

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

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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.

IMPLICATIONS FOR NURSING: Nurses play a key role in coordinating care, assessing symptoms, and addressing psychosocial concerns. Providing education and coaching can reduce stress and facilitate survivors' self-management and self-efficacy.

KEYWORDS gynecologic cancer; quality of life; unmet needs; survivorship care plan; mixed methods
ONF, 50(2), 185–200.
DOI 10.1188/23.ONF.185-200

Survivors of gynecologic cancer face multiple symptoms and long-term health effects from cancer and treatment and require comprehensive strategies to manage their needs (Beesley et al., 2018; Campbell et al., 2019). Many face physical and psychosocial concerns related to disease, treatment, and comorbidities (Campbell et al., 2019; Jacobs & Shulman, 2017). Although 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). The literature indicates that the most significant supportive care needs are related to care coordination and psychological concerns (Beesley et al., 2018; Lisy et al., 2019). 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).

Cancer survivors commonly experience a range of unmet needs that are not always managed effectively (Jefford et al., 2022). Quality survivorship care entails understanding patient-related factors, system-level issues, and the interplay between them that can affect care delivery (Jacobs & Shulman, 2017). Patient factors include unmet needs, symptom-related and financial concerns, perceptions of communication, and experience of care coordination (Beesley et al., 2018; Kanga et al., 2019). System-level issues include

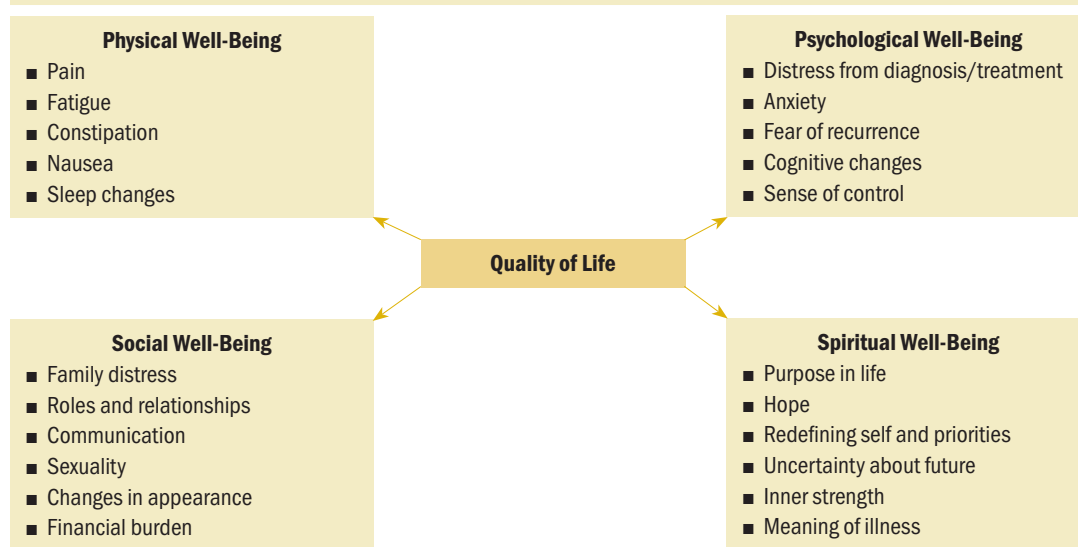
organization of care delivery, accessibility of supportive services, costs, and processes that promote care coordination. Attention is needed to better identify survivors' healthcare needs in practice and the structure and systems in place to support tailored follow-up care (Jacobsen et al., 2018; Jefford et al., 2022). Understanding the interrelationships between system- and patient-level factors can help to identify and inform the processes and resources needed to improve survivorship care. The goal of this study was to describe survivorship care processes and QOL outcomes for survivors of gynecologic cancer who have completed primary therapy. The specific aims were to describe (a) survivorship care processes as defined by supportive care referrals and survivorship care plan (SCP) implementation, (b) QOL, (c) unmet needs, (d) perceptions of communication, (e) confidence in survivorship knowledge, and (f) overall experience.

Conceptual Framework

The study was guided by the Quality of Life–Cancer Survivors Model (QOL-CS) and the Quality of Cancer Survivorship Care Framework (Nekhlyudov et al., 2019). The QOL-CS encompasses physical, psychological, social, and spiritual well-being domains (Ferrell et al., 1995) (see Figure 1). This holistic model addresses psychosocial and existential concerns that affect QOL as well as positive experiences contributing to adjustment and coping (Ferrell et al., 1995). The Quality of

Cancer Survivorship Care Framework encompasses several domains of cancer survivorship care quality pertaining to individual-level cancer-related and general care needs. Domains include prevention and surveillance for recurrence; surveillance and management of physical and psychosocial effects, as well as chronic medical conditions; health promotion and disease prevention; and contextual domains of healthcare delivery. This study looks at the contextual domains that influence the quality of survivorship care: clinical structure, communication and decision-making, care coordination, and the patient–caregiver experience. Clinical structure indicators include the availability of care providers and adequacy of access to care (e.g., appointment availability, financial counseling, navigators). Communication indicators include information provision, assessment of self-management skills, and discussion of sensitive topics. Care coordination indicators include documentation and sharing of the SCP, follow-up with appropriate providers, and the adequacy of care coordination. Patient–caregiver experience measures include access to and timeliness of care and services, satisfaction, and whether care meets survivors' needs (Nekhlyudov et al., 2019). The domains of quality survivorship care are interrelated. These domains cover system-level and process-related issues that directly affect survivors' QOL outcomes and their overall survivorship experience. For example, survivors frequently report stress, uncertainty,

FIGURE 1. Quality of Life–Cancer Survivors Model



Note. Adapted with permission from Betty R. Ferrell.

and dissatisfaction when they experience gaps in communication or care coordination or when supportive services are not readily accessible or affordable.

Method

Design

A descriptive mixed-methods approach was used. Data were collected about SCP delivery, supportive care referrals, and barriers to accessing services. Participants completed questionnaires assessing QOL, unmet needs, perceptions of communication from the care team, and confidence in their survivorship knowledge at three, six, and nine months after enrollment, as well as a satisfaction questionnaire and exit interview at the completion of the study. A convergent parallel mixed-methods approach was used. The quantitative and qualitative data were compared to see how the results confirmed, disconfirmed, or expanded on each other (Creswell & Plano Clark, 2017).

