undergo curative care, the medical care practice that treats survivors with the intent of curing them with the focus of disease management (Gardiner et al., 2015).	<ul style="list-style-type: none"> However, survivors' health status (e.g., cancer stage, progression, and comorbidities) may not allow them to receive curative treatment. At this point, a survivor may begin to feel helpless, worthless, and uncertain about how to continue a healthy life.
• Maintenance care:	Maintenance care refers to medical care provided with the intent to prevent further deterioration in a survivor's functional and current health status with the focus of disease and person management (National Cancer Institute, 2019).	<ul style="list-style-type: none"> Survivors with stages of II through IV may undergo maintenance care. However, a survivors' cancer disease is stable, with no progression (spread) or cancer tumour reduction in size or stage. Survivors may experience feelings of thankfulness and hope while receiving maintenance therapy. These survivors often report feelings of having been given a second chance and extended time with their family and friends. However, this may not be the case for all survivors.
• Palliative care:	Palliative care is medical care specialized for those living with a serious illness like cancer (Gardiner et al., 2015).	<ul style="list-style-type: none"> The palliative care approach aims to improve survivors', family members', and caregivers' quality of life associated with the survivors' life-threatening, chronic illnesses. Palliative care focuses on relieving distressing symptoms, side effects, and stress that influence the survivors' physical, psychosocial, and spiritual life (WHO, 2019). Overall, palliative care aims to improve the quality of life for both the survivor and family and may occur at any cancer survivorship phase (Harle and Knott, 2017).
• End of life care:	End of life refers to the care given to a survivor near the end of life, specifically when the likelihood of death is within six months (Namireddy et al., 2017).	<ul style="list-style-type: none"> During this time, curative and maintenance treatment has been stopped, and hospice and comfort measures are initiated to ease and support the last stages of life. End of life can occur at any point in the survivors' cancer survivorship continuum. End of life care aims to provide survivors with a "good death" by relieving, comforting, and supporting their last moments of life (Meier et al., 2016). The goal is to provide care that improves the survivors' and their family members', friends', and caregivers' quality of life during the dying process. End of life may occur in the survivors' house or a healthcare facility, because the place of death depends on the person's wishes and their immediate health status. Hospice and comfort care aim to provide comfort to the survivor, family, and caregivers during the last few months and moments of life that will continue until the survivor is deceased (Cohen et al., 2012).
Psychosocial care:	Psychosocial care addresses the survivors' psychological, social, emotional, spiritual, financial, and functional aspects of life.	<ul style="list-style-type: none"> Interdisciplinary teams consisting of healthcare providers, social workers, nurse, mental health specialties, and chaplains work together to provide clinical and community-based services to improve the survivors' well-being (Appleton et al., 2013; Grassi et al., 2017). Clinical-based psychosocial care may include, but is not limited to, counselling, educational, and coping support programs (group, individual, and family therapies) (Grassi et al., 2017). Community-based psychosocial care includes cancer survivors' support groups and activities like choral singing, weekly exercise classes, spiritual or religious services, and community/organizational volunteer work. The survivor's engagement depends on various factors, such as convenience, perceived benefits, and whether the psychosocial care services are culturally sensitive (Ashing et al., 2018). Nevertheless, comprehensive psychosocial care aims to support effective coping strategies and intervene when survivors are maladapting to their cancer survivorship continuum (Weis, 2015).

continued...

Well-Being:

Physical well-being:

Survivors' physical well-being consists of physical functions, role performance, absence of bodily illness, and physiological health indicators (Capio et al., 2014).

- Adverse symptoms may negatively disrupt the survivors' physical role functions and performance, reducing a survivor's physical well-being (Deimling et al. 2019; Sheikh-Wu et al., 2021).
- During acute cancer survivorship, a majority of the reported symptoms experienced are physical, such as pain, fatigue, incontinence, generalized weakness, neuropathy of the hands and feet, as well as nausea and vomiting (ACS, 2018b).
- These physical symptoms reduce the survivors' physical activity resulting in a poorer quality of life.
- Some of these physical symptoms (e.g., pain, incontinence, and neuropathy) may become chronic and reduce the survivors' physical well-being during their extended and long-term cancer survivorship.

Psychological well-being:

Psychological well-being is a person's functioning and attitudes that consist of six components: autonomy, competence, self-acceptance, personal growth, purpose in life, and healthy relationships (Burns, 2016).

- Additionally, survivors may become temporarily or permanently dependent upon others (e.g., caregivers, family, and friends) due to a decline in physical activity and function (Bellizzi et al., 2008).
- A survivor's perception of life purpose, self-autonomy, acceptance, maintenance of relationships, and the management of their psychological symptoms (e.g., stress, anxiety, fear, anger, and negative body perceptions) can alter their psychological well-being (Drury et al., 2017; Wood, 2018).
- For example, around the time of a cancer diagnosis, survivors' psychological well-being is significantly affected; survivors experience a psychological trauma that increases feelings of sadness, hopelessness, arousal, avoidance, shock, guilt, and psychological distress symptoms of stress, anxiety, and depression (Le Boutillier et al., 2019).
- However, if a survivor finds a deeper life purpose, their relationships (e.g., family, friends, religion, or community) can be strengthened throughout the cancer survivorship continuum (Jansen et al., 2011; Tomich and Helgeson, 2004); whereas other survivors may withdraw from all relationships during the acute survivorship phase.

Social well-being:

Social well-being is a survivor's perceived satisfaction of role performance and relationships in the context of social institutions and communities (Cicognani, 2014).

- Social well-being consists of social support, a person's perception that they are part of interpersonal relationships that include family and peers (Cicognani, 2014).
- Survivors' social well-being can influence other aspects of their life. For instance, if a survivor's social relationships change, that survivor may have a reduction in their sense of peace, contentment of self, and relationships to one's community (Chirico et al., 2020).
- A decrease in social well-being may negatively affect the survivors' community engagement through social isolation after receiving their cancer diagnosis. Social isolation can occur when survivors withdraw from family, friends, and their intimate partner(s).
- However, a survivor may experience an enhanced closeness that strengthens their relationships with friends, family, and intimate partner(s) (Appleton et al., 2013).
- Some survivors may spend less time engaging with their community because of their new focus on attending healthcare appointments and treatment.
- In comparison, other CRC survivors may maintain engagement with their social support within the community and develop additional support systems within the cancer community (e.g., other cancer survivors and healthcare providers) during cancer survivorship (Tomich and Helgeson, 2004).

