Mahidol University
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โรงเรียนพยาบาลรามาธิบดี
RAMATHIBODI
SCHOOL OF NURSING
FACULTY OF MEDICINE RAMATHIBODI HOSPITAL

A PATIENT-CENTER CARE

ผศ.ดร.ธิราภรณ์ จันทร์ดา โรงเรียนพยาบาลรามาธิบดี

TOPICS

- A CANCER SURVIVORSHIP MODEL FOR HOLISTIC CARE
- A PATIENT-CENTER CARE

SHARE EXPERIENCES OF CANCER CARE

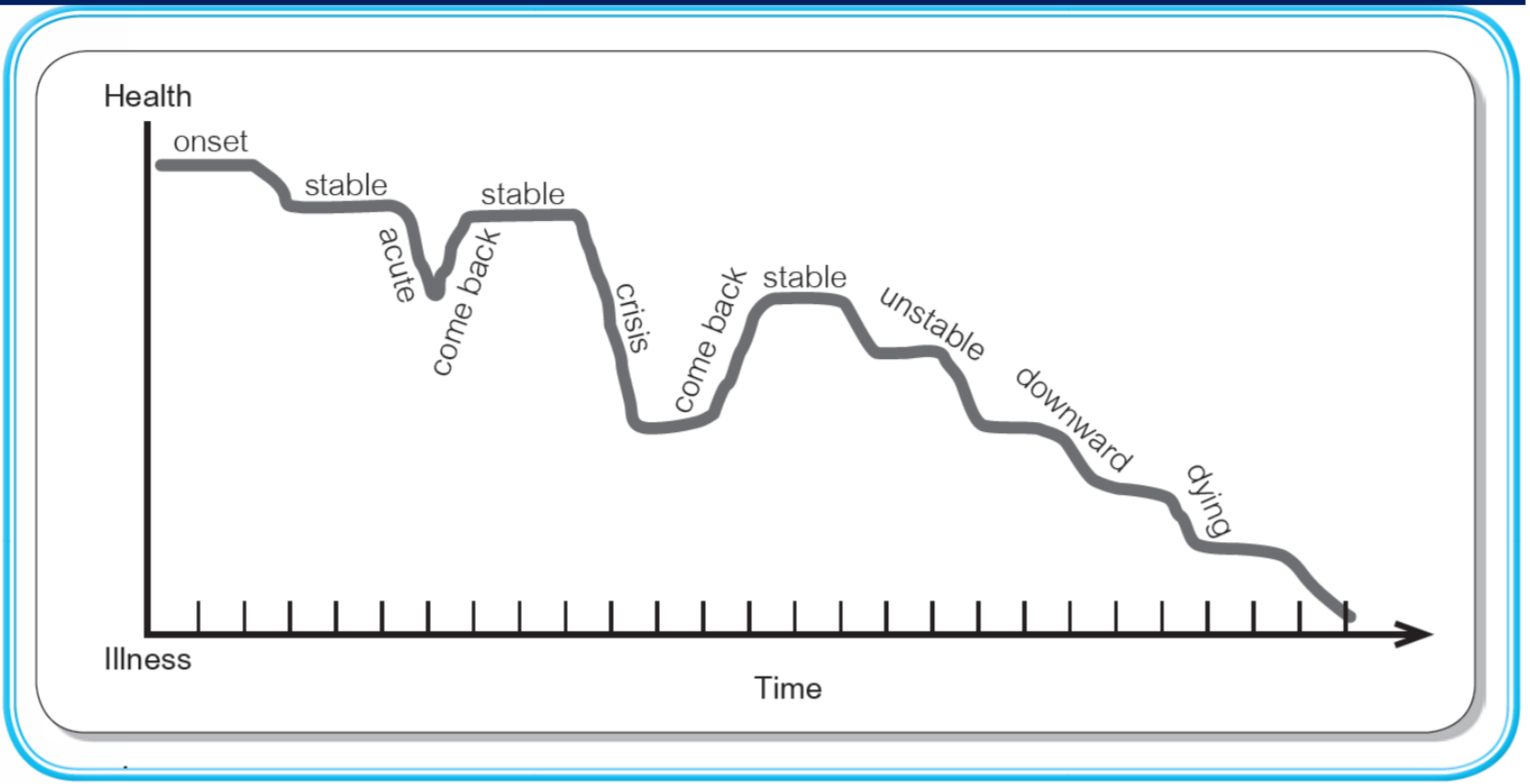
Chronic Illness Trajectory Model

ทฤษฎีของ Corbin & Strauss (1991) อธิบายธรรมชาติของโรคเรื้อรัง มี 9 ระยะ คือ

1. Pre-trajectory phase
2. Trajectory phase
3. Stable phase
4. Unstable phase
5. Acute phase
6. Crisis phase
7. Comeback phase
8. Downward phase
9. Dying phase