Setting and Sample

The study was conducted at the City of Hope National Medical Center, a National Cancer Institute–designated comprehensive cancer center in Duarte, California. Eligibility criteria were as follows: (a) having an initial diagnosis of endometrial, ovarian, cervical, vulvar, or vaginal cancer, (b) being within seven months of completing primary treatment, and (c) being without recurrent disease. Survivors were recruited from outpatient oncology clinics.

Procedures

Following approval from the institutional review board, the research coordinator and an advanced practice nurse screened electronic health records and appointment schedules to identify eligible survivors. Informed consent was obtained at post-treatment visits, and participants were enrolled in the program. Using the REDCap platform, participants completed a demographic form and surveys at three months (T1), six months (T2), and nine months (T3) after enrollment. The clinical nurse coordinator completed visit summary forms documenting SCP preparation and delivery as well as supportive care referrals. Chart audits and participant queries were conducted to assess referral completion.

Instruments

Demographic and clinical data, including disease and treatment status, medications, and comorbidities, were collected from the electronic health

record. The following instruments were used to gather data: Cancer Survivors' Unmet Needs Survey (CaSUN), QOL-CS tool, Patient Assessment of Cancer Communication Experiences (PACE) measure, Confidence in Survivorship Information (CSI) questionnaire, and Client Satisfaction Questionnaire (CSQ). In addition, a semistructured interview guide was developed to assess survivorship care experience (see Figure 2), and a chart audit form documented supportive care service referrals and any barriers to receiving services.

CaSUN: The CaSUN is a 35-item questionnaire assessing supportive care needs in the following five domains: (a) existential survivorship, (b) comprehensive care, (c) information, (d) QOL, and (e) relationships. Unmet needs are ranked as weak, moderate, or strong. The total score ranges from 0 to 35 and is the sum of all need items, with higher scores indicating greater unmet need. Domain scores are

FIGURE 2. Exit Interview Guide

- In general, can you tell us about your experience with follow-up care after completing treatment for your cancer? What did you find helpful? What did you find challenging or less helpful?
- Can you tell us about any concerns or needs you had when you were receiving follow-up care (e.g., finances, work issues, relationship concerns, child care)? Did you get the help you needed? Please explain.
- Can you tell us about any symptoms you had when you were receiving follow-up care (e.g., physical or emotional concerns)? Did you get the help you needed? Did you feel that you had enough time to discuss your concerns with your provider? Please explain.
- Thinking back about your overall experience with follow-up care, did you feel comfortable sharing all your concerns with your provider? Please explain.
- Can you describe any challenges or difficulties you experienced in the coordination of your follow-up care?
- Did you receive a survivorship care plan (i.e., a written summary of your treatment and plan of care going forward)? Can you tell us your thoughts about the plan?
- Did your provider refer you to any other services or resources at City of Hope or in the community? Did you seek out any services on your own? Did you experience any challenges or difficulties following up with these services? Please explain.
- Beyond the care you received, what other programs or services can be included that will help you thrive after treatment?
- What other suggestions do you have for making your follow-up care better for you or other patients in the future?

Note. Additional prompts and probes used for each question are not included.

the average needs score in each domain. Cronbach's alpha, which measures internal consistency, was 0.96 when tested in populations of survivors with a range of cancer types. Construct validity was demonstrated by significant correlations between higher total needs and anxiety, depression, and poor QOL (Hodgkinson et al., 2007).

QOL-CS: The QOL-CS contains 41 items representing physical, psychological, social, and spiritual well-being domains (Ferrell et al., 1995). This instrument is scored on a Likert-type scale with answers ranging from 0 to 10, with lower scores indicating worse QOL. Scores are categorized as low (0–3), moderate (4–6), and high (7–10). Item scores of 4 or less suggest a need for further assessment. Each subscale and the total scale are scored from 0 to 10 as the averages of items in each subscale or all items, respectively. The internal consistency ranges from 0.71 to 0.89 for the subscales and 0.93 for the overall score. Concurrent validity was demonstrated by a moderate to strong correlation between the QOL-CS and the Functional Assessment of Cancer Therapy–General subscales. The correlation between QOL-CS overall score and the Functional Assessment of Cancer Therapy–General score was 0.78.

PACE: The PACE is a 72-item measure designed to assess the patient's perception of communication from the care team during the cancer continuum (Mazor et al., 2016). This study used four items from the "core" item set (time from suspicion of cancer through the present) and six items from the "after treatment completed" set. Response options range from "never" to "always," and overall rating options range from "poor" to "excellent." Cronbach's alphas were 0.9 or greater for each item set and 0.92 for the "after treatment completed" set.

CSI: The CSI is a 13-item scale consisting of the following two subscales: confidence in knowledge of past cancer treatment (3 items) and confidence in knowledge about prevention or treatment of late effects, access to resources, and familial risk (10 items). Item scores range from 0 (not at all) to 2 (very confident); higher scores reflect greater confidence. The first subscale has a Cronbach's alpha of 0.77 and the second subscale has a Cronbach's alpha of 0.95 (Palmer et al., 2015). The CSI has been used to gather data from a wide range of cancer survivors (Majhail et al., 2019).

CSQ: The CSQ is an eight-item scale that assesses satisfaction with services (Larsen et al., 1979). Items are rated on a scale with scores ranging from 1 to 4, with a total score ranging from 8 to 32. Higher

numbers indicate greater satisfaction. Items on the CSQ are supplemented with open-ended questions. The Cronbach's alphas range from 0.92 to 0.93 in individuals receiving outpatient mental health treatment (Larsen et al., 1979) and from 0.86 to 0.94 in individuals receiving outpatient alcohol treatment (Dearing et al., 2005).

Data Analysis

The sample size was driven by the number of eligible gynecologic cancer survivors who were being treated at the study site and based on available resources. Assuming a potential 30% attrition, this study sought to enroll 45 participants anticipating that 30 participants would complete post-treatment measures.