Influencing Aspects

Life-changing experience:

A life-changing experience is an experience that involves change to one's life. When the change involves an actual or perceived threat to one's mortality, like cancer, the person perceives the life-change as a traumatic event (Appleton et al., 2013; Pai et al., 2017). In the context of cancer, life-changing experience is often seen in survivors at diagnosis or disease recurrence.

- The type and severity of life-changing experiences evolve over the cancer survivorship continuum.
- Survivors can have emotions of frustration, fear, and sadness that may increase psychological distress (Le Boutillier et al., 2019; Ramirez et al., 2014).
- Life-changing experiences influence the survivor's uncertainty, a characteristic perceived feeling of loss of -self, -control, and -security (Doyle, 2008).
- Survivors' trauma may trigger an accumulation of psychological distress, sleep difficulties, mood swings, and social isolation that may result in a loss of significant relationships and roles that impact the survivors' quality of life throughout their cancer survivorship continuum (Doyle, 2008; Drury et al., 2017).

continued...

Uncertainty:	Uncertainty is the feeling that encompasses a sense of unknown, unpreparedness, and loss of -self, -control, and -security, and is seen when a person gets diagnosed with cancer (Miller et al., 2014; Ramirez et al., 2014; Wood, 2018).	<ul style="list-style-type: none"> • Survivors may feel helpless because of the unknown that comes from the diagnosis and from being unprepared to cope. • Uncertainty may differ for every survivor and can be influenced by the survivor's previous and current health status. • Uncertainty may be seen as fear-of-recurrence because survivors are constantly reminded of their cancer status by attending healthcare treatments and follow-up appointments during extended and long-term cancer survivorship. • The survivors' uncertainty can increase their psychological and physical symptoms (Doyle, 2008; Miller et al., 2014; Wood, 2018).
Prioritizing life:	Prioritizing life is an act of adapting to a new "normal" life.	<ul style="list-style-type: none"> • A person's internal search for life meaning and purpose occurs because they perceive a heightened awareness of their mortality (Doyle, 2008; Peck, 2008). • The survivors begin to prioritize their life when they accept their "new" life (Appleton et al., 2013; Doyle, 2008; Wood, 2018). • Resilience, reflection, self-esteem, and assurance create a new self-identity that develops from understanding their current life (Appleton et al., 2013; Doyle, 2008; Drury et al., 2017; Shockney, 2015). • Survivors who begin to prioritize their lives by developing and adapting to their "new" life early on in their cancer survivorship continuum may have a more improved quality of life and health prognosis than survivors who are maladapting to their cancer diagnosis and cancer survivorship (Wood, 2018).
Wellness management:	Wellness management is the prioritization of living a healthy lifestyle and can occur throughout the cancer survivorship continuum.	<ul style="list-style-type: none"> • A survivor will begin to actively engage in wellness management by redirecting their lifestyle to optimize and regain health and quality of life, even when the survivor is still dealing with other comorbidities like hypertension or chronic pain (Hagan and Donovan, 2013). For example, survivors start to engage in wellness behaviors such as self-education, supportive care, and management in their healthcare (e.g., medical and psychosocial); the effects of wellness management are carried over into their well-being (Khan et al., 2012; Shockney, 2015; Wood, 2018). • Survivors continue to work on their goals of regaining health and quality of life in an optimistic approach. • Some survivors enter wellness management because they choose to develop healthier behaviours (mind and body) that improve their chances of surviving cancer and increase their quality of life throughout their cancer survivorship continuum.
Collateral damage:	Collateral damage refers to residual effects that accumulate from cancer (Susan Love Research Foundation, 2018; Eshraghi et al., 2017; Love et al., 2017).	<ul style="list-style-type: none"> • Collateral damage includes (a) medical (side-effects and comorbidities from the treatment); (b) physical (pain and cancer-related fatigue); (c) psychological (fear-of-recurrence and post-traumatic growth); (d) emotional (self-esteem, loss of self-identity and significant relationships); (e) financial (debt and insurance problems); (f) spiritual (belief system and values); (g) sociocultural (social isolation and role performance); and, (h) perceived life challenges that acutely or chronically affect a survivor's overall quality of life (Susan Love Research Foundation, 2018; Andrykowski et al., 2008; Doyle, 2008; Drury et al., 2017; Farmer and Smith, 2002; Hebden et al., 2015; Wood, 2018). • The effects of collateral damage begin to accumulate near the end of the acute cancer survivorship phase due to the passage of time and the compounding nature of collateral damages during diagnosis and initial treatment (Susan Love Research Foundation, 2018). • However, survivors do accumulate residual effects, such as, but not limited to, medical, physical, and/or financial toxicity that can persist throughout the cancer survivorship continuum.
Social Relationships	Survivors' perceived connections and networks exist between their family, friends, and caregivers.	<ul style="list-style-type: none"> • Survivors and their social relationships (e.g., family, friends, and caregivers) begin to adjust to the survivor's cancer diagnosis during acute cancer survivorship (Kroenke et al., 2013; Nightingale et al., 2013). • The adjustment to cancer will affect both the survivors' and their family, friends, and caregivers' quality of life through changes in their roles, daily functions, finances, and living arrangements (National Cancer Institute, 2020). • Frequently, the survivors' spouse and immediate family will experience a sudden change in their regular routines (McGeehan, McPherson & Roberts, 2018). However, depending on survivors' relationship with their extended family, friends, or caregivers, the roles and daily functions may significantly alter for them as well (Cotrim and Pereira, 2007; Henshall et al., 2018; Kroenke et al., 2013; National Cancer Institute, 2020; Nightingale et al., 2013; Woźniak and Izycki, 2014). • For example, specific family members will begin to take on additional roles and daily functions (e.g., grocery shopping, children's activities, to getting a job), which can be challenging to juggle when dealing with a person undergoing treatment and maintenance care (Cotrim and Pereira, 2007; Kroenke et al., 2013; National Cancer Institute, 2020; Nightingale et al. 2013). The additional role and daily responsibilities may sometimes be divided among several family members and/or close friends. However, this depends on the social support and network of the cancer survivor.