- Chronic Illness Trajectory Model ทำให้เข้าใจผู้ป่วยโรคเรื้อรังมากขึ้นทำให้เราสามารถสร้างแนวทางการดูแลตามแต่ละระยะแก่ผู้ป่วยได้เหมาะสมยิ่งขึ้น

CHRONIC ILLNESS TRAJECTORY MODEL



ภาพที่ 7.1 Chronic Illness Trajectory Model *(ดัดแปลงจาก Corbin &Strauss, 1991)*

สุมนี วัชรสินธุ์ (บรรณาธิการ). หลักสูตรพยาบาลผู้ประสานงานโรคไม่ติดต่อเรื้อรังในชุมชน(โรคเบาหวานและความดันโลหิตสูง). พิมพ์ครั้งที่ 1. กรุงเทพ : ศูนย์สื่อและสิ่งพิมพ์แก้วเจ้าจอม มหาวิทยาลัยราชภัฏสวนสุนันทา. 2560

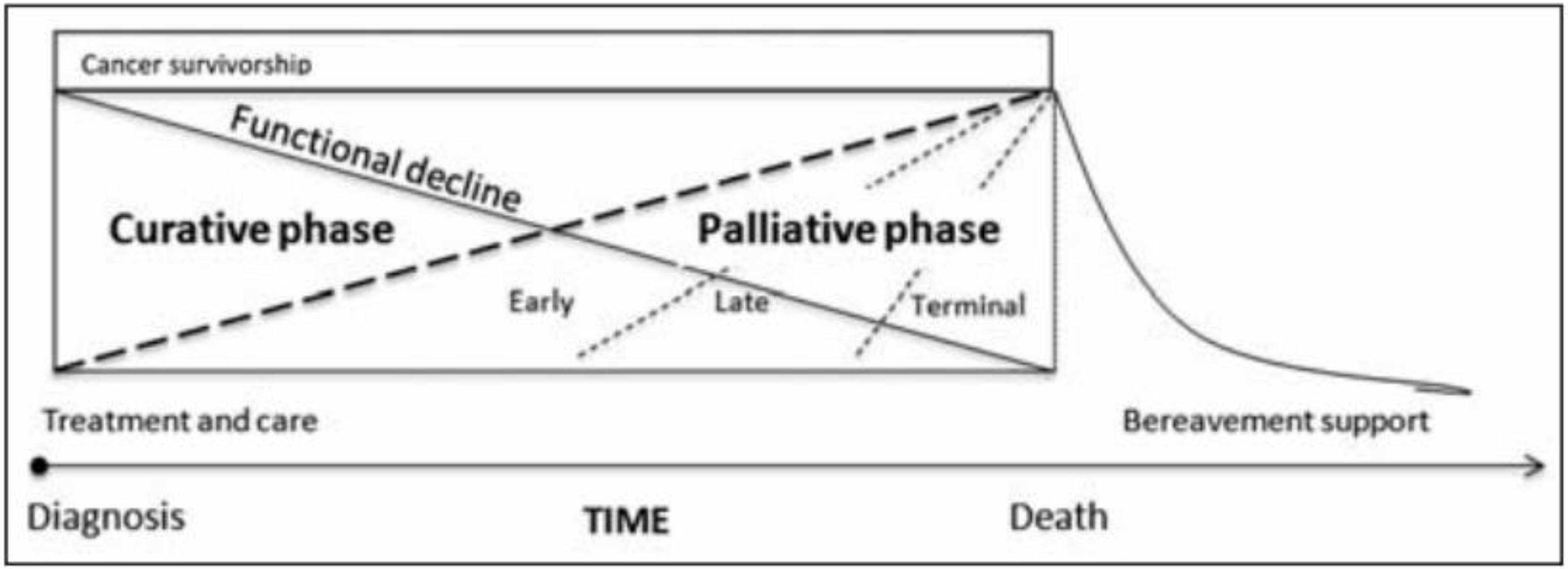
CANCER TRAJECTORY

- เล่าตามประสบการณ์ว่ามีการดูแลเน้นตรงระยะไหน
- คิดว่าการดูแลที่เรามีที่ยังไม่ครอบคลุมคือระยะไหน

Cancer survivorship starts with the period after initial cancer treatment, and includes the further trajectory of treatment strategies, either curative, adjuvant, supportive or palliative. However, there exists several definitions of what it means to become a cancer survivor, some are related to a time frame, such as being a ‘short term cancer survivor’with the distinction e.g. less than five year after finished treatment, or being a ‘long term cancer survivor’ with five or more than five years of survivorship after initial treatment

This classification might be limited since many cancer patients continue with various treatment strategies and supportive approaches for decades until death. Therefore, the term cancer survivorship is left as an overall heading in the model, showing that cancer survivorship might cover all phases of the cancer trajectory. Thus descriptions have to be added in order to distinguish this broad part of the patient’s cancer trajectory.