Descriptive statistics were used to summarize demographic and clinical characteristics. QOL-CS scores were reported using means and standard deviations (SDs). For CaSUN scores, the means and SDs for the number and strength of each need were reported. Within each domain, the average magnitude of unmet needs was calculated. Continuous data were reported using means and SDs or medians and interquartile ranges. Categorical data were reported using numbers and percentages. Differences were tested using chi-square or Fisher's exact test. Changes over time in QOL-CS and CaSUN scores were analyzed using linear mixed models with repeated measures, which provide unbiased estimates for data with missing values at random (Gadbury et al., 2003). The Tukey-adjusted p values assessed the significance of changes between T1 and T2, and T1 and T3. In exploratory analysis, differences between early- and late-stage survivors were examined. A two-sided type I error of 0.05 was the threshold for significance. Because the analysis was exploratory, no adjustment was made for multiple comparisons. SAS, version 9.4, was used for statistical analyses.

The research coordinator conducted exit interviews. Interviews were audio recorded and transcribed. The qualitative data were analyzed independently by three team members using content analysis with an inductive approach (Elo & Kyngäs, 2008). Responses to open-ended questions were transcribed into a table. Categories and themes were identified for each question. The responses contributing to each response category were counted and tabulated, and response patterns were identified (Sandelowski, 2000). Related themes and categories were grouped together and coded, and illustrative quotes for each theme and category were chosen. Data saturation was reached with no new themes or

categories identified during analysis of the final interviews. Throughout the analysis process, each team member strived to remain neutral by bracketing, or setting aside their personal views and reactions that might influence the study (Olmos-Vega et al., 2022). Following the initial coding process, the researchers wrote reflective memos noting their reactions to and interpretations of the data. Team members met regularly to discuss their interpretations, biases, and orientations that influenced their decisions in generating the final themes and categories. For interrater reliability, three nurses on the team read the transcripts and independently identified the categories and themes (Coleman, 2021). Team members met several times to refine the themes and resolve differences.

The quantitative and qualitative data were collected concurrently and analyzed separately. The datasets were compared to identify common concepts. For each concept, the results were compared to identify how they confirmed, disconfirmed, or expanded on the findings. In interpreting the results, equal weight was given to each dataset (Creswell & Plano Clark, 2017).

Results

Demographics

Of the 55 eligible survivors approached for this study, 44 consented and 11 declined to participate. Reasons for declining to participate were as follows: too busy ($n = 3$), feeling tired ($n = 2$), not interested ($n = 2$), feeling overwhelmed ($n = 1$), thinking about cancer causes stress ($n = 1$), feeling anxious/does not want to talk about cancer experience ($n = 1$), and uneasy about having medical records reviewed ($n = 1$). Of the 44 enrolled patients, 42 patients were considered “evaluable” (i.e., completed at least one set of surveys). Thirty-four survivors completed the study including the exit interview. Reasons for attrition were as follows: too ill or recurrence ($n = 4$), lost to follow-up ($n = 3$), and other reasons ($n = 3$). The majority were White ($n = 28$) with a median age of 59.2 years (see Table 1). The median time from treatment completion to study entry was 3.4 months. The sample had the following cancer sites: endometrial ($n = 22$), ovarian ($n = 11$), cervical ($n = 6$), and vulvar ($n = 3$).

CaSUN

At T1, the mean number of unmet needs as scored by the CaSUN was 8.4 (standard error [SE] = 1.5, range = 0–35) based on least squares means estimates (see Table 2). The mean scores in each unmet needs

domain were as follows: existential survivorship ($\bar{X} = 3.4$, SE = 0.7, range = 0–14), comprehensive care ($\bar{X} = 1.6$, SE = 0.3, range = 0–6), information ($\bar{X} = 0.7$, SE = 0.1, range = 0–3), QOL ($\bar{X} = 0.7$, SE = 0.1, range = 0–2), and relationships ($\bar{X} = 0.6$, SE = 0.1, range = 0–3). At T1, the most common unmet needs were reducing stress ($n = 17$, 43.6%), managing side effects ($n = 15$, 38.5%), knowing providers talk to each other ($n = 15$, 38.5%), recurrence concerns ($n = 13$, 33.3%), access to complementary therapies ($n = 12$, 30.7%), and body image ($n = 12$, 30.7%). The average total unmet needs score was 1.6 (SD = 0.6, range = 1–3). Over time, no significant changes were noted in the total score and most domain scores. In the QOL needs domain, a significant improvement was noted from T1 to T3, with an average decline of 0.5 (out of 2 points) ($p = 0.004$). Different numbers of patients completed the questionnaire at different time points.

QOL

At T1, total QOL-CS scores were in the moderate range ($\bar{X} = 6.4$, SE = 0.2, range = 1–10). The mean scores in each QOL-CS domain were as follows: physical ($\bar{X} = 7$, SE = 0.3), spiritual ($\bar{X} = 6.9$, SE = 0.3), social ($\bar{X} = 6.5$, SE = 0.4), and psychological ($\bar{X} = 5.9$, SE = 0.3). At T1, the lowest ranking items indicating lower QOL were as follows: distress from initial diagnosis ($\bar{X} = 2.1$, SD = 2.9), treatment distress ($\bar{X} = 3.2$, SD = 3.3), family distress ($\bar{X} = 3.8$, SD = 3.2), FCR ($\bar{X} = 4.7$, SD = 3.4), uncertainty about the future ($\bar{X} = 5$, SD = 3.3), and secondary cancer ($\bar{X} = 5.2$, SD = 3.2). In most QOL-CS domains and items, there were no patterns of change over time. The social domain score increased 0.7 points from T1 to T3 ($p = 0.03$). Changes in scores over time between early- and late-stage survivors were comparable (see Figure 3). Across time points, psychological domain scores were significantly lower for late-stage survivors ($p = 0.02$).

