Contents lists available at ScienceDirect

Gynecologic Oncology Reports

Research Report

Surviving and thriving: What do survivors of gynecologic cancer want?

Rayne Peerenboom [a,b], Sarah A. Ackroyd [a,c], Cecilia Chang [a], Elena Diaz Moore [a], Tilley Jenkins Vogel [a], Melissa H. Lippitt [a], Gustavo Rodriguez [a], Carolyn V. Kirschner [a,*]

[a] NorthShore University Health System, Department of Obstetrics and Gynecology, Evanston, IL, United States
[b] University of Chicago Pritzker School of Medicine, Chicago, IL, United States
[c] University of Chicago Medicine, Department of Obstetrics and Gynecology, Section of Gynecologic Oncology, Chicago, IL, United States

ARTICLE INFO

ABSTRACT

The purpose of this study was to characterize survivorship concerns and survivorship program preferences among gynecologic cancer survivors. Women treated for gynecologic malignancy at our cancer center were surveyed from 1/2019 to 10/2020 on concerns and preferences using a 5-point Likert scale. Descriptive analysis and multivariable logistic regression were performed to describe survivors' concerns/preferences. The most frequent survivorship concerns were fear of cancer recurrence (49.6%), desire to lose weight (40.0%), and long-term side effects (30.7%). The highest ranked survivorship program components included assistance with nutrition (36.5%), weight loss (30.4%), and stress reduction (29.0%). Older patients ($\geq$64 y) were less likely to report concern with losing weight (OR 0.26, $p < 0.05$), sex life (OR 0.18, $p < 0.01$), and strain in family relationships (OR 0.27, $p < 0.05$) compared with younger patients. Compared with ovarian/fallopian tube/primary peritoneal cancer survivors, endometrial cancer survivors were less likely to desire nutritional education (OR 0.06, $p < 0.01$). Participants with advanced cancer were less likely to desire assistance with weight loss than those with early stage cancer (OR 0.23, $p < 0.05$). A significant portion of gynecologic cancer survivors reported a fear of cancer recurrence. Assistance with nutrition and weight loss were the most desired survivorship program components. Variation in patient preferences and differences among clinical subgroups highlight the need for tailored survivorship care.

1. Introduction

By 2030, there will be over 1.5 million survivors of gynecologic cancer in the US (Miller et al., 2019). With ongoing advances in early detection and treatment, this number is only expected to grow (Miller et al., 2019). Survivors of gynecologic cancer experience distinctive disease and treatment-related symptoms, including sexual dysfunction, bladder and bowel dysfunction, lymphedema, peripheral neuropathy, and elevated rates of depression and anxiety (Grover et al., 2012; Horsboel et al., 2019; Lokich, 2019; Schmeler et al., 2010). These late and long-term effects can persist well beyond completion of treatment and greatly impact quality of life (Grover et al., 2012). If we hope to provide effective care across the cancer spectrum, we must work to address the unmet physical, mental, and emotional needs of this unique patient population.

Over 15 years ago, the Institute of Medicine (IOM) released a pivotal report on cancer survivorship, in which they stressed the importance of survivorship care and recommended that all cancer survivors receive a survivorship care plan (SCP) (Hewitt et al., 2006). Although prior models of SCPs have failed to yield significant benefits to patients in randomized controlled trials (Brothers et al., 2013; de Rooij et al., 2017; Hill et al., 2020), gynecologic cancer survivors continue to report substantial unmet informational needs (de Rooij et al., 2018). Survivors therefore need and desire alternative models of survivorship care. Given the variability in gynecologic cancer patients' informational needs (de Rooij et al., 2018), previous survivorship programs may have fallen short due to a lack of patient-centered, disease-specific design, stemming from a paucity of information about what patients desire. In order to implement reliable, effective survivorship programs, we must first understand survivors' self-reported needs and preferences.

Previous studies of gynecologic cancer patients' supportive care needs have focused on preferences during active treatment or utilized measurement tools not specific to gynecologic cancer (Hediya Putri et al., 2018; Hodgkinson et al., 2007). In a recent qualitative study of patient and provider perspectives on gynecological cancer survivorship planning, participants expressed varied preferences for SCP content,

---

* Corresponding author.

although no specific sub-themes were identified (de Rooij et al., 2018). In a Canadian quantitative study of informational needs among gynecologic cancer patients that were either newly diagnosed or undergoing long-term follow-up, six broad educational domains were identified, with patients expressing the highest interest in the medical domain (Papadakos et al., 2012). While these studies provide valuable insight into the supportive care needs of gynecologic cancer patients, there remains a lack of information about gynecologic cancer survivors' specific concerns and preferences for a survivorship program.

The primary objective of this study was to describe gynecologic cancer patients' concerns and care preferences during the survivorship period. Secondary objectives were to assess overall quality of life (QOL) in this patient population and to identify differences in concerns, preferences, and QOL within clinical and demographic subgroups.

2. Methods

2.1. Participants

A cross-sectional observational study was conducted. English-speaking women aged 18 or older who were diagnosed and treated for a gynecologic malignancy at our cancer center between 2018 and 2020 were asked to participate in a survivorship survey by mail between 1/2019 and 3/2019 or prior to attending an in-person survivorship visit between 12/2019 and 10/2020. Participation was voluntary and anonymous. This study was performed in accordance with ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments. As this study was conducted as a quality improvement project it received Institutional Review Board exemption from the Northshore University Institutional Review Board.

