Survivorship concerns among individuals diagnosed with metastatic cancer: Findings from the Cancer Experience Registry

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Abstract

Introduction Individuals with metastatic cancer experience many medical, physical, and emotional challenges due to changing medical regimens, oscillating disease states, and side effects. The purpose of this study was to describe the type and prevalence of survivorship concerns reported by individuals with metastatic cancer, and their associations with cancer diagnosis, treatment, and socio-demographic variables.

Methods This study utilized data from the Cancer Support Community's Cancer Experience Registry. Individuals were included if they self-reported a solid tumor metastatic cancer and completed CancerSupportSource, which evaluates five domains of concerns (emotional well-being, symptom burden, body image/healthy lifestyle, healthcare team communication, and relationships/intimacy). Multivariable linear regression examined associations between independent predictors of each survivorship concern domain.

Results Of the 403 included participants, individuals reported a metastatic diagnosis of breast (43%), colorectal (20%), prostate (7%), lung (7%), gynecologic cancer (6%) and other. Nearly all (96%) reported at least one survivorship concern, with the most prevalent concern about cancer progression or recurrence. Survivorship concerns were higher across multiple domains for individuals unemployed due to disability. Individuals who were less than five years since diagnosis reported higher concerns related to emotional well-being, symptom burden, and healthcare communication compared to those more than five years since diagnosis.

Conclusion Individuals with metastatic cancer experience a variety of moderate-to-severe survivorship concerns that warrant additional investigation.

Implications for cancer survivors As the population of individuals with metastatic cancer lives longer, future research must investigate solutions to address modifiable factors associated with survivorship concerns, such as unemployment due to disability.

Keywords Metastatic · Distress · Cancer · Concerns · Survivor · Unmet needs

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Introduction

By 2025, it is estimated that there will be nearly 700,000 individuals living with the most common metastatic cancers in the United States, [1] with an increasing proportion of individuals surviving five or more years post-diagnosis [1]. As people with cancer continue to live longer with the disease, they face unique emotional, physical, behavioral, practical, and social challenges compared to individuals diagnosed with earlier-stage cancer for a variety of reasons. For example, individuals diagnosed with metastatic cancer are more likely to be treated with newer therapies with unanticipated acute and long-term side effects, and

can experience periods with and without active disease [2]. Yet, despite this knowledge, limited research evidence has documented the unique challenges (henceforth referred to as "survivorship concerns") across the metastatic cancer experience [3].

In 2021, the National Cancer Institute hosted a meeting of subject matter experts, researchers, clinicians, survivors, and advocates to evaluate the state-of-the-science surrounding survivorship for individuals living with metastatic cancer [2]. Experts recommended that identifying, characterizing, and tracking survivorship concerns should be a first step to developing survivor-centric intervention and care delivery strategies. Furthermore, these strategies would be strengthened by determining the socio-demographic, clinical, and behavioral factors associated with these concerns. This work would raise awareness of and identify solutions to address survivorship concerns in order to explore new models of care, tailor future metastatic survivorship care plans, and address the holistic needs of individuals diagnosed with metastatic cancer [4]. Previous systematic reviews have captured the types of survivorship concerns in this cancer survivor population [5–8]. However, the included studies were limited by insufficient sample sizes to explore the associations between explanatory factors and survivorship concerns and/or had limited representation from certain subpopulations, including those with less common cancer types, as well as those who have lived long term (5 or more years) with metastatic cancer [5, 9].

Therefore, the goal of this study was to examine the type and prevalence of survivorship concerns of individuals diagnosed with metastatic cancer using the nationwide Cancer Support Community's (CSC's) Cancer Experience Registry. In addition, we sought to identify clinical and socio-demographic characteristics associated with survivorship concerns to inform development of relevant intervention and care delivery strategies for individuals living with metastatic cancer.

Methods

Study sample

The Cancer Experience Registry is an online, community-based research initiative designed to investigate the emotional, physical, practical, and financial impact of cancer. Adults (18 years or older) diagnosed with any cancer type are eligible to participate and invited to complete a web-based survey. Participants are recruited through CSC's network of 190 psychosocial support centers, including CSC and Gilda's Club partners, hospital and healthcare partners, advocacy partnerships, and social media platforms [10].