PACE

Participants rated their communication with the healthcare team using the PACE measure. At T3, the most highly rated items (“usually/always”) were as follows: knowing where to go for my healthcare needs ($n = 27$, 90%), knowing what follow-up care I should receive ($n = 27$, 90%), feeling comfortable asking questions or expressing concerns ($n = 29$, 97%), teamwork ($n = 29$, 97%), and receiving information when needed ($n = 29$, 97%). Lower-rated items were as follows: having help dealing with difficult feelings ($n = 15$, 50%) and having help to cope with uncertainty ($n = 25$, 83.3%). Across time, overall communication

TABLE 1. Clinical and Sociodemographic Characteristics (N = 42)

Characteristic	\bar{X}	SD	Median	Range
Age at enrollment (years)	-	-	59.2	28-76
Time since diagnosis (months)	9.2	4.5	9.4	0.1-16.5
Time since end of treatment (months)	3.9	2.4	3.4	1.3-11
Comorbidities	2	1.8	1.5	0-7
Packs smoked per day	-	-	1	0-2
Time smoked (years)	-	-	10	4-68
Characteristic	n			
Race				
American Indian	1			
Asian	6			
Black	1			
White	28			
Multiple races	1			
Do not know or decline to answer	5			
Ethnicity				
Hispanic	9			
Non-Hispanic	32			
Decline to answer	1			
Education level				
Some high school, high school graduate, or equivalent	13			
Some college or trade school	13			
Bachelor's degree	8			
Graduate or professional degree	8			
Employment status				
Unemployed, homemaker, or volunteer	9			
Employed full-time	16			
Employed part-time	5			
Retired	11			
Medical leave from employer	1			
Marital status				
Married or partnered	23			
Never married	10			
Divorced, widowed, or separated	9			

Continued in the next column

TABLE 1. Clinical and Sociodemographic Characteristics (N = 42) (Continued)

Characteristic	n
Household income (\$)	
20,000 or less	3
20,001-60,000	6
60,001-100,000	10
More than 100,000	12
Decline to answer	11
Primary care provider	
Yes	32
No	10
Cancer site	
Endometrial	22
Ovarian	11
Cervical	6
Vulvar	3
Cancer stage	
I	22
II	3
III	12
IV	5
Treatment received ^a	
Surgery	41
Chemotherapy	24
Radiation therapy	10
Distance traveled to care	
40 miles or fewer	28
More than 40 miles	14
Smoke currently or ever	
Yes	35
No	7

^aSome participants received multiple types of treatment.

ratings improved, with 76.9% (n = 30) rating communication with the care team as “excellent/very good” at T1 and 96.6% (n = 29) giving that rating at T3 (p = 0.04). Different numbers of patients completed the questionnaire at different time points.

CSI

At T1, the items on the CSI demonstrating the lowest confidence in knowledge were as follows: things to do to prevent recurrence ($\bar{X} = 1.1$, SD = 0.7, range = 0-2), long-term physical effects ($\bar{X} = 1.2$, SD = 0.7), long-term emotional effects ($\bar{X} = 1.2$, SD = 0.7), and strategies for

TABLE 2. Linear Mixed Model With Repeated Measures

	Least Squares Means ^a							Difference Between Time Points ^{a,b}					
	T1		T2		T3		p ^c	T2-T1			T3-T1		
	est	SE	est	SE	est	SE		\bar{X}	SE	p ^d	\bar{X}	SE	p ^d
CaSUN													
Total score	8.4	1.5	6.7	1.6	6.5	1.6	0.2	-1.6	1.1	0.3	-1.9	1.1	0.2
Existential	3.4	0.7	3	0.7	3	0.8	0.7	-0.4	0.6	0.7	-0.4	0.6	0.7
Comprehensive	1.6	0.3	1.2	0.3	1.2	0.3	0.4	-0.4	0.4	0.5	-0.5	0.4	0.4
Information	0.7	0.1	0.5	0.2	0.5	0.2	0.3	-0.2	0.1	0.4	-0.2	0.1	0.3
QOL	0.7	0.1	0.3	0.1	0.2	0.1	0.003	-0.4	0.1	0.027	-0.5	0.1	0.004
Relationship	0.6	0.1	0.5	0.2	0.5	0.2	0.6	-0.1	0.1	0.6	-0.04	0.1	0.9
QOL-CS													
Total score	6.4	0.2	6.7	0.2	6.8	0.2	0.05	0.4	0.2	0.09	0.4	0.2	0.08
Physical	7	0.3	7.7	0.3	7.5	0.3	0.02	0.7	0.2	0.014	0.4	0.3	0.2
Psychological	5.9	0.3	6.2	0.3	6.1	0.3	0.3	0.3	0.2	0.3	0.3	0.2	0.4
Social	6.5	0.4	6.9	0.4	7.2	0.4	0.03	0.4	0.3	0.3	0.7	0.2	0.03
Spiritual	6.9	0.3	7	0.3	7.1	0.3	0.8	0.04	0.2	1	0.1	0.2	0.8

^a Describes estimates from the linear mixed models with repeated-measures analyses that included a time variable

^b Mean difference between T2 and T3 is not shown in this table.

^c F-test p value

^d Tukey-adjusted p value

CaSUN—Cancer Survivors Unmet Needs Survey; est—estimate; QOL—quality of life; QOL-CS—QOL—Cancer Survivors Model; SE—standard error; T1—3 months after enrollment; T2—6 months after enrollment; T3—9 months after enrollment

Note. The total score on the CaSUN ranges from 0 to 35 and is the sum of all need items, with higher scores indicating greater unmet need. Domain scores are the average number of needs in each domain. Of the CaSUN subscales, existential needs range from 0 to 14, comprehensive care needs range from 0 to 6, information needs range from 0 to 3, QOL needs range from 0 to 2, and relationship needs range from 0 to 3. The QOL-CS is scored on a Likert-type scale with answers ranging from 0 to 10, with lower scores indicating worse QOL. Item scores of 4 or less suggest a need for further assessment. Each subscale and the total scale are scored from 0 to 10 as the averages of items in each subscale or of all items, respectively.

preventing and treating long-term emotional effects ($\bar{X} = 1.2$, $SD = 0.7$). All total and subscale scores were stable over time. At T3, participants scored highest on the confidence in knowledge of past cancer treatment subscale ($\bar{X} = 1.7$, $SD = 0.5$) and lowest on the confidence in knowledge of late effects subscale ($\bar{X} = 1.3$, $SD = 0.5$).

CSQ

The average total satisfaction score was 30.5 ($SD = 2.3$, range = 8–32) ($n = 34$). Twenty-six participants who filled out the CSQ reported that almost all their needs were met. For the item “Have the services received helped you deal more effectively with problems?” 22 said they helped a great deal. For the item “overall satisfaction with services,” 27 participants were very satisfied.