(Geffen, 2010; Seely & Ennis 2018). Clinical practice focuses on CS care plans that include both medical and psychosocial care to improve the survivors' quality of life and health outcomes (Appleton et al., 2013; Sheikh-Wu et al., 2021).

Well-being

The World Health Organization states that health is a state of complete physical, mental, and social well-being and not the absence of disease, including life satisfaction and healthiness as aspects of a person's life (Topp et al., 2015). Well-being has three domains (e.g., physical, psychological, and social), each playing a significant role within a person's CS continuum. A survivor's experience changes their well-being, a dynamic state based on physical, psychological, and social states, and is affected once they receive a cancer diagnosis; it will also change depending on their cancer experience (e.g., care and symptoms), social relationships, economic, spiritual, and functional status. In turn, there is potential to affect their physical, psychological, and social well-being.

Influencing aspects

Synthesized from the literature, CS has five distinct influencing aspects that all survivors experience: life-changing experiences, uncertainty, prioritizing life, wellness management, and collateral damage. CS influencing aspects may help survivors positively cope with their diagnosis and their new life. Not all influencing aspects will occur during each CS phase. However, this does not mean that survivors will never develop all the CS defining influencing aspects. Across the CS continuum, persons will experience influencing factors; these influencing factors may exacerbate symptoms (e.g., depressed mood and anxiety) and can affect their survivorship experience and health outcomes. Survivors' well-being and CS will begin to transform once they receive their cancer diagnosis, as hearing about life-threatening illness is perceived as emotionally traumatic. Influencing factors may not be perceived in the same way by all persons during CS phases – each survivor will experience a unique CS journey. Some survivors may not begin prioritizing their lives or engaging in wellness management behaviours until they reach the extended or long-term CS phase. Nevertheless, studies suggest that individuals with a positive coping mechanism report a higher quality of life throughout the CS continuum, and the associated outcomes may range from disease remission health engagement to decreased adverse symptoms (Ashing et al., 2018; Carver & Antoni, 2004; Grassi et al., 2017; Jansen et al., 2015; Wang & Hoyt, 2018).

Social relationships

Survivors' close social relationships and their attributes can profoundly affect health through social influence, norms, perception of social support, and flow of information and resource (Guida et al., 2020). Survivors are not the only persons who have to adjust to their cancer diagnosis, treatment, and new normal life; their family, friends, and caregivers also must adapt. Likewise, the survivors' social relationships, including family, friends, and caregivers, evolve and influence the survivors' CS continuum (NCI, 2020b). In addition to the survivors

themselves, the cancer diagnosis and its treatment may affect the quality of life of the family, friends, and caregivers. The dynamics of the survivors' social relationships may impact their survivorship experience and health outcomes including quality of life throughout their CS continuum.

Personal beliefs and ambiguity of cancer survivorship.

Persons' life-changing processes of physical, psychological, spiritual, and socioeconomic ambiguity may affect their CS experiences and health outcomes throughout the continuum (Hebdon et al., 2015). However, survivors' perceived quality of life depends on their individualized sense of self-personal beliefs, values, attitudes, and behaviour system that a person holds as being true. The sense of self is unique for each person; it is based on their experiences and affects how they perceive their diagnosis and CS continuum.

At the time of diagnosis, survivors' psychological distress can be amplified and can reduce their critical thinking and cognitive processing ability (Michalos, 2014). Additionally, certain types of treatments can cause side effects that diminish their intellectual capacity to process information. For example, chemotherapy can result in cognitive impairment for some individuals (e.g., forgetfulness, sense of fogginess, and slower thought process) during the treatment course, which will reduce the person's ability to think clearly and critically (de Boer et al., 2020). Symptoms of cognitive impairment may persist well into long-term CS.

The ability to work and maintain occupational involvement may reflect on survivors' well-being (de Boer et al., 2020; Doble & Santha, 2008; Feuerstein et al., 2010). For example, a person's reduced physical ability or function during CS may alter their ability to maintain their career, altering how they perceive their overall well-being (de Boer et al., 2020). The survivor's psychological and social well-being may be affected because they have a reduction in their quality of life by the loss of social relationships, which may increase their psychological distress symptoms. Whereas other survivors can maintain their career throughout or take a leave of absence and return to work when able, not affecting their overall well-being (Appleton et al., 2013; Feuerstein et al., 2010).

Socioeconomic status and social determinants of health (e.g., educational level, occupation, transportation issues, and race) may have an impact on individuals' survival rates, health-care access, and personal behaviours and lifestyles, which could result in reduced well-being and quality of life (Drury et al., 2017). For example, a reduction in psychological well-being is commonly seen when the survivors experience financial toxicity (e.g., debt or insurance problems) (Fessele, 2017, 2019; Michalos, 2014). Financial toxicity is the detrimental effect of financial strain related to cancer and its treatments, which may introduce additional distress for survivors and their families (Desai & Gyawali, 2020). Financial toxicity may occur throughout the CS continuum when family members begin to manage the cost of cancer treatments and learn of any potential challenges with health insurance coverage (Cotrim & Pereira, 2008; Kroenke et al., 2013; NCI, 2020a; Nightingale et al., 2013; Woźniak & Izyczki 2014).

A commonly experienced financial cost for cancer survivors relates to travel for treatment. For example, the survivor may have to travel far from home for treatment and follow-up care. Depending on their health status and medical care they may need to stay close to or at the hospital until treatment is completed (Woźniak & Izycki, 2014). In some situations, people may lack transportation, which can directly impact their medical care adherence, ultimately reducing their health prognosis and quality of life. Additionally, should the survivor not be able to maintain their job, their health insurance plan may change, introducing additional distress that may reduce the survivors' health prognosis and the family's well-being (Desai and Gyawali, 2020). The living arrangements for the survivors and immediate family members may be temporarily disrupted (Cotrim and Pereira, 2008; Henshall et al., 2018; Woźniak and Izycki, 2014).