2.2. Survey instruments

All data was self-reported including demographics, treatment, survivorship concerns, and preferences for survivorship program content. The survey instrument included 3 major sections relevant to this study: demographic and clinical information, survivorship concerns and preferences for survivorship program content, and the Functional Assessment of Cancer Therapy – General (FACT-G) (Cella et al., 2016).

(1) *Demographic and clinical information.* Demographic information included method of survey administration, timing of survey completion relative to both completion of cancer treatment and the COVID-19 pandemic, race and ethnicity, highest level of education, and relationship status. Clinical information included age at the time of cancer diagnosis, cancer site and stage, date of initial diagnosis, type of prior treatment(s), date treatment was completed (except for oral hormones), and type of current treatment(s).

(2) *Survivorship concerns and preferences for survivorship program content.* A 21-item, non-validated questionnaire was designed to assess participants' concerns regarding their current situation (11 items) and patient preferences for survivorship program content (10 items). Items related to concerns regarding current situation included fear of cancer recurrence, financial concerns, desire to lose weight, strain in family relationships, effect of cancer diagnosis on family, strain on relationship (with spouse, partner, or significant other), concern with sex life, physically not feeling well, emotional wellbeing (stress, anxiety, and depression), body image concerns, and long term side effects of treatment. Items related to survivorship program content included help with managing finances, assistance with weight loss, instruction in nutrition, stress reduction, help with sex life, assistance with relationships, reduction in fatigue, help getting better sleep, treatment of anxiety, and improvement of long-term side effects. Patients' concerns and desires for assistance were assessed using

a 5-point Likert scale with 0 = not helpful/no concern to 4 = extremely helpful/very concerning. The questionnaire was tested for face validity with healthcare providers and refined through an iterative process of review.

(3) *FACT-G (Version 4).* Patients' quality of life was assessed with the FACT-G, a validated 27-question survey addressing physical, social, emotional, and functional well-being among cancer patients using 5-point Likert scales (Cella et al., 2016).

2.3. Analysis measures

Outcome measures of interest included (i) survivorship concerns, (ii) preferences for survivorship program content, and (iii) overall QOL as measured by FACT-G. For the purpose of statistical analysis, survivorship concerns and preferences for survivorship program content were categorized into two groups: Likert score of 0, indicating items that were not helpful or of no concern, vs Likert scores of 1–4, indicating items that were at least somewhat helpful or of some concern. QOL was defined as a continuous variable, according to previously established FACT-G scoring guidelines (Scoring, n.d.).

Six predictor variables were assessed for their impact on each outcome measure. For the purpose of statistical analysis, predictor variables were categorized as follows: timing relative to the COVID-19 pandemic (survey completed before vs during the COVID-19 pandemic), months since completion of treatment (above vs below the median), age at diagnosis (above vs below the median), cancer site (endometrial vs ovarian/fallopian tube/primary peritoneal vs cervical vs uterine sarcoma), stage (0–1 vs 2–4), and relationship status (married/life partner vs separated/divorced/single/widowed).

2.4. Statistical analysis

FACT-G was scored according to established guidelines (Scoring, n. d.). Negatively slated items were reversed before scoring. Individual cases were excluded if the overall response rate was <80% or if the response rate within a subscale was <50%. If the response rate in a subscale was >50%, any missing data was prorated using the average of other answers in the scale. Total scores were calculated as the sum of the un-weighted subscale scores.

Categorical variables were summarized with counts and percentages. Continuous variables were summarized with medians, ranges, and interquartile ranges. Univariate tests of association between clinical and demographic predictor variables and the three outcome measures of interest were performed using Chi-square, Fisher's exact, Wilcoxon rank sum, or Kruskal-Wallis tests, as appropriate. In cases where one or more predictor variable was significantly associated with a survivorship program component or survivorship concern on univariate analysis, multivariable logistic regression was performed. Data were analyzed using SAS 9.4 (Cary, NC). Alpha was set at 0.05 for significance.

3. Results

3.1. Demographic and clinical characteristics

Forty-two of 103 gynecologic cancer survivors completed the survey by mail, and 74 of 74 completed the survey in person, representing an overall response rate of 116 out of 177 (65.5%). Demographic and clinical characteristics are detailed in Table 1. Seventy-four (64%) participants completed the survey prior to their first survivorship visit and 42 (36%) completed the survey by mail. Sixty-two (53%) participants completed the survey prior to the COVID-19 pandemic, and 54 (47%) completed the survey during the pandemic. Median age at diagnosis was 64 years (IQR 56–70). The majority of the participants identified as white/Caucasian (86%), completed some degree of tertiary education (88%), and were either married or had a life partner (63%).

The frequency of gynecologic tumor sites were: 46 (40%) ovarian/

Table 1

Demographic and clinical characteristics of gynecologic cancer survivors.