SCP

Adapted based on the Society of Gynecologic Oncology guidelines (Salani et al., 2017) and

American Society of Clinical Oncology (n.d.) templates, the SCPs consisted of a treatment summary, surveillance and screening schedules, education about late effects, and healthy lifestyle resources. Thirty-eight survivors received an SCP approximately three months following completion of primary therapy. The nurse coordinator prepared and delivered 35 SCPs, and 3 were delivered by the nurse practitioner. Most were delivered in person ($n = 32$). The majority were generated from the electronic health record with a copy sent to the primary care provider ($n = 31$) or another type of provider ($n = 6$), with one not sent because the patient wanted to establish a new primary care provider ($n = 1$).

Qualitative Data

Analysis of participant experiences was based on responses to the exit interviews ($n = 33$) and open-ended questions from the CSQ, PACE, and CaSUN (Krippendorff, 2012). Most reported that post-treatment follow-up was well organized. Participants

described the nurses and physicians as caring, knowledgeable, and supportive. Five themes were identified: (a) communication: the essence of care, (b) battling the demons, (c) coordinated care heightens the patient experience, (d) financial distress, and (e) navigating supportive services (see Table 3).

Communication: The Essence of Care

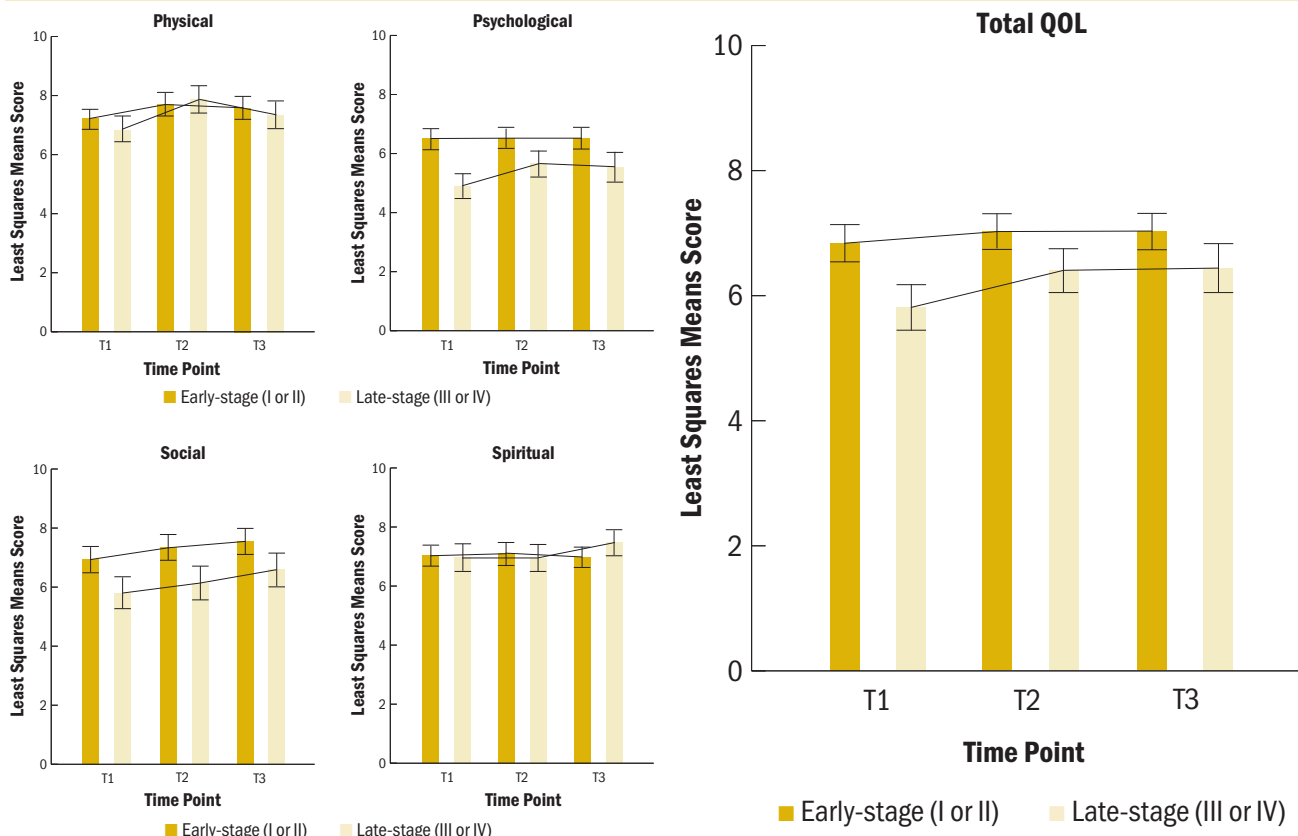
Many participants (n = 11) were very satisfied with communication with their doctors. Most comments focused on symptoms and care team communication. Subthemes were feeling comforted and reassured and communication gaps.

Feeling comforted and reassured: The majority of participants (n = 23) were comfortable communicating their symptoms. They expressed needing to be open in sharing concerns such as fatigue, sexual difficulties, and sleep problems. As a result, they felt

encouraged. One participant stated, “[The doctor] spent extensive time when I came in, which put my mind at ease.” The majority received help to address physical symptoms and sexual concerns. However, some survivors felt uncomfortable discussing emotional and psychosocial concerns.

Communication gaps: Some participants (n = 5) reported limited or inconsistent communication with their cancer team, particularly those who had received care at more than one healthcare site. This resulted in confusion and anxiety. One participant stated, “It seemed like sometimes there were different interpretations by the different doctors of some of my test results. . . . It is just something I am trying to get used to.” One participant voiced concern about missing information regarding osteoporosis and another about next steps with her follow-up care.

FIGURE 3. Mean QOL-CS Total and Subscale Scores Over Time With Standard Error for Survivors of Early- (N = 25) and Late-Stage (N = 18) Gynecologic Cancer



QOL—quality of life; QOL-CS—QOL—Cancer Survivors Model; T1—3 months after enrollment; T2—6 months after enrollment; T3—9 months after enrollment
Note. The QOL-CS is a 41-item instrument with total and subscale scores ranging from 0 to 10, with higher scores indicating better QOL. The subscales of the QOL-CS are as follows: physical (8 items), psychological (18 items), social (8 items), and spiritual (7 items).