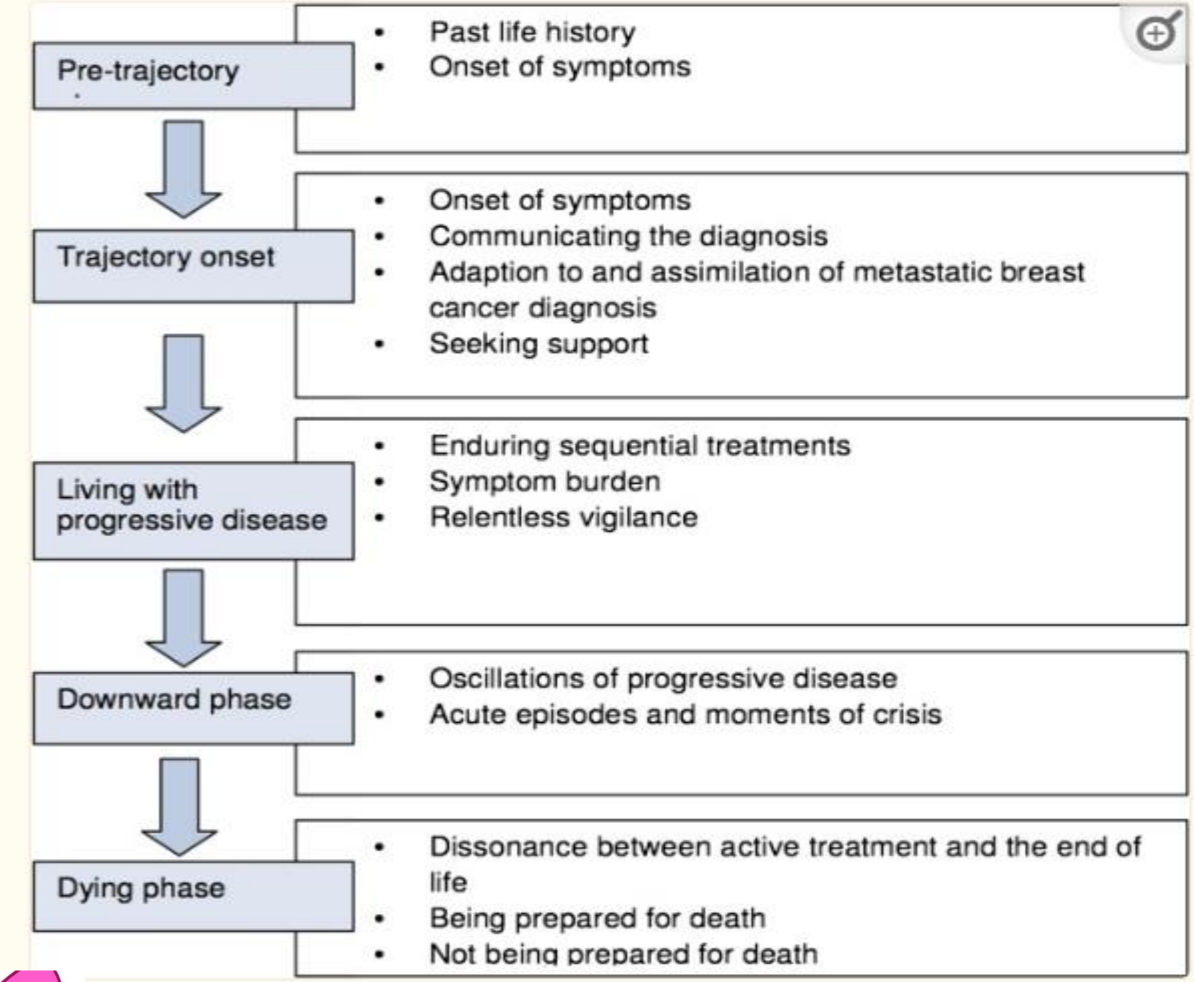
Figure 1: Phases of treatment and care for cancer patients



Karine, 2014

https://journals.sagepub.com/doi/pdf/10.1177/010740831403400111

Reed E, Corner J. Defining the illness trajectory of metastatic breast cancer. BMJ Support Palliat Care. 2015 Dec;5(4):358-65.