Financial toxicity can increase survivors' psychological distress and uncertainty, which may potentially affect their treatment adherence. For example, younger survivors from lower socioeconomic and educational levels are likely to have higher levels of unmanaged symptoms during the first five years after their diagnosis compared to older survivors (> 65 years old; Dunn et al., 2013; Huang et al., 2018; Tantoy et al., 2018). Survivors' symptom burden may disrupt functional ability, social relationships, and can negatively have an impact on their survivorship experience and health outcome – ultimately leading to increased utilization of the healthcare system throughout CS (Barsevick, 2016; Miaskowski et al., 2017; Palesh et al., 2007). If survivors do not adhere to their treatment and maintenance care, they may have disease progression or relapse and an increase in unmanaged symptoms that will ultimately reduce their well-being. Financial instability is a direct indicator of poorer perceived health status and quality of life, and has been associated with increased morbidity and mortality (Fessele, 2017). Survivors' quality of life, health outcomes and perceived well-being are affected by these circumstances.

Symptom Burden

Throughout the cancer continuum, survivors can experience a wide range of symptoms (Barsevick, 2016; Sheikh-Wu et al., 2020), ranging from pain or discomfort, psychological distress (stress, anxiety, and depressive symptoms), weight loss, anemia, sexual dysfunction, to fatigue (Juul et al., 2018; Rasmussen et al., 2015; Siminoff et al., 2014). Symptoms vary based on the cancer type, stage, location, and treatment, and are likely to be more abundant during acute cancer treatments. Approximately 45% of survivors report psychological symptoms (e.g., stress, anxiety, and depression), which are associated with poorer quality of life and adverse health outcomes (Dunn et al., 2013; Gonzalez-Saenz De Tejada et al., 2016; Han et al., 2015). Unmanaged symptoms put survivors at a higher risk of developing chronic conditions that can lead to an increase in symptom burden (Gapstur, 2007; Stark et al., 2012).

The CSM includes survivors' symptoms, which should be systematically assessed to understand what the person is experiencing during CS, to identify potential risks and modifiable

factors that could be targeted to improve quality of life and health outcomes, and to determine which interventions need development. Thus, research is warranted for understanding symptoms risks and influencing factors such as the survivors' cancer stage, current or past treatment, and trajectory along the survivorship continuum. Understanding common influencing factors would efficiently further symptom management options for survivors. Additional emphasis needs to be placed on understanding the symptoms' patterns and influencing factors.

Experience of Survivorship: Quality of Life and Health Outcomes

Predisposing factors, diagnosis, influencing factors, and symptom burden influence a cancer survivor throughout their experience with cancer and consistently affect their quality of life and health outcomes. Quality of life, defined as a person's perception of life in the context of their culture and value systems that they live and are concerned with, includes physical, psychological, and social domains (Karimi & Brazier, 2016), and depends on how survivors adapt to the residual effects of cancer that accumulate throughout their CS continuum. Research suggests that persons with a positive coping mechanism report an improved quality of life and health engagement/outcomes and decreased adverse symptoms (Ashing et al., 2018; Carver & Antoni, 2004; Grassi et al., 2017; Jansen et al., 2015; Wang & Hoyt, 2018). At the same time, the predisposing factors (cancer diagnosis, treatment and maintenance care, and symptom burden) may significantly affect survivors' perceived health outcomes. If a survivor perceives their health status and quality of life as poor, their life expectancy is reduced (DuMontier et al., 2018).

POTENTIAL IMPLICATIONS OF THE MODEL FOR CANCER SURVIVORS

The CSM is a model that can guide our integrative and comprehensive understanding of what happens during the CS continuum. Survivors' experience of CS can affect their quality of life, survival rates, and long-term health maintenance. Therefore, the CSM can be helpful for promoting survivors' health and quality of life by overcoming negative cancer consequences (e.g., unmanaged symptoms and social isolation) and inform clinical practice and research through the development of complementary treatment across multiple cancer types. Identifying and resolving challenges that arise throughout CS will promote positive outcomes, ultimately improving the quality of survivorship.

Implications for Practice

In clinical practice, the CSM could be used to guide a holistic, interdisciplinary approach to caring for survivors throughout the CS continuum, by identifying potential resources to address survivors' treatment and maintenance adherence and symptom burden, to aid in the development of personalized care plans. Interdisciplinary healthcare teams need to continue to assess knowledge deficits in treating survivors' influencing factors, symptom burden, quality of life, and health outcomes throughout the CS continuum. The additional insight may help

survivors positively cope with their CS experience, to improve health outcomes across multiple cancer survivor populations (Doyle, 2008). Additionally, healthcare team members need to understand that an individual survivor will have a unique CS continuum, based on their cancer (type and stage), comorbidities, and influencing factors affecting how they perceive their CS. The CSM will allow survivors, caregivers, clinical staff, and researchers to understand the trajectory of CS, facilitate rapport between clinical staff and survivors/caregivers, and identify challenges that arise to preventatively and proactively intervene when challenges occur. In addition, the CSM could lead to the development of innovative, holistic (medical and psychosocial) interventions that improve survivors' quality of life and could be applied across populations throughout the CS continuum. Finally, healthcare providers, particularly nurses, need to continue to educate survivors and their family members, friends, and caregivers about CS to improve communication, treatment engagement, and health outcomes that may result in a successful patient-centred care plan. Open communication about survivors' CS between survivors and their healthcare team may facilitate rapport and allow healthcare providers to assess and intervene, when survivors begin to maladapt to their CS continuum. Both the survivor and the healthcare team can promote positive coping mechanisms and establish a healthy new normal life.