Demographic or clinical variable	Count (%)[a] unless otherwise noted
Survey administration	
During survivorship visit	74 (64%)
By mail	42 (36%)
Timing relative to pandemic	
Pre-pandemic	62 (53%)
Pandemic	54 (47%)
Age at diagnosis	
Median (IQR[b])	64 (56–70)
Range	28–83
Months from completion of treatment	
Median (IQR)	4.5 (3–7)
Race and ethnicity	
White/Caucasian	100 (86%)
Latinx	5 (4%)
Asian	6 (5%)
Black/African-American	3 (3%)
Other/unknown/declined	2 (2%)
Education	
High school/GED	10 (9%)
Bachelor's Degree	43 (37%)
Master's Degree	46 (40%)
Doctorate	6 (5%)
Some college or 2 year associate	7 (6%)
Other/unknown/declined	4 (4%)
Relationship status	
Single	27 (23%)
Married	69 (60%)
Separated	1 (1%)
Divorced	14 (12%)
Life partner	3 (3%)
Widow	2 (2%)
Tumor site	
Endometrial	40 (34%)
Ovarian	41 (35%)
Fallopian tube	4 (3%)
Peritoneal	1 (1%)
Cervical	6 (5%)
Uterine sarcoma	15 (13%)
Other gyn	3 (3%)
Unknown/declined	6 (5%)
Initial stage	
0	2 (2%)
1	53 (46%)
2	8 (7%)
3	19 (16%)
4	9 (8%)
Unknown	25 (22%)
Past treatment	
Surgery	107 (95%)
Chemotherapy	67 (59%)
Radiation therapy	26 (23%)
Oral hormone	3 (3%)
PARP[c] inhibitor	7 (6%)
Immunotherapy	0 (0%)
Current treatment	
Surgery	0 (0%)
Chemotherapy	1 (1%)
Radiation therapy	0 (0%)
Oral hormone	2 (2%)

Table 1 (*continued*)

Demographic or clinical variable	Count (%)[a] unless otherwise noted
PARP inhibitor	9 (8%)
Immunotherapy	0 (0%)

[a] Percentages may not sum to 100% due to rounding.

[b] IQR refers to interquartile range.

[c] PARP refers to poly adenosine diphosphate-ribose polymerase.

fallopian tube/primary peritoneal, 40 (34%) endometrial, 15 (13%) uterine sarcoma, 6 (5%) cervical, 3 (3%) other gynecologic malignancy, and 6 (5%) unknown/declined. Stage at diagnosis was: 55 (47%) stage 0–1, 36 (31%) stage 2–4, and 25 (22%) unknown. One hundred seven (94%) participants received initial surgery and 96 (83%) received adjuvant chemotherapy and/or radiation therapy, with a median time from completion of treatment to survey administration of 4.5 (3–7) months. Twelve (10%) participants were undergoing maintenance therapy at the time of survey administration, of which 9 (75%) were taking a poly adenosine diphosphate-ribose polymerase (PARP) inhibitor, 2 (17%) were undergoing oral hormone maintenance therapy, and 1 (8.3%) was undergoing cytotoxic chemotherapy.

3.2. Patient-reported survivorship concerns and survivorship care program content preferences

Table 2 details the percent of patients who ranked each survey item on Likert scale above 3 and the percent of patients who ranked each item above 0, as well as median, IQR, and ranges of each item. The top 5 survivorship concerns most frequently ranked 3 or 4 were: fear of recurrence (49.6%), desire to lose weight (40.0%), long-term side effects (30.7%), stress, anxiety, depression (23.5%), and effect of diagnosis on

Table 2

Survivorship concerns and survivorship program content preferences among gynecologic cancer survivors.

Survey Item	% of patients that ranked item 3 or 4	% of patients that ranked item > 0	Median (IQR)	Range
Survivorship Concern				
Fear of recurrence	50	87	2 (1–4)	0–4
Desire to lose weight	40	66	2 (0–4)	0–4
Long-term side effects	31	66	1 (0–3)	0–4
Stress, anxiety, depression	24	68	1 (0–2)	0–4
Effect of diagnosis on family	22	63	1 (0–2)	0–4
Physically not feeling well	19	62	1 (0–2)	0–4
Body image concerns	18	51	1 (0–2)	0–4
Financial concern	15	44	0 (0–2)	0–4
Effect on significant other	8	38	0 (0–1)	0–4
Sex life	8	39	0 (0–1)	0–4
Strain in family relationships	6	33	0 (0–1)	0–4
Survivorship Program Component				
Nutrition	37	64	2 (0–3)	0–4
Weight loss	30	53	1 (0–3)	0–4
Stress reduction	29	60	1.5 (0–3)	0–4
Help with sleep	29	59	1 (0–3)	0–4
Long-term side effects	27	55	1 (0–3)	0–4
Fatigue reduction	25	60	1 (0–3)	0–4
Anxiety	14	48	0 (0–2)	0–4
Sex life	8	29	0 (0–1)	0–4
Finances	7	26	0 (0–1)	0–4
Relationships	4	27	0 (0–1)	0–4

family (22.4%). Physically not feeling well, body image concerns, and financial concerns were ranked 3 or 4 by 19.3%, 18.1%, and 14.8% of participants, respectively. Less than 10% ranked effect on significant other, sex life, and strain in family relationships 3 or 4.