Pre-trajectory
- Past life history
- Onset of symptoms

Trajectory onset
- Onset of symptoms
- Communicating the diagnosis
- Adaption to and assimilation of metastatic breast cancer diagnosis
- Seeking support

Living with progressive disease
- Enduring sequential treatments
- Symptom burden
- Relentless vigilance

Downward phase
- Oscillations of progressive disease
- Acute episodes and moments of crisis

Dying phase
- Dissonance between active treatment and the end of life
- Being prepared for death
- Not being prepared for death

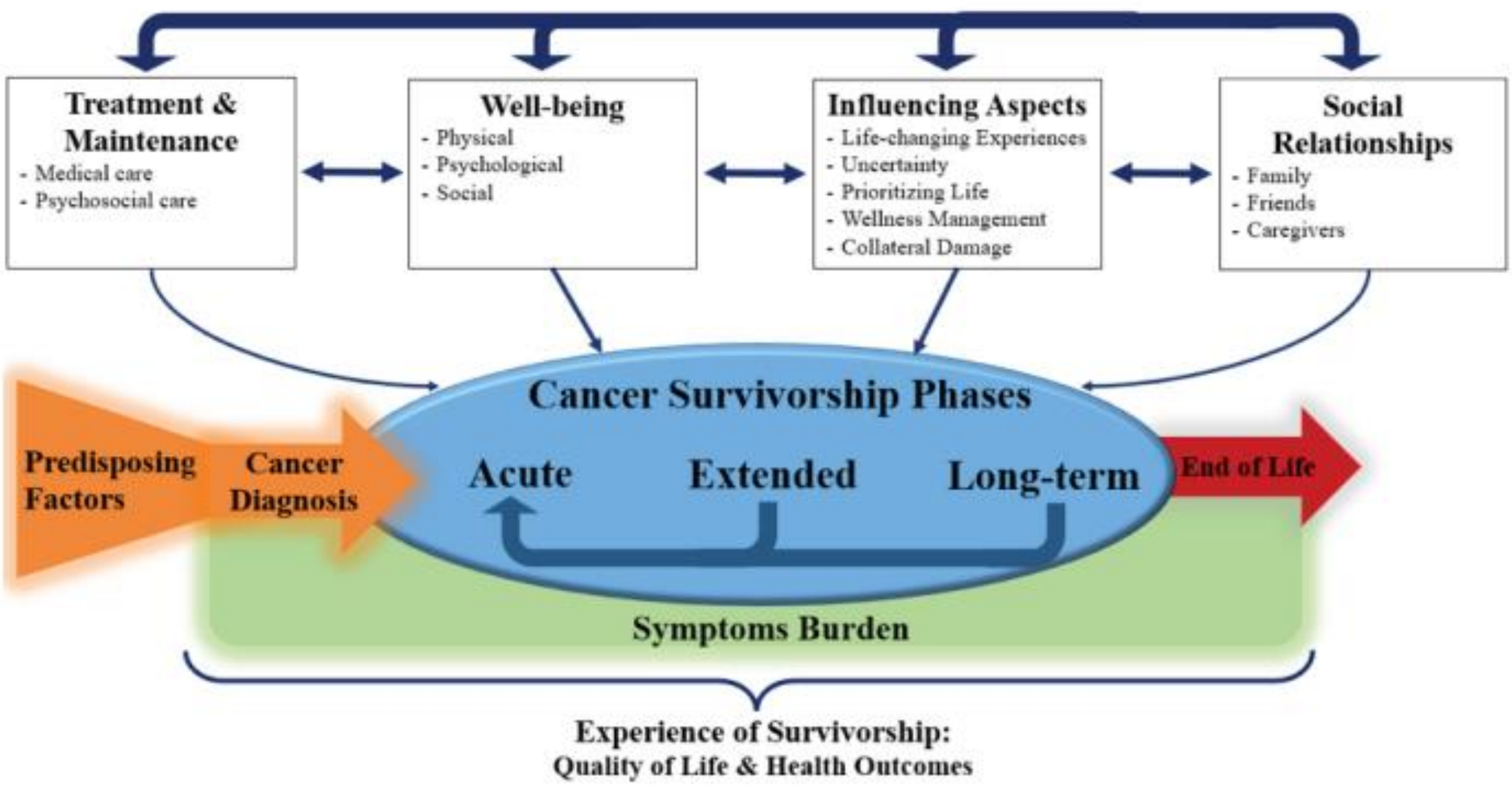
Metastatic breast cancer illness trajectory phases.