Implications for Research

The CSM (a) demonstrates a structured framework of CS that can be used across a variety of survivor populations (e.g., CRC, breast, head/neck) to produce a comprehensive understanding of CS and the associated causes or influences of adverse health outcomes during the CS continuum and (b) holds the potential for researchers across multiple disciplines to use the model as the theoretical underpinning for future studies to identify gaps within the CS continuum. Future research needs a holistic model with beginning efforts to reflect survivors' CS continuum, to cumulate cross-cutting findings that can ultimately become an evidence-based practice to improve survivors' quality of life and health outcomes. It would be of interest to use the CSM to identify influencing factors that more heavily impact survivors' positive or negative outcomes or per cancer type to intervene when challenges arise. Further clarification and insight into the CS continuum may lead to an improved quality of life and health outcomes across all survivor populations. It is necessary for the CSM to be tested and applied in the clinical setting to identify and modify the model, because CS is a

dynamic process that will continually evolve as more knowledge and advancements are known. Lastly, the CSM can aid in interventions and instrument development that may help improve survivors' CS continuum (e.g., symptom burden, quality of life, well-being, and health prognosis). Therefore, survivors' quality of life and health outcomes can be addressed throughout the CS phases. Scientific research has the potential to expand the literature on precision science, symptom science, symptom management, and self-management research to promote quality of life and health outcomes regardless of the prognosis or severity of the survivors' disease status (National Institute of Nursing Research, [NINR], 2016).

CONCLUSION

This paper describes the holistic CSM, a framework representing a large body of literature that has the potential to inform survivors, healthcare providers, and researchers about gaps within the CS continuum, to improve public health awareness and survivors' quality of life and health outcomes. The CSM includes the predisposing factors of survivors, cancer diagnosis, CS phases (e.g., acute, extended, and long-term), influencing factors of treatment and maintenance (e.g., medical and psychosocial care), well-being domains (e.g., physical, psychological, and social), influencing aspects (e.g., life-changing experience, uncertainty, prioritizing life, wellness management, and collateral damage), and social relationship (e.g., family, friends, and caregivers), that may have an impact on the survivors' symptoms burden, until end of life. The goal is to improve the understanding of CS and survivors' survivorship experience (quality of life and health outcomes) throughout the continuum. The CSM will allow survivors, caregivers, clinical staff, and researchers to understand the trajectory of survivorship, facilitate rapport between clinical staff and survivors/caregivers, and identify challenges that arise to preventatively and proactively intervene when challenges occur. The CSM has the potential to guide future clinical practice and research by integrative and comprehensively understanding that can be used to guide complementary treatment and research across multiple cancer types that are essential for further investigation.

CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest to report for all authors.

FUNDING INFORMATION

No funding supported this research.

REFERENCES

- Andrykowski, M. A., Lykins, E., & Floyd, A. (2008). Psychological health in cancer survivors. *Semin Oncol Nurs*, 24(3), 193–201. <https://doi.org/10.1016/j.soncn.2008.05.007>
- American Cancer Society. (2018). *Colorectal cancer early detection, diagnosis, and staging*. Author.
- ACS. (2018b). *Treating colorectal cancer*. American Cancer Society. <https://www.cancer.org/content/dam/CRC/PDF/Public/8607.00.pdf>
- American Cancer Society. (2019). *Cancer Facts & Figures 2019*. Author.
- American Cancer Society. (2020a). *Colorectal cancer rates rise in younger adults*. Author.
- American Cancer Society. (2020b). *Treating colorectal cancer*. Author.
- Appleton, L., Goodlad, S., Irvine, F., Poole, H., & Wall, C. (2013). Patients' experiences of living beyond colorectal cancer: A qualitative study. *European Journal of Oncology Nursing*, 17(5), 610–617.
- Ashing, K. T., George, M., & Jones, V. (2018). Health-related quality of life and care satisfaction outcomes: Informing psychosocial oncology care among Latina and African-American young breast cancer survivors. *Psycho-Oncology*, 27(4), 1213–1220.