TABLE 3. Themes and Quotes

Themes and Subthemes	Description	Quotes
Communication: The essence of care	Healthcare providers' open communication was a source of support affecting women's overall experience of care.	<ul style="list-style-type: none"> ■ "The doctors are absolutely the most knowledgeable and compassionate doctors I have ever had; they saved my life with always being direct and explaining every step and continue to with great love and care. Because of their care I am so confident and at peace with surviving my uterine cancer." ■ "Asking open-ended questions and things that made you feel important. . . . They really were concerned about what was going on. It wasn't just clinical. So, having people who are around who are really interested in you, it helps you feel uplifted, and that's a good thing."
Feeling comforted and reassured	Most participants felt comfortable sharing symptom concerns and felt encouraged by the support received, but some were uncomfortable discussing emotional or other symptoms.	<ul style="list-style-type: none"> ■ "And they always gave me their assurance that everything was going to be OK, everything was moving in the right steps and that it was good for me to . . . express my opinion and ask any questions." ■ "Sleeping is a real issue with me. I sleep maybe 3 hours a night. . . . I never knew who to talk to or anything about it. . . . I guess I just don't share a lot with a lot of people so . . . I just have a hard time talking to people about this stuff."
Communication gaps	Limited or inconsistent communication increased women's anxiety.	<ul style="list-style-type: none"> ■ "I had 3 doctors at City of Hope for a while, but sometimes it seems like doctors don't communicate. For example, sometimes Dr. X tells me to tell Dr. Y, 'x, y, z.'" ■ "Right after I finished the chemo . . . I missed it, or it just wasn't communicated. I felt like I just fell off. I was unsure what happened next." ■ "I found my [computed tomography] scan on my portal after seeing the oncologist and the surgeon. It was not discussed with me."
Battling the demons	Fear of cancer recurrence and uncertainty were common challenges.	<ul style="list-style-type: none"> ■ "I'm already, like, concerned . . . thinking about it. Like, 'Oh, is it coming back? Is it the cancer, or it's something else.' . . . The thought of survival, what I'm gonna do now, what's gonna happen, this fear." ■ "I think I will always have that fear of, you know, the cancer coming back. In a different area of my body. I think I'm learning to deal with it. The fear is always there in the back of my head."
Struggling to cope with the fear	Triggers included emotional or physical symptoms and upcoming scans or laboratory results.	<ul style="list-style-type: none"> ■ "Well, you're always worried that it's come back. And so, every time they do the blood work it's like, OK, when do I get to see the results for the CA-125? . . . My CA-125 was really good. . . . You immediately think, OK, the cancer's back . . . we're gonna have to do all this all over again. . . . It's like, it's not very intelligent to react that way."
Empowered to face the uncertainties	Participants used various strategies to overcome fears, such as reaching out for support and adopting a healthy lifestyle.	<ul style="list-style-type: none"> ■ "I never did talk to my doctors about [recurrence]. I have a counselor up here that I have been seeing since I first got diagnosed. . . . So, I talk about that a lot with her, and . . . I think that helps because she is a cancer survivor as well. . . . So, she completely understands what I'm talking about." ■ "You know you are concerned about cancer coming back and wanting to know how not to have it come back, so I am still trying to get my diet better, less sugar, and concern that the water had chromium-6 in it. . . . Let's get a water filter." ■ "The fear is always there in the back of my head. . . . The way that I've learned to deal with it is having changes in my lifestyle, changes in diet, changes in exercise, and changes in my mindset."

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TABLE 3. Themes and Quotes (Continued)

Themes and Subthemes	Description	Quotes
Coordinated care heightens the patient experience.	Coordinated care fostered well-being as participants navigated treatments and appointments.	<ul style="list-style-type: none"> ■ “They’re always really good about getting me in, and I appreciate that because I’m usually coming from work, and so being able to not have to wait for a really, really long time, the schedules are always trying to make it so you don’t have to drive back here.”
Easing the burden	With good communication and organized care, participants felt supported and less stressed.	<ul style="list-style-type: none"> ■ “City of Hope has a system. That I don’t have to deal with any stress, all I have to do is be well. I don’t have to worry about anything, appointments, finances from my insurance. . . . Everything is excellent.” ■ “You know, I have to say, they have always worked with me really well. I mean, there have been times that I have been scheduled for stuff and I’ve had to call up, and moved stuff or canceled, because I wasn’t doing well. And, you know, it was never a problem.”
Struggling to navigate the system	Care coordination challenges resulted in distress and frustration.	<ul style="list-style-type: none"> ■ “[I had to] make sure my [laboratory tests] were turned in and . . . appointments were coordinated correctly. . . . People taking down information don’t always put all the information that the doctor needs to be able to answer the question. . . . There’s a lot of going back and forth to try to get the correct question to the doctor.” ■ “Communication between doctors at the main campus and the oncologist doctor at the [community satellite] center was very poor. The doctors did not come together as one agreeing to my treatments and the results of my [computed tomography] scan as they should have.”
Survivorship care plan facilitates care coordination.	The survivorship care plan facilitated knowledge about follow-up care. However, some survivors did not find it that helpful.	<ul style="list-style-type: none"> ■ “I think there’s a section in there about who to contact . . . if you have any particular symptoms. Do I go to my local provider here or call them, call City of Hope? Or who do I see about certain things? So I have referred back to that.” ■ “I mean, she went over it with me. . . . I comprehended what was in the plan. I didn’t give it a lot of credibility, and it really wasn’t until the bone thing crept up and I got a little scared that what I should have done is dig it out of the drawer.”
Financial distress	Participants felt stress about treatment costs.	<ul style="list-style-type: none"> ■ “My main concern is the financial part. I haven’t done anything because I’ve been kind of waiting to see at the end what this whole thing was going to be. I really don’t know who to talk to or anything.” ■ “But when I saw what the bill was like \$11,000 for that, and I just . . . I really would have liked to know that it was going to cost that much.”
Navigating supportive care services	Participants expressed needs for accessible supportive services.	<ul style="list-style-type: none"> ■ “Possibly emotional support; however, I live too far away to take advantage of City of Hope resources.”
Access challenges	Some participants experienced challenges related to costs, work- or time-related constraints, or distance from the hospital.	<ul style="list-style-type: none"> ■ “It was more about counseling for mindfulness. I think I used it twice, and I did wanna go more often. . . . It was more misunderstanding of the insurance. . . . They didn’t want to provide the services, so I had to pay out of my pocket, and it was . . . financially, it was hard for me.” ■ “My lymph system was interrupted . . . so I had a lot of swelling in my lower limb and . . . they wanted me here every day for 2 weeks. Well, that’s . . . 4 hours uncomfortable in the car, there was nothing you could do that would make that worth it. . . . Just, the thing that I don’t have is time, because of the job that I have. So, I went back to my employer . . . and they found me a provider that was closer to my home.”