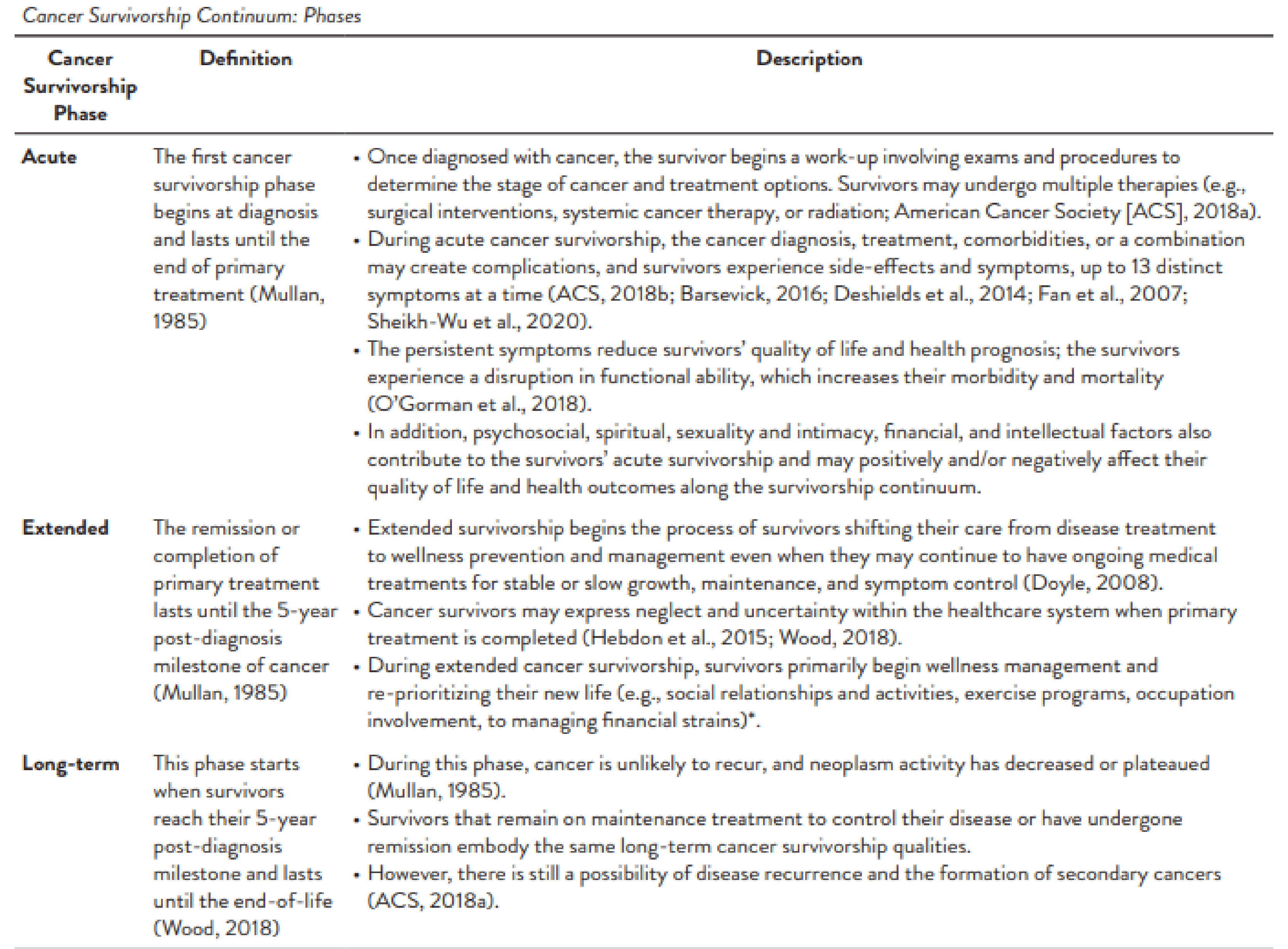
SURVIVORSHIP AND CARE PROCESS

A cancer survivorship model for holistic cancer care and research

(Sheikh-Wu, S., Anglade, D., & Downs, C. A. (2023). A cancer survivorship model for holistic cancer care and research: CAANT journal. CANNT Journal, 33(1), 4-30. doi:https://doi.org/10.5737/236880763314)

Cancer Survivorship Model





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)	• 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)	• 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)	• 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).

- Personal beliefs and ambiguity of cancer survivorship.
- Symptom Burden
- Experience of Survivorship: Quality of Life and Health Outcomes

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 & Iżycki, 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 Iżycki, 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.

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).

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).

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).

Care Processes and Quality of-Life Outcomes Affecting the Gynecologic Cancer Survivorship Experience

Reb, A.M, Economou, D., Cope, D. G, Borneman, Tami, T., Han, E A., . . . Ferrell, B. (2023). Care processes and quality- of-life outcomes affecting the gynecologic cancer survivorship experience. Oncology Nursing Forum, 50(2), 185-200. doi:https://doi.org/10.1188/23.ONF.185-200

PURPOSE: To describe and assess physical and psychosocial concerns and care processes related to cancer and treatment in gynecologic cancer survivors.

PARTICIPANTS & SETTING: 44 survivors of gynecologic cancer at City of Hope National Medical Center in southern California were enrolled.

METHODOLOGIC APPROACH: A descriptive mixed methods approach was used. Data were collected on survivorship care plan implementation, supportive care referrals, and barriers to receiving care. Participants completed questionnaires assessing quality of life, unmet needs, and other outcomes at three, six, and nine months after enrollment. Changes over time were analyzed, and quantitative and qualitative results were compared.