- Barsevick, A. M. (2016). Symptom clusters. *Semin Oncol Nurs*, 32(4), 333–333.
- Barsevick, A. M., Beck, S. L., Dudley, W. N., Wong, B., Berger, A. M., Whitmer, K., Newhall, T., Brown, S., & Stewart, K. (2010). Efficacy of an intervention for fatigue and sleep disturbance during cancer chemotherapy. *J Pain Symptom Manage*, 40(2), 200–216.
- Bellizzi, K. M., Mustian, K. M., Palesh, O. G., & Diefenbach, M. (2008). Cancer survivorship and aging: Moving the science forward. *Cancer*, 113(12), 3530–3539. <https://doi.org/10.1002/cncr.23942>
- Brennan, T. A., Egan, K. P., Lindborg, C. M., Chen, Q., Sweetwyne, M. T., Hankenson, K. D., Xie, S. X., Johnson, F. B., & Pignolo, R. J. (2014). Mouse models of telomere dysfunction phenocopy skeletal changes found in human age-related osteoporosis. *Dis Model Mech*, 7(5), 583–592.
- Burns, R. A. (2016). Psychosocial well-being. *Encyclopedia of Geropsychology*, 1–8. http://doi.org/10.1007/978-981-287-080-3_251-1
- Capio, C. M., Sit, C. H. P., & Abernethy, B. (2014). *Physical well-being*. Encyclopedia of Quality of Life and Well-Being Research.
- Carver, C. S., & Antoni, M. H. (2004). Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology*, 23(6), 595–598.
- Chirico, A., Maiorano, P., Indovina, P., Milanese, C., Giordano, G. G., Alivernini, F., Iodice, G., Gallo, L., De Pietro, G., Lucidi, F., Botti, G., De Laurentiis, M., & Giordano, A. (2020). Virtual reality and music therapy as distraction interventions to alleviate anxiety and improve mood states in breast cancer patients during chemotherapy. *Journal of Cellular Physiology*, 235(6), 5353–5362. <https://doi.org/10.1002/jcp.29422>
- Cicognani, E. (2014). *Social well-being*. Encyclopedia of Quality of Life and Well-Being Research. Springer Netherlands. <http://doi.org/10.1007/978-94007-0735-5>
- Cohen, M. Z., Rozmus, C. L., Mendoza, T. R., Padhye, N. S., Neumann, J., Gning, I., Aleman, A., Giralt, S., & Cleeland, C. S. (2012). Symptoms and quality of life in diverse patients undergoing hematopoietic stem cell transplantation. *J Pain Symptom Manage*, 44(2), 168–180. <https://doi.org/10.1016/j.jpainsymman.2011.08.011>
- Cotrim, H., & Perreira, G. (2008). Impact of colorectal cancer on patient and family: Implications for care. *European Journal of Oncology Nursing*, 12(3), 217–226.
- de Boer, A. G. E. M., Greidanus, M. A., Dewa, C. S., Duijts, S. F. A., & Tamminga, S. J. (2020). Introduction to special section on: Current topics in cancer survivorship and work. *Journal of Cancer Survivorship*, 14(2), 101–105.
- Deimling, G., Phelps, E. K., Gilbert, M., & Ciaralli, S. (2019). Life satisfaction among older adult, long-term cancer survivors: A comparison of Black with White survivors. *Psycho-Oncology*, 28(6), 1335–1341. <https://doi.org/10.1002/pon.5087>
- Desai, A., & Gyawali, B. (2020). Financial toxicity of cancer treatment: Moving the discussion from acknowledgement of the problem to identifying solutions. *EClinicalMedicine*, 20, 100269–100269.
- Deshields, T., Potter, P., Olsen, S., & Liu, J. (2014). The persistence of symptom burden: Symptom experience and quality of life of cancer patients across one year. *Supportive Care in Cancer*, 22(4), 1089–1096.
- Doble, S. E. & Santha, J. C. (2008). Occupational well-being: Rethinking occupational therapy outcomes. *Canadian Journal of Occupational Therapy*, 75(3), 184–190.
- Doyle, N. (2008). Cancer survivorship: Evolutionary concept analysis. *Journal of Advanced Nursing*, 62(4), 499–509.
- Drury, A., Payne, S., & Brady, A-M. (2017). Cancer survivorship: Advancing the concept in the context of colorectal cancer. *European Journal of Oncology Nursing*, 29, 135–147.
- DuMontier, C., Clough-Gorr, K. M., Silliman, R. A., Stuck, A. E., & Moser, A. (2018). Health-related quality of life in a predictive model for mortality in older breast cancer survivors. *Journal of the American Geriatrics Society*, 66(6), 1115–1122.
- Dunn, J., Ng, S. K., Holland, J., Aitken, J., Youl, P., Baade, P. D., & Chambers, S. K. (2013). Trajectories of psychological distress after colorectal cancer. *Psycho-Oncology*, 22(8), 1759–1765.
- Eshraghi, L., Cooper Ortner, H., DeHart, J. N. C., Stanton, A., Williamson, T., Jorge, A., Obidegwu, N., & Love, S. M. (2017). Metastatic Breast Cancer Collateral Damage (MBCCD) project: Think tank of advocates and provider-survivors. *Journal of Clinical Oncology*, 35(31_suppl), 55–55. https://doi.org/10.1200/JCO.2017.35.31_suppl.55
- Fan, G., Filipczak, L., & Chow, E. (2007). Symptom clusters in cancer patients: A review of the literature. *Current Oncology*, 14(5), 173–179.
- Farmer, B. J., & Smith, E. D. (2002). Breast cancer survivorship: Are African American women considered? A concept analysis. *Oncol Nurs Forum*, 29(5), 779–787.
- Fessele, K. L. (2017). Financial toxicity: Management as an adverse effect of cancer treatment. *Clin J Oncol Nurs*, 21(6), 762.
- Fessele, K. L. (2019). It is time to ask about financial toxicity. *Clin J Oncol Nurs*, 23(5), 3A.
- Feuerstein, M., Todd, B., Moskowitz, M., Bruns, G., Stoler, M., Nassif, T., & Yu, X. (2010). Work in cancer survivors: A model for practice and research. *Journal of Cancer Survivorship*, 4(4), 415–437.
- Gapstur, R. L. (2007). Symptom burden: A concept analysis and implications for oncology nurses. *Oncol Nurs Forum*, 34(3), 673.
- Gardiner, C., Ingleton, C., Gott, M., & Ryan, T. (2015). Exploring the transition from curative care to palliative care: A systematic review of the literature. *Supportive and Palliative Care*, 5(4), 335–342.
- Geffen, J. R. (2010). Integrative oncology for the whole person: A multidimensional approach to cancer care. *Integr Cancer Ther*, 9(1), 105–121.
- Gonzalez-Saenz De Tejada, M., Bilbao, A., Baré, M., Briones, E., Sarasqueta, C., Quintana, J. M., & Escobar, A. (2016). Association of social support, functional status, and psychological variables with changes in health-related quality of life outcomes in patients with colorectal cancer. *Psycho-Oncology*, 25(8), 891–897.
- Grassi, L., Spiegel, D., & Riba, M. (2017, Dec.). Advancing psychosocial care in cancer patients. *F1000Res*, 4(6), 2083. <https://doi.org/10.12688/f1000research.11902.1> eCollection 2017
- Guida, J. L., Holt, C. L., Dallal, C. M., He, X., Gold, R., & Liu, H. (2020). Social relationships and functional impairment in aging cancer survivors: A longitudinal social network study. *Gerontologist*, 60(4), 607–616.
- Hagan, T. L., & Donovan, H. S. (2013). Self-advocacy and cancer: A concept analysis. *Journal of Advanced Nursing*, 69(10), 2348–2359. <https://doi.org/10.1111/jan.12084>
- Halpern, M. T., McCabe, M. S., & Burg, M-A. (2016). The cancer survivorship journey: Models of care, disparities, barriers, and future directions. *American Society of Clinical Oncology Educational Book*, (36), 231–239.
- Han, X., Lin, C. C., Li, C., Moor, J. S., Rodriguez, J. L., Kent, E. E., & Forsythe, L. P. (2015). Association between serious psychological distress and health care use and expenditures by cancer history. *Cancer*, 121(4), 614–622.
- Hebdon, M., Foli, K., & McComb, S. (2015). Survivor in the cancer context: A concept analysis. *Journal of Advanced Nursing*, 71(8), 1774–1786.
- Henshall, C. L., Greenfield, S. M., & Gale, N. K. (2018). Typologies for restructuring relationships in cancer survivorship: Temporal changes in social support and engagement with self-management practices. *Cancer Nurs*, 41(6), E32–E40.