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TABLE 3. Themes and Quotes (Continued)

Themes and Subthemes	Description	Quotes
Peer support	Several requested peer support, including a gynecologic cancer-specific support group, wellness classes, Facebook group, or access to a peer navigator.	<ul style="list-style-type: none"> ■ “I think that a support group for just your type of cancer would be helpful. . . . From a medical standpoint . . . ‘I know what you’re going through.’ You know, ‘This is my story,’ or an activity room that you can go to while you’re getting chemo or something like that, so people are exchanging phone numbers and encouraging one another.” ■ “Maybe have a volunteer reach out to the survivor. Because sometimes people may not always be comfortable reaching out, so it’s good to maybe just, you know, anticipate a need and, you know, have a volunteer group.”

Note. Themes in this table are bolded, whereas subthemes are not bolded.

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: Seven participants expressed worry about cancer recurrence. One stated, “[It’s] a problem for your whole life.” Another stated, “I think just learning to live with that uncertainty has been the hardest part for me.” Four women reported that emotional and physical symptoms contributed to fears including feeling overwhelmed and alone. Distress was heightened when they experienced, as they put it, “[a] little twinge here or there,” “scanxiety,” and while “waiting for CA-125 [laboratory] results.” Three participants had difficulty communicating their fears, with one stating, “I never knew who to talk to. . . . I don’t share a lot with a lot of people so . . . I just have a hard time talking to people about this stuff.”

Empowered to face the uncertainties: To manage uncertainty, participants used various strategies such as reaching out for support, seeking reassurance, adopting a healthier lifestyle, and drawing on inner strength. One participant did not talk with her doctor but reached out to a counselor. Three participants focused on being positive and changing their lifestyles.

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. One participant stated the following:

I was seeing the doctor at a satellite site . . . and I got a really high fever. . . . Getting a hold of somebody that could really help me and tell me what to do . . . took quite a bit of hours and coordinating.

Another participant needed to coordinate aspects of her care. Some reported communication gaps when receiving care at more than one facility.

SCP facilitates care coordination: The SCP provided a record of future appointments and an opportunity for supportive service referrals. Many participants (n = 18) found the SCP information thorough, timely, and helpful. Some reported that it was helpful to know who to contact for symptoms and to understand next steps. Others (n = 6) felt that they, as one participant stated, “could hardly remember anything.” Participants requested more information about nutrition (n = 1) and cancer prevention (n = 1). Sixteen participants felt the timing of delivery was appropriate.

Financial Distress

Financial issues were a common stressor. Participants expressed concerns about a lack of communication and coordination about expenses and resources for assistance (n = 4) and missing work (n = 5). Some became overwhelmed with mounting bills including co-pays and out-of-pocket expenses. One participant stated, “An extra thousand dollars a month in co-pays, it’s starting to get a little pricey.” Another said, “I was concerned about my work and worried that if I had too many [missed] days, it would really affect my work and would create an issue financially and be a burden.”

One participant expressed relief with the assistance from financial services. Although providers discussed financial services with some survivors, not all accepted a referral. Five sought out services on their own, and some developed strategies to prioritize their bills.

Navigating Supportive Care Services

Participants were asked about their follow-up care experience and suggestions for improvement. Comments centered around needing peer support, information about psychosocial services, and access to healthy lifestyle resources. Some participants experienced barriers to accessing services, and others desired additional service availability or referrals. Subthemes were access challenges and peer support.

Access challenges: Twenty-five referrals were documented for 15 survivors including cancer genetics (n = 4), social work for distress (n = 4), lifestyle or integrative therapies (n = 6), and several for exercise, nutrition, pain, physical therapy, or occupational therapy. Seven survivors self-referred to financial services (n = 5), social work (n = 1), and physical therapy (n = 1). Although several were offered information or referrals (n = 15), nine declined, stating they “didn’t need it,” and five declined because of cost, time constraints, or travel distance. Participants requested more information on nutrition (n = 8) and exercise (n = 7). Five suggested integrative therapy services such as meditation or yoga.

Peer support: The most frequently expressed need was a gynecologic cancer-specific support group or program for information exchange and emotional support (n = 7). Other suggestions included a Facebook group, wellness classes, and connecting with a peer volunteer. One participant stated the following:

I think the one-on-one more is just somebody that I could reach out to that wasn’t a doctor. . . . I

wasn’t seeking medical advice, just give me some words of wisdom to get me through because I’m having a tough day.

Discussion

The purpose of this study was to describe survivorship care processes and QOL outcomes following primary treatment completion. Predominant themes were psychosocial concerns, managing side effects, and care coordination. The most common unmet needs as measured by the CaSUN were reducing stress, managing side effects, handling recurrence concerns, and perceiving effective communication between members of the care team. The lowest ranking items on the QOL-CS were distress from initial diagnosis, family distress, and FCR. Participants endorsed high communication ratings in feeling comfortable expressing concerns and follow-up care knowledge but lower ratings in help dealing with difficult feelings. They endorsed low confidence in their knowledge of treatment and prevention of late-stage effects. According to the literature, the most common unmet needs in patients with gynecologic cancer include psychosocial concerns, information, support, being informed about side effects, and care coordination (Beesley et al., 2018; Galica et al., 2022). Younger gynecologic cancer survivors have also reported unmet psychological needs, sexuality concerns, and lack of information about late-stage effects (Mattsson et al., 2020). Other studies confirm that survivors receive inadequate information related to late-stage treatment effects. (Antalis et al., 2019; Galica et al., 2022).