FINDINGS: The most common unmet needs were stress reduction, side effect management, fear of cancer recurrence (FCR), and perception of adequate communication among the care team. Qualitative themes centered around communication, care coordination, FCR, financial distress, and need for information about peer support and healthy lifestyles.

Many survivors function well, 25%–40% experience distress, difficulty concentrating, fear of cancer recurrence (FCR), depression, bowel or bladder dysfunction, sexuality concerns, and difficulty sleeping (Beesley et al., 2018; Campbell et al., 2019). In addition, 30%–54% also experience significant financial toxicity (Campbell et al., 2019; Esselen et al., 2020)

Survivors of gynecologic cancer most at risk for unmet needs include those experiencing advanced disease, distress, higher symptom burden, and less social support; those living in remote locations; and younger women (Beesley et al., 2018). Survivors with multiple comorbidities and advanced disease may need additional support because they are less likely to show improvement in quality of life (QOL) over time (Zandbergen et al., 2019).

Battling the Demons

FCR was a common theme. Women reported living with fear and uncertainty about the possibility of recurrence. Participants described triggers for fears, needs for reassurance mixed with worries about asking for help, and strategies to work through their fears. Subthemes were struggling to cope with fear and empowered to face the uncertainties.

Struggling to cope with fear, Empowered to face the uncertainties:

Coordinated Care Heightens the Patient Experience Some participants (n = 9) reported that coordinated care was essential, with the majority juggling doctors’ visits, laboratory testing, and chemotherapy. Many reported having individualized support to accommodate appointments and schedules. When care was organized, participants felt less stressed. However, some reported communication gaps, inconsistencies, or system-level issues. Subthemes were easing the burden, struggling to navigate the system, and SCP facilitates care coordination. **Easing the burden:** Most participants reported feeling supported and reassured with their care coordination. Having care arranged with minimal wait times and ongoing communication regarding appointments decreased stress.

Struggling to navigate the system: Six participants encountered challenges such as seeking help when sick or with scheduling, resulting in anxiety and effort.

Breast Cancer Patients' Experience of Current Health Services as A Holistic Care: A Qualitative Study

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ABSTRACT

Introduction: Breast cancer is now one of the leading causes of death and morbidity worldwide, including in Indonesia. Every health care professional and community member should pay close attention to these issues. Women diagnosed with breast cancer will experience physical, psychological, and social issues. **Methods:** This study looked into breast cancer patients' experiences with holistic nursing care. The complexity of the difficulties confronting breast cancer patients will influence their experiences and perceptions, necessitating a holistic approach to nursing services. A qualitative exploratory, descriptive method was adopted in the investigation. During data collection, fifteen participants were recruited and interviewed. Focus Group Discussion (FGD) was utilized to collect data. **Result:** The study's findings provide five significant themes: (1) knowledge and understanding of breast cancer; (2) experiences felt at the beginning of breast cancer complaints; (3) non-health breast cancer treatment; (4) perception of nursing services received by breast cancer patients; (5) facts and holistic needs during and beyond treatment; and (6) patients' expectations of nursing services to help their needs. **Conclusion:** The findings provide information on how breast cancer patients understand the examination procedure, accept a diagnosis, and proceed to treatments.
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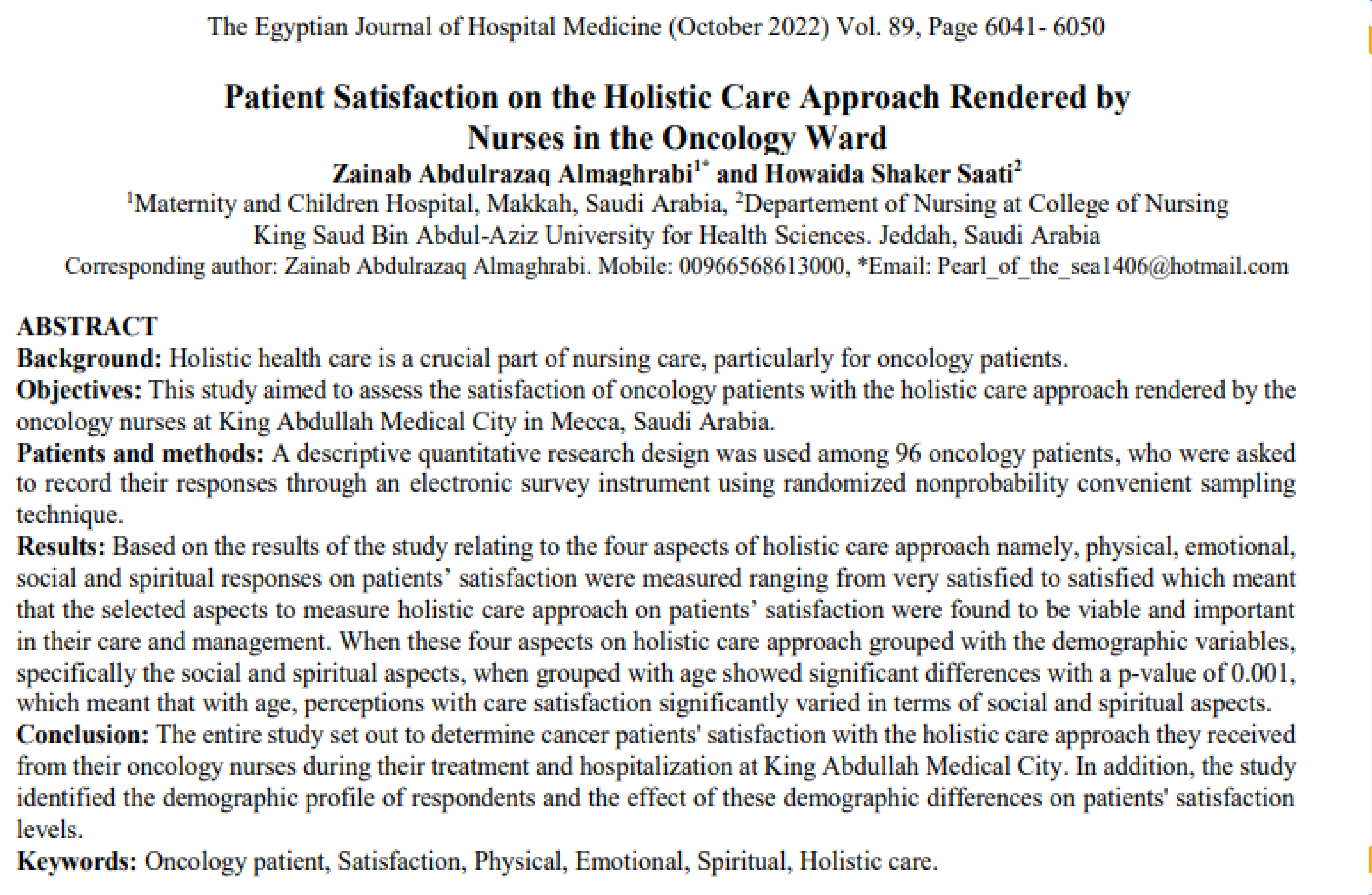
Keywords: Breast Cancer, Experience, Health Services, Holistic Care