The top 5 survivorship program components most frequently ranked 3 or 4 were: instruction in nutrition (36.5%), assistance with weight loss (30.4%), stress reduction (29.0%), sleep (29.0%), and improved long-term side effects (27.0%). Twenty-five percent of respondents desired survivorship program components focused on reduction in fatigue, and 14% desired assistance with anxiety. Less than 10% desired help with sex life, finances, and relationships.

3.3. Association between clinical/demographic characteristics and survivorship concerns and preferences

We further assessed the association between clinical and demographic factors and the likelihood of ranking each survivorship concern >0 on the 5-point Likert scale (Table 3). On univariate analysis, there was no association between any of the clinical or demographic variables and likelihood of reporting concern regarding fear of recurrence; long-term side effects; stress, anxiety, and depression; effect of diagnosis on family; physically not feeling well; body image concerns; or financial concerns. There was no significant difference in survivorship concerns or survivorship program content preferences before vs during the COVID-19 pandemic (Supplementary Table 1); therefore, timing relative to the pandemic was not included in the multivariable models. On multivariable logistic regression, patients ≥64 years old at initial diagnosis were less likely than patients <64 years old at diagnosis to report concerns regarding desire to lose weight (OR 0.26, 95% CI 0.08–0.82, $P = 0.02$), concerns with sex life (OR 0.18, 95% CI 0.05–0.59, $P = 0.004$), and strain in family relationships (OR 0.27, 95% CI 0.09–0.83, $P = 0.02$). In our sample, cervical cancer survivors were less likely to report concern regarding effect of the diagnosis on spouse, partner, or significant other compared to ovarian/fallopian tube/primary peritoneal cancer survivors (OR 0.23, 95% CI 0.06–0.92, $P = 0.04$).

We similarly assessed the association between clinical and demographic factors and the likelihood of ranking each survivorship program component > 0 on the 5-point Likert scale (Table 3). On univariate analysis, there was no association between any of the clinical or demographic variables of interest and desire for stress reduction, help with sleep, long-term side effects, fatigue reduction, anxiety, sex life, or relationship with significant other as part of the survivorship program. On multivariable logistic regression, patients ≥64 years old at initial diagnosis were less likely to desire assistance with weight loss (OR 0.29, 95% CI 0.10–0.88, $P = 0.03$) and finances (OR 0.17, 95% CI 0.05–0.64, $P = 0.009$) than patients <64 years old at diagnosis. Endometrial cancer survivors were less likely to desire education regarding nutrition compared to ovarian/fallopian tube/primary peritoneal cancer survivors (OR 0.06, 95% CI 0.01–0.36, $P = 0.003$). Participants diagnosed with stage 3–4 cancer were less likely to desire assistance with weight loss than those diagnosed with stage 0–2 cancer (OR 0.23, 95% CI 0.07–0.79, $P = 0.02$).

3.4. Quality of life

Of the 116 gynecologic cancer survivors, 107 (92%) submitted adequate FACT-G responses for analysis, defined as ≥80% of questions answered overall and ≥50% of questions answered in each subscale. FACT-G is a validated 27-question survey assessing physical, social, emotional, and functional well-being among cancer patients using 5-point Likert scales, with a minimum possible score of 0 and maximum possible score of 108. Median QOL in our cohort was 84 (IQR 74–94) (Table 4). There were no significant differences in median QOL when stratified by timing relative to the pandemic (pre-pandemic vs pandemic), marital status (married/life partner vs widowed/divorced/

Table 3
Association between clinical/demographic factors and survivorship concerns and program preferences among gynecologic cancer survivors.

Clinical or demographic variable	Survivorship Concern												Survivorship Program Content								
	Desire to lose weight			Effect on significant other			Sex life			Family relationship strain			Nutrition			Weight Loss			Finances		
	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Months since treatment																					
≥4.5 vs. <4.5	2.26	0.76–6.74	0.14	0.61	0.21–1.78	0.36	1.55	0.50–4.85	0.45	1.47	0.50–4.29	0.48	0.62	0.19–1.98	0.42	2.05	0.72–5.84	0.18	1.28	0.39–4.15	0.69
Marital status																					
Single vs partner[a]	2.60	0.82–8.27	0.10	0.45	0.14–1.41	0.17	0.31	0.09–1.00	0.05	1.00	0.33–3.00	0.98	2.70	0.77–9.50	0.12	2.76	0.91–8.34	0.07	2.40	0.71–8.05	0.16
Age (years)																					
≥64 vs. <64	0.26	0.08–0.82	**0.02**	0.35	0.12–1.05	0.06	0.18	0.05–0.59	**0.004**	0.27	0.09–0.83	**0.02**	0.35	0.10–1.17	0.09	0.29	0.10–0.88	**0.03**	0.17	0.05–0.64	**0.009**
Tumor site																					
Ovarian/fallopian/peritoneal (ref)	–	–		–	–		–	–		–	–		–	–		–	–		–	–	
Cervical	0.93	0.26–3.35	0.91	0.23	0.06–0.92	**0.04**	0.33	0.08–1.35	0.12	1.36	0.38–4.90	0.64	0.37	0.09–1.47	0.16	0.86	0.25–3.01	0.81	0.37	0.09–1.51	0.17
Endometrial	0.59	0.11–3.02	0.52	1.04	0.21–5.19	0.96	2.10	0.36–12.37	0.41	4.83	0.83–28.17	0.08	0.06	0.01–0.36	**0.003**	0.43	0.08–2.22	0.31	0.12	0.01–2.67	0.18
Uterine sarcoma	0.48	0.04–5.30	0.55	0.75	0.09–6.15	0.79	1.55	0.14–17.16	0.72	1.73	0.21–14.40	0.61	0.30	0.02–3.70	0.35	0.37	0.04–3.17	0.36	0.59	0.07–4.97	0.63
Stage																					
3,4 vs. 0,1,2	0.42	0.13–1.38	0.15	0.63	0.18–2.13	0.45	0.96	0.26–3.53	0.96	3.67	1.03–13.13	0.05	0.34	0.09–1.32	0.12	0.23	0.07–0.79	**0.02**	0.69	0.18–2.60	0.58