The qualitative findings confirm the quantitative data and provide additional insight about needs and care processes. Financial distress emerged as an additional theme. Although most participants felt supported by their providers’ communication, some reported communication gaps. Seeing multiple specialists may contribute to communication disconnects (Haase et al., 2021). Survivors reported high overall satisfaction with care. However, the qualitative data revealed unmet psychosocial and information needs. Many survivors struggled with ongoing FCR. Fear triggers included experiencing symptoms and waiting for upcoming scans or laboratory results. Needing help with FCR is a prevalent concern in gynecologic cancer survivors (Beesley et al., 2018; Williams et al., 2018). Being informed about test results as soon as possible ranks among the highest needs (Williams et al., 2018). In a study gathering data from an online Twitter discussion forum, ovarian cancer survivors reported feeling lost and receiving

minimal guidance about FCR and common symptoms. Despite these challenges, women found ways to manage their health, including engaging in healthy behaviors and being involved in advocacy or support groups (Thomas et al., 2018).

Although many survivors reported excellent care coordination, some experienced challenges navigating the healthcare system. In other studies, survivors have reported challenges coordinating appointments across multiple health facilities, a lack of local supportive services to address symptoms and concerns, and the need for provider continuity (Mattsson et al., 2020; Williams et al., 2018). Survivors want to be proactively informed about resources to address symptoms and emotional needs (Mattsson et al., 2020; Thomas et al., 2018). In this study, many commented that the SCP facilitated knowledge about follow-up appointments. SCPs may be a practical communication tool and facilitate care coordination (Jefford et al., 2022). For example, SCPs communicate information about late-stage effects and health promotion strategies, and they increase confidence in survivorship knowledge (Antalis et al., 2019; Mayer et al., 2016; Overholser & Callaway, 2019).

Several participants reported ongoing financial strain. Other studies confirm the prevalence of financial toxicity, which is associated with worse QOL outcomes (Bouberhan et al., 2019; Esselen et al., 2020; Ver Hoeve et al., 2021). Incorporating an assessment of financial toxicity into the process of survivorship planning can help identify those needing assistance (Ver Hoeve et al., 2021). The most frequently requested supportive services were peer support and healthy lifestyle resources. Other studies confirm the need for supportive service information and disease-specific peer support (Beesley et al., 2018; Galica et al., 2022; Lisy et al., 2019). Other needs include information about cancer, side effects, support groups, and local services (Williams et al., 2020).

Study limitations included a small convenience sample of survivors presenting with different disease stages. The majority were White and well educated, which limits generalizability of the results.

Implications for Nursing

This research provides insight into survivors' needs and care processes that affect QOL and overall experience. Cancer treatment settings should implement quality indicators to evaluate supportive service delivery in areas including access, provider availability, information provision, and care coordination (Nekhlyudov et al., 2019). These should include

KNOWLEDGE TRANSLATION

- Oncology nurses are ideally suited to assess symptoms, address psychosocial concerns, and provide holistic coaching and education to facilitate self-management skills.
 - Targeted communication approaches and quality indicators, based on input from survivors, caregivers, clinicians, and the community, are needed to facilitate coordinated care, particularly for survivors receiving care at multiple healthcare facilities.
 - Fear of cancer progression or recurrence and other emotional concerns are prevalent and underreported among survivors of gynecologic cancer, requiring ongoing evaluation and individualized care by healthcare teams.
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routine assessment of psychosocial and physical symptoms and treatment side effects using brief screening instruments completed before appointments (Nekhlyudov et al., 2019). Needs assessments can help to guide on-site service delivery or development through community partnerships (Nekhlyudov et al., 2019). Health providers should ask about the effects of cancer treatment on financial status and initiate referrals to social workers or financial support services (Emery et al., 2022).

Survivors want more information about supportive resources, particularly psychosocial, lifestyle, and peer support resources. Nurses play a key role in coordinating care, facilitating communication, and helping survivors cope with emotional concerns (Sekse et al., 2018). Oncology nurse navigators have been shown to improve care continuity, access to services, and patient satisfaction, as well as reduce distress (Rodrigues et al., 2021). With an understanding of healthcare system-level issues and gaps affecting quality survivorship care delivery, nurses can work closely with social workers, psychologists, and other clinicians to facilitate access to psychosocial and supportive care services. Nurses should be familiar with community, local, state, and national support services so they can initiate referrals to cancer support communities and other providers. Providing tailored information can empower survivors to self-manage symptoms, which may facilitate psychological well-being (Galica et al., 2022).

Conclusion

This study describes survivorship care processes, QOL, unmet needs, communication perceptions, confidence in survivorship knowledge, and overall experience with survivorship care. Common unmet

needs include care coordination, symptom management, psychosocial, and financial concerns. Survivors of gynecologic cancer want peer support, accessible psychosocial support services, and healthy lifestyle resources. Using a teamwork approach, nurses should provide education and coaching for managing symptoms and facilitate referrals for psychosocial support and other resources. Healthcare organizations should evaluate system-level factors affecting the patient's experience of care coordination and implement tailored SCPs. Working closely with patient advisory groups and community support organizations will facilitate high-quality survivorship care delivery.

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The authors gratefully acknowledge the patients who generously contributed their time to support this study; the City of Hope clinicians who supported this research; Nora Ruel, MA, for statistical consultation and analysis and Maria De Castro, BSN, RN, for assistance with recruitment and data collection; Maribel Tejada, BS, and Nancy Guerrero-Llamas, MPH, for assistance with data management; Yesel Arvizu, MBA, for technical support; and Deborah Mayer, PhD, RN, AOCN®, FAAN, for her thoughtful review and comments on the manuscript.

No financial relationships to disclose.

Reb, Economou, Cope, Cristea, and Ferrell contributed to the conceptualization and design. Economou completed the data

collection. Tejada provided statistical support. Reb, Economou, Cope, Borneman, Tejada, and Ferrell provided the analysis. Reb, Economou, Cope, Tejada, Han, Cristea, and Ferrell contributed to the manuscript preparation.

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