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Patient Satisfaction on the Holistic Care Approach Rendered by Nurses in the Oncology Ward

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ABSTRACT

Background: Holistic health care is a crucial part of nursing care, particularly for oncology patients.

Objectives: This study aimed to assess the satisfaction of oncology patients with the holistic care approach rendered by the oncology nurses at King Abdullah Medical City in Mecca, Saudi Arabia.

Patients and methods: A descriptive quantitative research design was used among 96 oncology patients, who were asked to record their responses through an electronic survey instrument using randomized nonprobability convenient sampling technique.

Results: Based on the results of the study relating to the four aspects of holistic care approach namely, physical, emotional, social and spiritual responses on patients' satisfaction were measured ranging from very satisfied to satisfied which meant that the selected aspects to measure holistic care approach on patients' satisfaction were found to be viable and important in their care and management. When these four aspects on holistic care approach grouped with the demographic variables, specifically the social and spiritual aspects, when grouped with age showed significant differences with a p-value of 0.001, which meant that with age, perceptions with care satisfaction significantly varied in terms of social and spiritual aspects.

Conclusion: The entire study set out to determine cancer patients' satisfaction with the holistic care approach they received from their oncology nurses during their treatment and hospitalization at King Abdullah Medical City. In addition, the study identified the demographic profile of respondents and the effect of these demographic differences on patients' satisfaction levels.

Keywords: Oncology patient, Satisfaction, Physical, Emotional, Spiritual, Holistic care.