- Huang, W., Yang, L., Liu, Y., Liu, C., Zhang, X., Fu, W., Shi, L., & Liu, G. (2018). Assessing health-related quality of life of patients with colorectal cancer using EQ-5D-5L: A cross-sectional study in Heilongjiang of China. *BMJ Open*, 8(12).
- Jansen, L., Hoffmeister, M., Chang-Claude, J., Brenner, H., & Arndt, V. (2011). Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: Prevalence, determinants, and associations with quality of life. *Br J Cancer*, 105(8), 1158. <https://doi.org/10.1038/bjc.2011.335>
- Jansen, F., van Uden-Kraan, C., Braakman, J., van Keizerswaard, P. M., Witte, B. I., & Verdonck-de Leeuw, I. M. (2015). A mixed-method study on the generic and ostomy-specific quality of life of cancer and non-cancer ostomy patients. *Supportive Care in Cancer*, 23(6), 1689–1697.
- Juul, J. S., Hornung, N., Andersen, B., Laurberg, S., Olesen, F., & Vedsted, P. (2018). The value of using the faecal immunochemical test in general practice on patients presenting with non-alarm symptoms of colorectal cancer. *Br J Cancer*, 119(4), 471.
- Karimi, M. & Brazier, J. (2016). Health, health-related quality of life, and quality of life: What is the difference? *Pharmacoeconomics*, 34(7), 645–649.
- Khan, N., Rose, P., & Evans, E. (2012). Defining cancer survivorship: A more transparent approach is needed. *Journal of Cancer Survivorship*, 6(1), 3–36.
- Kroenke, C. H., Quesenberry, C., Kwan, M. L., Sweeney, C., Castillo, A., & Caan, B. J. (2013). Social networks, social support, and burden in relationships, and mortality after breast cancer diagnosis in the Life After Breast Cancer Epidemiology (LACE) Study. *Breast Cancer Res Treat*, 137(1), 261–271.
- Kunthur, A., Xiang, Z., Kaur, H., Jewell, S., & Mehta, P. (2015). Updates on cancer survivorship care planning. *Federal Practitioner: For the Health Care Professionals of the VA, DoD, and PHS*, 32(7), 64S.
- Le Boutillier, C., Archer, S., Barry, C., King, A., Mansfield, L., & Urch, C. (2019). Conceptual framework for living with and beyond cancer: A systematic review and narrative synthesis. *Psycho-Oncology*, 28(5), 948–959. <https://doi.org/10.1002/pon.5046>
- Levit, L. A. (2013). *Delivering high-quality cancer care: Charting a new course for a system in crisis*. The National Academies Press.
- Love, S. M., Bernstein, L., Obidegwu, A., Ottenbacher, A., Eshraghi, L., & Clague, J. (2017). Collateral damage from metastatic breast cancer –Preliminary results. *Cancer Research*, 77(4 Supplement), P4-P4-20-03. <https://doi.org/10.1158/1538-7445.SABCS16-P4-20-03>
- McGeechan, G. J., McPherson, K. E., & Roberts, K. (2018). An interpretative phenomenological analysis of the experience of living with colorectal cancer as a chronic illness. *Journal of Clinical Nursing*, 27(1516), 3148–3156. <https://doi.org/10.1111/jocn.14509>
- Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, 24(4), 261–271. <https://doi.org/10.1016/j.jagp.2016.01.135>
- Miaskowski, C., Barsevick, A., Berger, A., Casagrande, R., Grady, P.A., Jacobsen, P., Kutner, J., Patrick, D., Zimmerman, L., Xiao, C., Matocha, M., & Marden, S. (2017). Advancing symptom science through symptom cluster research: Expert panel proceedings and recommendations. *Journal of National Cancer Institute*, 109(4).
- Michalos, A. (2014). Well-being. *Encyclopedia of Quality of Life and Well-Being Research*. Springer.
- Miller, G. E., Murphy, M. L. M., Cashman, R., Ma, R., Ma, J., Arevalo, J. M. G., Kobor, M. S., & Cole, S. W. (2014). Greater inflammatory activity and blunted glucocorticoid signaling in monocytes of chronically stressed caregivers. *Brain Behavior and Immunity*, 41(1), 191–199. <https://doi.org/10.1016/j.bbi.2014.05.016>
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *The New England Journal of Medicine*, 313(4), 270.
- Nam, S. Y., Lee, H., Kim, S., & Lee, R.-A. (2018). Factors affecting body image and sexual life for the colorectal cancer patients with stoma. *Asian Oncology Nursing*, 18(1), 1. <https://doi.org/10.5388/aon.2018.18.1.1>
- National Cancer Institute. (2018). *Cancer statistics*. National Cancer Institute.
- National Cancer Institute. (2020a). *Cancer survivorship*. Office of Cancer Survivorship.
- National Cancer Institute. (2020b). *Coping with cancer: Changes for the family*.
- Nightingale, C. L., Rodriguez, C., & Carnaby, G. (2013). The impact of music interventions on anxiety for adult cancer patients: A meta-analysis and systematic review. *Integr Cancer Ther*, 12(5), 393–403.
- Nursing Institute of Nursing Research. (2016). *Implementing NINR's 2011 Strategic Plan: Key themes*. <https://search.nih.gov/search?utf8=%E2%9C%93&affiliate=nih&query=implementing+2011+strategic+plan&commit=Search>
- O'Gorman, C., Stack, L., O'ceilleachair, A., Denieffe, S., Gooney, M., McKnight, M., & Sharp, L. (2018). Colorectal cancer survivors: An investigation of symptom burden and influencing factors. *BMC Cancer*, 18(1), 1022. <https://doi.org/10.1186/s12885-018-4923-3>
- Oliveira, R. A. A., Conceição, V. M., Araujo, J. S., & Zago, M. M. F. (2018). Concept analysis of cancer survivorship and contributions to oncological nursing. *International Journal of Nursing Practice*, 24(1).
- Pai, A., Suris, A. M., & North, C. S. (2017). Posttraumatic stress disorder in the DSM-5: Controversy, change, and conceptual considerations. *Behavioral Sciences*, 7(1). <https://doi.org/10.3390/bs7010007>
- Palesh, O. G., Collie, K., Batiuchok, D., Tilston, J., Koopman, C., Perlis, M. L., Butler, L. D., Carlson, R., & Spiegel, D. (2007). A longitudinal study of depression, pain, and stress as predictors of sleep disturbance among women with metastatic breast cancer. *Biological Psychology*, 75(1), 37–44.
- Paskett, E. D., Herndon, J. E., Day, J. M., Stark, N. N., Winer, E. P., Grubbs, S. S., Pavy, M. D., Shapiro, C. L., List, M. A., Hensley, M. L., Naughton, M. A., Kornblith, A.B., Habin, K.R., Fleming, G.F., & Bittoni, M.A. (2008). Applying a conceptual model for examining health-related quality of life in long-term breast cancer survivors: CALGB study 79804. *Psycho-Oncology*, 17(11), 1108–1120.
- Peck, S. (2008). Survivorship: A concept analysis. *Nursing Forum*, 43(2), 91–102. <https://doi.org/10.1111/j.1744-6198.2008.00100.x>
- Ramirez, M., Altschuler, A., McMullen, C., Grant, M., Hornbrook, M., & Krouse, R. (2014). “I didn't feel like I was a person anymore”: Realigning full adult personhood after ostomy surgery. *Medical Anthropology Quarterly*, 28(2), 242–259. <https://doi.org/10.1111/maq.12095>
- Rasmussen, S., Larsen, P. V., Søndergaard, J., Elnegaard, S., Svendsen, R. P., & Jarbøl, D. E. (2015). Specific and non-specific symptoms of colorectal cancer and contact to general practice. *Family Practice*, 32(4), 387–394.
- Reese, J., Handorf, E., & Haythornthwaite, J. (2018). Sexual quality of life, body image distress, and psychosocial outcomes in colorectal cancer: A longitudinal study. *Supportive Care in Cancer*, 26(10), 3431–3440.
- Rowland, J. H., Gallicchio, L., Mollica, M., Saiontz, N., Falisi, A. L., & Tesaro, G. (2019). Survivorship science at the NIH: Lessons learned from grants funded in fiscal year 2016. *J Natl Cancer Inst*, 111(2), 109–117.