[a] Widowed/divorced/separated/single vs married/life partner.

Table 4
Median QOL as measured by FACT-G, stratified by key demographic and clinical factors.

Demographic or Clinical Variable	QOL, median (IQR)	P-value*
Overall (n = 107)	84 (74–94)	
Relation to pandemic		0.95
Pre-pandemic (n = 58)	84 (74–96)	
Pandemic (n = 49)	84 (72–94)	
Months since completion of treatment		**0.02**
<4.5 (n = 49)	79 (70–90)	
≥4.5 (n = 51)	90 (78–98)	
Marital status		0.84
Married/life partner (n = 65)	84 (71–94)	
Widowed/divorced/separated/single (n = 42)	82 (75–95)	
Age		0.71
<64 years old (n = 60)	84.5 (75.5–94)	
≥64 years old (n = 47)	82 (72–94)	
Tumor site		0.92
Ovarian/fallopian/peritoneal (n = 40)	82 (75.5–96.5)	
Endometrial (n = 39)	85 (74–94)	
Uterine sarcoma (n = 13)	83 (79–90)	
Cervical (n = 6)	85 (82–101)	
Stage		**0.03**
0, 1, 2 (n = 58)	85.5 (78–95)	
3, 4 (n = 26)	76 (67–93)	

P-values represent Wilcoxon rank sum in cases with 2 comparison groups and Kruskal-Wallis in cases with >2 comparison groups.

separated/single), age (<64 years old at diagnosis vs ≥64 years), or tumor site (ovarian/fallopian/peritoneal vs endometrial vs uterine sarcoma vs cervical). Median QOL of respondents who were ≥4.5 months from treatment was significantly higher than the median QOL of respondents who were <4.5 months from treatment (90 vs 79, p = 0.02). The median QOL of stage 0–2 respondents was significantly higher than that of stage 3–4 respondents (85.5 vs 76, p = 0.03).

4. Discussion

Survivorship is a vital component of cancer care, yet little is known regarding gynecologic cancer survivors' specific needs. In this study we detail key survivorship concerns and preferences for survivorship program content in this patient population. Fear of cancer recurrence and desire to lose weight were the two most prevalent concerns, while assistance with nutrition and weight loss were the two most desired survivorship program components. Importantly, our results demonstrate wide variability in survivorship concerns and survivorship program preferences as well as heterogeneity among clinical and demographic subgroups. These findings add to the literature in support of disease and patient-specific survivorship care (de Rooij et al., 2018; Papadakos et al., 2012). We argue that targeted, precision medicine must not only be applied to cells and molecules during treatment, but also to individuals during the survivorship portion of their journey.

In our study, fear of cancer recurrence (FCR) was the most prevalent survivorship concern. FCR has been previously recognized as a common concern among survivors of gynecologic cancers that may impact various aspects of survivors' psychosocial wellbeing, including emotional and mental functioning, global fatigue, and likelihood of experiencing depression or anxiety (Beesley et al., 2008; Ozga et al., 2015; Simard et al., 2013). Promising interventions to address FCR have emerged in recent years (Tauber et al., 2019). Within this context, our results highlight the need for survivorship programs that not only include information regarding recommended surveillance but also offer evidence-based strategies to mitigate FCR.

Assistance with nutrition and weight loss were the two most desired survivorship program components, which is consistent with existing literature among breast cancer survivors (Smith et al., 2011). In our study, patients with endometrial cancer were less likely to desire assistance with nutrition than patients with ovarian, fallopian tube, or

primary peritoneal tumors. This finding is concerning given the high prevalence of obesity and increased risk of death due to obesity-related factors among endometrial cancer survivors as well as recent evidence that a healthy lifestyle is associated with lower risk of developing cardiovascular disease and type two diabetes among cancer patients (Cao et al., 2021; Güzel et al., 2020). Despite this, few endometrial cancer patients change behavior to achieve diet and exercise recommendations following diagnosis (von Gruenigen et al., 2011). Thus, weight loss is of great concern to gynecologic cancer survivors, yet most face barriers to attempting and achieving weight loss goals. That being said, survivors are more likely to attempt weight loss when counseled by a physician (Clark et al., 2016), and several promising clinical trials are underway to evaluate weight loss interventions among endometrial cancer patients (Case Comprehensive Cancer Center, 2018). Healthcare providers can support patients with weight loss during and after treatment through various interventions, including concurrent bariatric and endometrial cancer surgery, immediate referral to bariatrics during treatment, or referral to weight loss support groups.