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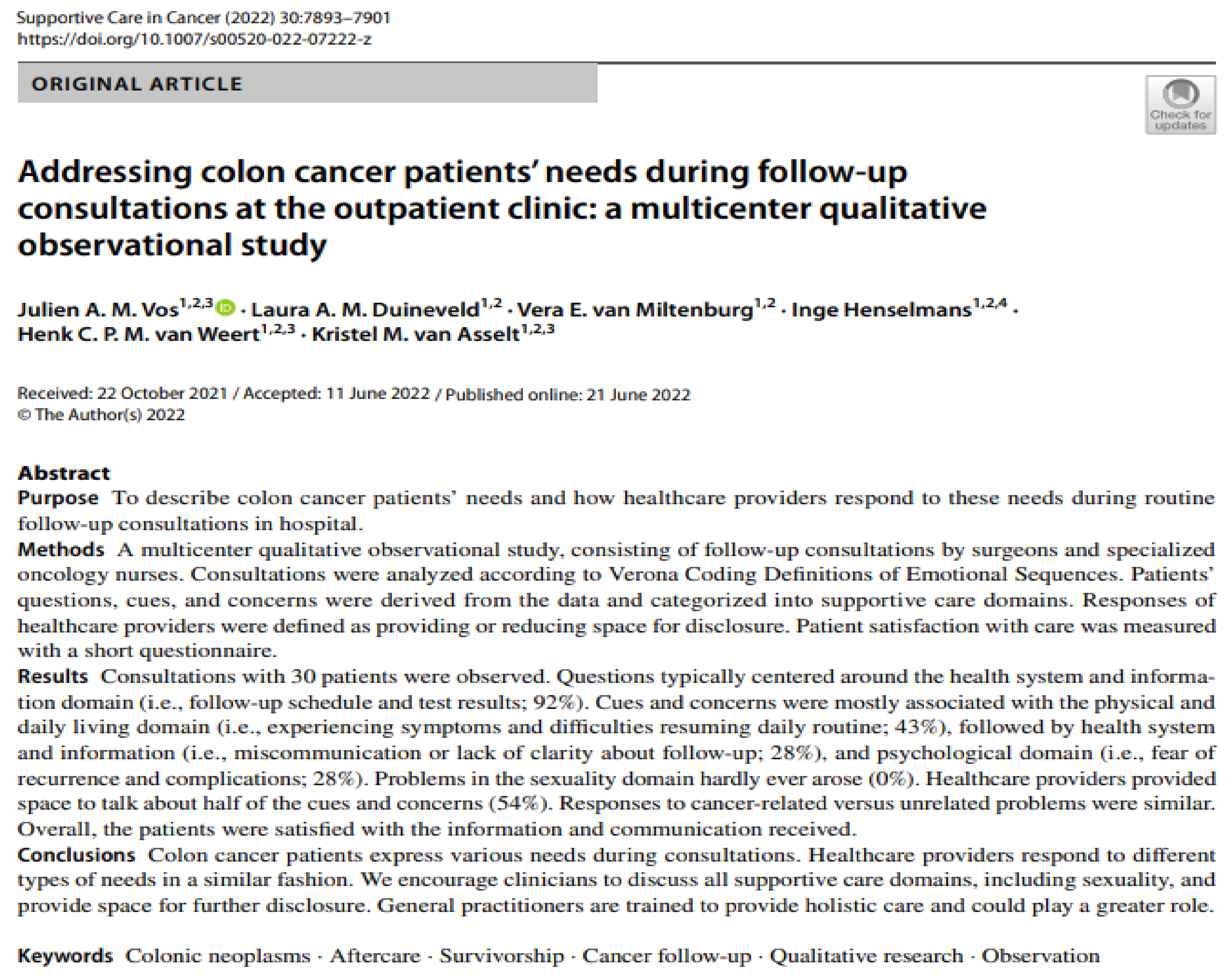

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https://doi.org/10.1007/s00520-022-07222-z

ORIGINAL ARTICLE

Addressing colon cancer patients' needs during follow-up consultations at the outpatient clinic: a multicenter qualitative observational study

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Abstract

Purpose To describe colon cancer patients' needs and how healthcare providers respond to these needs during routine follow-up consultations in hospital.

Methods A multicenter qualitative observational study, consisting of follow-up consultations by surgeons and specialized oncology nurses. Consultations were analyzed according to Verona Coding Definitions of Emotional Sequences. Patients' questions, cues, and concerns were derived from the data and categorized into supportive care domains. Responses of healthcare providers were defined as providing or reducing space for disclosure. Patient satisfaction with care was measured with a short questionnaire.

Results Consultations with 30 patients were observed. Questions typically centered around the health system and information domain (i.e., follow-up schedule and test results; 92%). Cues and concerns were mostly associated with the physical and daily living domain (i.e., experiencing symptoms and difficulties resuming daily routine; 43%), followed by health system and information (i.e., miscommunication or lack of clarity about follow-up; 28%), and psychological domain (i.e., fear of recurrence and complications; 28%). Problems in the sexuality domain hardly ever arose (0%). Healthcare providers provided space to talk about half of the cues and concerns (54%). Responses to cancer-related versus unrelated problems were similar. Overall, the patients were satisfied with the information and communication received.

Conclusions Colon cancer patients express various needs during consultations. Healthcare providers respond to different types of needs in a similar fashion. We encourage clinicians to discuss all supportive care domains, including sexuality, and provide space for further disclosure. General practitioners are trained to provide holistic care and could play a greater role.

Keywords Colonic neoplasms · Aftercare · Survivorship · Cancer follow-up · Qualitative research · Observation

https://www.youtube.com/watch?v=zzJr4Enfleodd Text

HIGHLIGHT

แชร์ประสบการณ์ตรง
จากผู้ป่วยมะเร็งระยะที่ 4