- Rutherford, C., Müller, F., Faiz, N., King, M.T., & White, K. (2020). Patient-reported outcomes and experiences from the perspective of colorectal cancer survivors: Meta-synthesis of qualitative studies. *Journal of Patient-Reported Outcomes*, 4(1), 27–27.
- Sanford, S. D., Beaumont, J. L., Butt, Z., Sweet, J. J., Cella, D., & Wagner, L. I. (2014). Prospective longitudinal evaluation of a symptom cluster in breast cancer. *J Pain Symptom Manage*, 47(4), 721–730.
- Sanford, S. D., Zhao, F., Salsman, J. M., Chang, V. T., Wagner, L. I., & Fisch, M. J. (2014). Symptom burden among young adults with breast or colorectal cancer. *Cancer*, 120(15), 2255–2263.
- Seely, D., & Ennis, J. (2018). Whole person integrative cancer care in action – An overview of its implementation and patient related outcomes. *International Journal of Whole Person Care*, 5(1). <https://doi.org/10.26443/ijwpc.v5i1.136>
- Sheikh-Wu, S. F., Downs, C. A., & Anglade, D. (2020). Interventions for managing a symptom cluster of pain, fatigue, and sleep disturbances during cancer survivorship: A systematic review. *Oncol Nurs Forum*, 47(4), E107–E119.
- Sheikh-Wu, S. F., Kauffman, M. A., Anglade, D., Shamsaldeen, F., Ahn, S., & Downs, C. A. (2021). Effectiveness of different music interventions on managing symptoms in cancer survivors: A meta-analysis. *European Journal of Oncology Nursing*, 52, 101968–101968.
- Shockney, L. D. (2015). The evolution of breast cancer navigation and survivorship care. *Breast Journal*, 21(1), 104–110.
- Siegel, R. L., Miller, K. D., & Jemal, A. (2019). Cancer statistics, 2019. *CA Cancer J Clin*, 69(1), 7–34.
- Siminoff, L., Thomson, M., & Dumenci, L. (2014). Factors associated with delayed patient appraisal of colorectal cancer symptoms. *Psycho-Oncology*, 23(9), 981–988.
- Stark, L. L., Tofthagen, C., Visovsky, C., & McMillan, S. C. (2012). The symptom experience of patients with cancer. *Journal of Hospice & Palliative Nursing*, 14(1), 61–70.
- Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*, 71(3), 209–249.
- Susan Love Research Foundation. (2018). *Collateral damage: An overview*. <https://www.drSusanLoveResearch.org/videos/collateral-damage-overview>
- Tantoy, I. Y., Cooper, B. A., Dhruva, A., Cataldo, J., Paul, S. M., Conley, Y. P., Hammer, M., Wright, F., Dunn, L. B., Levine, J. D., & Miaskowski, C. (2018). Changes in the occurrence, severity, and distress of symptoms in patients with gastrointestinal cancers receiving chemotherapy. *J Pain Symptom Manage*, 55(3), 808–834.
- Tomich, P. L., & Helgeson, V. S. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology*, 23(1), 16–23. <https://doi.org/10.1037/0278-6133.23.1.16>
- Topp, C. W., Østergaard, S. D., Søndergaard, S., & Bech, P. (2015). The WHO-5 Well-Being Index: A systematic review of the literature. *Psychotherapy and Psychosomatics*, 84(3), 167.
- Wang, A. W., & Hoyt, M. A. (2018). Benefit finding and diurnal cortisol after prostate cancer: The mediating role of positive affect. *Psycho-Oncology*, 27(4), 1200–1205.
- Weis, J. (2015). Psychosocial care for cancer patients. *Breast Care*, 10(2), 84–86. <https://doi.org/10.1159/000381969>
- WHO. (2019). *WHO definition of palliative care*. World Health Organization. <https://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (2020). WHOQOL: Measuring quality of life. In *Health Statistics and Information Systems*.
- Wood, K. S. (2018). Transition to cancer survivorship: A concept analysis. *Advances in Nursing Science*, 41(2), 145–160.
- Woźniak, K., & Iżycki, D. (2014). Cancer: A family at risk. *Przegląd Menopauzalny*, 13(4), 253–261.