A central finding of this study is the substantial heterogeneity in patient concerns and preferences regarding survivorship care. First, we demonstrate that clinical and demographic factors such as age, tumor site, and stage significantly impact survivorship care preferences. Similar differences by age and cancer type have been observed among Canadian gynecologic cancer survivors (Papadakos et al., 2012). Second, we demonstrate wide ranges in responses for each survey item. Put another way, each survivorship concern and each survivorship program component was of no concern to some patients and of the utmost concern to other patients. Thus, in order to effectively address survivors' most salient concerns while simultaneously excluding irrelevant material to avoid information overload, survivorship programs must be tailored to the individual patient.

In our study, younger patients were more likely to desire assistance with weight management, sex life, strain in family relationships, and finances. Younger breast cancer survivors similarly report higher concern levels with exercise, diet, changes to sex life, and the impact of diagnosis on career trajectory (Thewes et al., 2004). By contrast, in a study of supportive care needs of women with gynecologic cancer, finances and sexual functioning were important to patients of all ages (Lopez et al., 2019). Notably, the majority of survivorship concerns were shared by older and younger participants, both in our study and the aforementioned studies. Thus, while age appears to influence survivorship needs and preferences in a few key areas, we caution against uniform changes to survivorship care solely on the basis of age until more nuanced and consistent relationships are elucidated.

We further demonstrate an association between site and stage and survivorship concerns. As previously discussed, endometrial cancer survivors were less likely to desire assistance with nutrition than survivors of ovarian, fallopian tube, or primary peritoneal cancers. In our cohort, survivors of ovarian, fallopian tube, or primary peritoneal cancer were more likely than survivors of cervical cancer to report concern with the effect of their diagnosis on their significant other. Although this is reported as statistically significant, this finding should be further explored in larger cohorts given the low incidence of cervical cancer in our sample. Lastly, patients diagnosed with higher stage cancer were less likely to report concern with weight loss than those with early stage cancer. Given that patients with higher stage disease also reported lower QOL, one potential explanation for these findings is that patients with higher stage disease may be concerned with more basic needs rather than health promotion. Further exploration is necessary to understand these findings; however, what remains clear is that survivorship programs should be developed with each patient's specific disease and treatment history as well as current priorities in mind.

Median QOL as measured by FACT-G in our cohort was consistent with similar cohorts in the literature (Wilailak et al., 2011). In our study, QOL improved significantly with time since treatment and with lower stage disease. This is in accordance with previous evidence of a time

effect on QOL following treatment for gynecologic malignancy (Dos Santos et al., 2019; von Gruenigen et al., 2005). While we may expect QOL to improve over time, these results also highlight an opportunity for providers to proactively intervene earlier in the survivorship period in order to support patients through this difficult time.

Our study provides insight into patient perspectives on specific survivorship program components that would be most useful to gynecologic cancer survivors. However, this study has a number of limitations. First, our sample predominantly identified as white and/or Caucasian, married, and completed tertiary education or more, which may impact generalizability. Second, due to the purely quantitative design of this study, there may be factors not included in our survey instrument that are of concern to gynecologic cancer patients. Future studies could employ a mixed methods design, incorporating open-ended questions to capture additional concerns not included in the quantitative portion. Third, due to the lower incidence of cervical cancer in our sample, our study may not be powered to detect differences in the outcome measures of interest between cervical cancer survivors and other groups. Fourth, although we adjusted for relevant variables in our multivariable models, there may be additional confounders not included in our model which may influence survivorship concerns. Lastly, this study utilized a non-validated survey instrument, as there are no existing validated surveys to assess gynecologic cancer survivors' needs. Notably, patients and providers alike express interest in developing needs assessments to inform survivorship care (Beesley et al., 2020). Thus, the validation of such tools may represent an important future direction in gynecologic cancer survivorship care.

We have characterized key survivorship concerns and preferences of gynecologic cancer survivors, an essential first step towards the development of effective, personalized survivorship care. Fear of cancer recurrence was the most prevalent survivorship concern, while assistance with nutrition and weight loss were the two most desired survivorship program components. Our results demonstrate heterogeneity in self-reported survivorship preferences. Patients therefore need and deserve personalized survivorship care tailored to their unique experiences. Just as precision medicine and targeted molecular therapies have transformed the world of cancer therapeutics, personalized survivorship programs have the potential to transform survivorship care.

Statements and Declarations

CRediT authorship contribution statement

Rayne Peerenboom: Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Sarah A. Ackroyd:** Formal analysis, Writing – review & editing. **Cecilia Chang:** Formal analysis, Writing – review & editing. **Elena Diaz Moore:** Conceptualization, Validation, Writing – review & editing. **Tilley Jenkins Vogel:** Conceptualization, Validation, Writing – review & editing. **Melissa H. Lippitt:** Conceptualization, Validation, Writing – review & editing. **Gustavo Rodriguez:** Conceptualization, Validation, Writing – review & editing. **Carolyn V. Kirschner:** Investigation, Data curation, Supervision, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.gore.2022.101011.

References

Beesley, V., Eakin, E., Steginga, S., Aitken, J., Dunn, J., Battistutta, D., 2008. Unmet needs of gynaecological cancer survivors: implications for developing community support services. Psycho-Oncol. 17, 392–400. https://doi.org/10.1002/pon.1249.

Beesley, V.L., Staneva, A., Nehill, C., Milch, V., Hughes, F., Webb, P.M., 2020. Patterns of, and barriers to supportive care needs assessment and provision for Australian women with gynecological cancer and their caregivers: a mixed-methods study of clinical practice. Pallia. Support. Care 18, 170–177. https://doi.org/10.1017/S147895151900052X.

Brothers, B.M., Easley, A., Salani, R., Andersen, B.L., 2013. Do Survivorship care plans impact patients' evaluations of care? A randomized evaluation with gynecologic oncology patients. Gynecol. Oncol. 129, 554–558. https://doi.org/10.1016/j.ygyno.2013.02.037.

Cao, Z., Xu, C., Yang, H., Li, S., Wang, Y., 2021. The role of healthy lifestyle in cancer incidence and temporal transitions to cardiometabolic disease. JACC: CardioOncol. 3, 663–674. https://doi.org/10.1016/j.jaccao.2021.09.016.

Case Comprehensive Cancer Center, 2018. Referral of Obese Endometrial Cancer Survivors to a Bariatric Specialist and a Healthier Survivorship: A Prospective Intervention Cohort Study (Clinical trial registration No. NCT02342730). clinicaltrials.gov.

Cella, D.F., Tulsky, D.S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S.B., Winicour, P., Brannon, J., 2016. The functional assessment of cancer therapy scale: development and validation of the general measure. J. Clin. Oncol. 11 (3), 570–579.

Clark, L.H., Ko, E.M., Kernodle, A., Harris, A., Moore, D.T., Gehrig, P.A., Bae-Jump, V., 2016. Endometrial cancer survivors' perceptions of provider obesity counseling and attempted behavior change: are we seizing the moment? Int. J. Gynecol. Cancer 26 (2), 318–324.

de Rooij, B.H., Ezendam, N.P.M., Nicolaije, K.A.H., Caroline Vos, M., Pijnenborg, J.M.A., Boll, D., Boss, E.A., Hermans, R.H.M., Engelhart, K.C.M., Haartsen, J.E., Pijlman, B.M., van Loon-Baelemans, I.E.A.M., Mertens, H.J.M.M., Nolting, W.E., van Beek, J.J., Roukema, J.A., Kruitwagen, R.F.P.M., van de Poll-Franse, L.V., 2017. Effects of survivorship care plans on patient reported outcomes in ovarian cancer during 2-year follow-up – the ROGY care trial. Gynecol. Oncol. 145, 319–328. https://doi.org/10.1016/j.ygyno.2017.02.041.

de Rooij, B.H., Thomas, T.H., Post, K.E., Flanagan, J., Ezendam, N.P.M., Peppercorn, J., Dizon, D.S., 2018. Survivorship care planning in gynecologic oncology—perspectives from patients, caregivers, and health care providers. J. Cancer Surviv. 12, 762–774. https://doi.org/10.1007/s11764-018-0713-9.

Dos Santos, L.N., Castaneda, L., de Aguiar, S.S., Thuler, L.C.S., Koifman, R.J., Bergmann, A., 2019. Health-related quality of life in women with cervical cancer. Rev. Bras. Ginecol. Obstet. 41, 242–248. https://doi.org/10.1055/s-0039-1683355.

Grover, S., Hill-Kayser, C.E., Vachani, C., Hampshire, M.K., DiLullo, G.A., Metz, J.M., 2012. Patient reported late effects of gynecological cancer treatment. Gynecol. Oncol. Surviv. CAM Special Sect. 124, 399–403. https://doi.org/10.1016/j.ygyno.2011.11.034.

Güzel, A.B., Khatib, G., Küçükgöz Güleç, Ü., Gümürdülü, D., Vardar, M.A., 2020. The impact of morbid obesity on survival of endometrial cancer. Turk. J. Obstet. Gynecol. 17, 209–214. https://doi.org/10.4274/tjod.galenos.2020.83773.

Hediya Putri, R., Afiyanti, Y., Ungsianik, T., Milanti, A., 2018. Supportive care needs and quality of life of patients with gynecological cancer undergoing therapy. Enferm. Clin. 28, 222–226. https://doi.org/10.1016/S1130-8621(18)30072-X.

Hewitt, M., Greenfield, S., Stovall, E., 2006. From Cancer Patient to Cancer Survivor: Lost in Translation. Committee on Cancer Survivorship: Improving Quality Care and Quality of Life, National Cancer Policy Board. National Academies Press, Washington, DC.

Hill, R.E., Wakefield, C.E., Cohn, R.J., Fardell, J.E., Brierley, M.E., Kothe, E., Jacobsen, P. B., Hetherington, K., Mercieca-Bebber, R., 2020. Survivorship care plans in cancer: a meta-analysis and systematic review of care plan outcomes. Oncologist 25, e351–e372. https://doi.org/10.1634/theoncologist.2019-0184.

Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G.E., Stenlake, A., Hobbs, K.M., Brand, A., Wain, G., 2007. Long-term survival from gynecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes. Gynecol. Oncol. 104, 381–389. https://doi.org/10.1016/j.ygyno.2006.08.036.

Horsboel, T.A., Kjaer, S.K., Johansen, C., Suppli, N.P., Ammitzbøll, G., Frøding, L.P., Lajer, H., Dalton, S.O., 2019. Increased risk for depression persists for years among women treated for gynecological cancers – a register-based cohort study with up to 19 years of follow-up. Gynecol. Oncol. 153, 625–632. https://doi.org/10.1016/j.ygyno.2019.03.259.

Lokich, E., 2019. Gynecologic Cancer Survivorship. Obstetrics and Gynecology Clinics of North America. Gynecol. Cancer Care: Innov. Prog. 46, 165–178. https://doi.org/10.1016/j.ogc.2018.10.002.

Lopez, A.-L.-J., Butow, P.N., Philp, S., Hobbs, K., Phillips, E., Robertson, R., Juraskova, I., 2019. Age-related supportive care needs of women with gynaecological cancer: a qualitative exploration. Euro. J. Cancer Care 28, e13070. https://doi.org/10.1111/ecc.13070.

Miller, K.D., Nogueira, L., Mariotto, A.B., Rowland, J.H., Yabroff, K.R., Alfano, C.M., Jemal, A., Kramer, J.L., Siegel, R.L., 2019. Cancer treatment and survivorship statistics, 2019. CA A Cancer J. Clin. 69 (5), 363–385.

Ozga, M., Aghajanian, C., Myers-Virtue, S., McDonnell, G., Jhanwar, S., Hichenberg, S., Sulimanoff, I., 2015. A systematic review of ovarian cancer and fear of recurrence. Palliat Support Care 13, 1771–1780. https://doi.org/10.1017/S1478951515000127.

Papadakos, J., Bussière-Côté, S., Abdelmutti, N., Catton, P., Friedman, A.J., Massey, C., Urowitz, S., Ferguson, S.E., 2012. Informational needs of gynecologic cancer survivors. Gynecol. Oncol. Surviv. CAM Special Sect. 124, 452–457. https://doi.org/10.1016/j.ygyno.2011.10.030.

Schmeler, K.M., Jhingran, A., Iyer, R.B., Sun, C.C., Eifel, P.J., Soliman, P.T., Ramirez, P. T., Frumovitz, M., Bodurka, D.C., Sood, A.K., 2010. Pelvic fractures after radiotherapy for cervical cancer. Cancer 116, 625–630. https://doi.org/10.1002/cncr.24811.

Scoring [WWW Document], n.d. . FACIT Group. URL https://www.facit.org/scoring (accessed 9.14.21).

Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., Ozakinci, G., 2013. Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. J. Cancer Surviv. 7, 300–322. https://doi.org/10.1007/s11764-013-0272-z.

Smith, S.L., Singh-Carlson, S., Downie, L., Payeur, N., Wai, E.S., 2011. Survivors of breast cancer: patient perspectives on survivorship care planning. J. Cancer Surviv. 5, 337–344. https://doi.org/10.1007/s11764-011-0185-7.

Tauber, N.M., O'Toole, M.S., Dinkel, A., Galica, J., Humphris, G., Lebel, S., Maheu, C., Ozakinci, G., Prins, J., Sharpe, L., Smith, A.".., Thewes, B., Simard, S., Zachariae, R., 2019. Effect of psychological intervention on fear of cancer recurrence: a systematic review and meta-analysis. J. Clin. Oncol. 37 (31), 2899–2915.

Thewes, B., Butow, P., Girgis, A., Pendlebury, S., 2004. The psychosocial needs of breast cancer survivors; a qualitative study of the shared and unique needs of younger versus older survivors. Psycho-Oncology 13, 177–189. https://doi.org/10.1002/pon.710.

von Gruenigen, V.E., Gil, K.M., Frasure, H.E., Jenison, E.L., Hopkins, M.P., 2005. The impact of obesity and age on quality of life in gynecologic surgery. Am. J. Obstet. Gynecol. 193, 1369–1375. https://doi.org/10.1016/j.ajog.2005.03.038.

von Gruenigen, V.E., Waggoner, S.E., Frasure, H.E., Kavanagh, M.B., Janata, J.W., Rose, P.G., Courneya, K.S., Lerner, E., 2011. Lifestyle challenges in endometrial cancer survivorship. Obstet. Gynecol. 117, 93–100. https://doi.org/10.1097/AOG.0b013e31820205b3.

Wilailak, S., Lertkhachonsuk, A., Lohacharoenvanich, N., Luengsukcharoen, S.C., Jirajaras, M., Likitanasombat, P., Sirilerttrakul, S., 2011. Quality of life in gynecologic cancer survivors compared to healthy check-up women. J. Gynecol. Oncol. 22, 103–109. https://doi.org/10.3802/jgo.2011.22.2.103.