Eligibility criteria for study sample inclusion were: (1) participation in the CSC Cancer Experience Registry survey between October 2021 to March 2023, (2) living in the U.S., and (3) self-identifying as having a Stage IV or currently metastatic solid tumor. Ethical and Independent Review Services (E&I, Independence, MO) served as the IRB of record (Study #23044-01). Registrants independently reviewed an IRB-approved consent form online and provided their consent by checking an acceptance button prior to beginning the survey. A downloadable copy of the consent form was sent to their email. All procedures were in accordance with the ethical standards of the institutional research committee for studies involving human participants and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The datasets generated from the Cancer Experience Registry for the current study are available upon request of the corresponding author.

Measures

Socio-demographics and clinical history

Participants provided information about age, gender identity, race, Hispanic or Latino ethnicity, annual household income, education, employment status, and insurance coverage. Rural-Urban Commuting Area (RUCA) codes were determined for all respondents who provided their zip code, using census data from January 2022. RUCA codes combine population density with commuting patterns to classify geographies from 1 (most urban) to 10 (most rural); geographical residence was categorized as rural (RUCA code ≥ 4), suburban (RUCA code 2 or 3), and urban (RUCA code 1) [11]. Participants also reported clinical history including primary cancer diagnosis, year first diagnosed with cancer, whether they were currently receiving treatment, and the type of facility where they received treatment.

Survivorship concerns

Survivorship concerns were evaluated using CancerSupportSource (CSS-25), a 25-item distress screening tool that examines physical, social, emotional, and practical concerns plus one additional item examining concern about cancer progression or recurrence (Supplemental Materials) [12–14]. Participants rated their level of concern (0 = not at all; 4 = very seriously) for each item that began with the stem, "Today, how concerned are you about..." (e.g., "Today, how concerned are you about feeling lonely or isolated?" or "Today, how concerned are you about pain and/or physical discomfort?"). Responses were used to compute a domain specific score for each of the five factors identified in prior research [13]: emotional well-being (9 items,

α = 0.90, including one additional item evaluating concerns about cancer progression or recurrence); symptom burden/impact (7 items, α = 0.86, excluding transportation); body image and healthy lifestyle (4 items, α = 0.75); health care team communication (2 items, α = 0.64); and relationships/intimacy (2 items, α = 0.67) [13]. The domain score was calculated as the average item rating across the items comprising the domain.

Analysis

Data were analyzed using Stata, version 17.0 (StataCorp LLP). Descriptive statistics were calculated for all study variables. Survivorship concerns were assessed descriptively by calculating the proportion of respondents who reported being moderately, seriously, or very seriously concerned (scores of 2, 3, or 4, respectively) compared to not at all or slightly concerned (scores of 0 or 1, respectively) for each item. This proportion represented the prevalence of survivorship concerns experienced across the study sample. Analysis of variance and t-tests were used to examine bivariate associations between the five survivorship concern domain scores and potential covariates/independent variables: gender identity (man, woman), married (yes, no), non-Hispanic non-Latino White (yes, no), annual household income <$60K (yes, no), geographic region (urban, rural, suburban), education of at least college degree (yes, no), not employed due to disability (yes, no), insurance type (private, government, private plus government, not insured, other), currently receiving treatment (yes, no), time since diagnosis (< = 2 years, 3–5 years, more than 5 years), most recent primary cancer diagnosis (breast, colorectal, lung, and prostate, other), stage IV at diagnosis (yes, no), has a caregiver (yes, no), and where received most of cancer treatment (large academic or comprehensive cancer center, community hospital or cancer center, private oncology practice, other). Pearson's correlation coefficients were calculated to examine the relationship between survivorship domain scores and age (years).

Multiple linear regression models were built to examine the independent associations of the sociodemographic and clinical history variables with each of the five survivorship concern domains. Variables included in the multivariable models were selected *a priori* based on a literature review of factors associated with unmet needs and concerns in populations with cancer [5–7]. For variables with more than 2 levels, the largest group was chosen as the reference group; pairwise comparisons between group means were performed using contrast tests. To retain the full sample, missing data were imputed using multivariable normal distribution such that the full sample was retained in regression models. The variables with the highest proportion of missing information

were income (21%), geographical region (8%), and insurance type (6%). The STATA suite of mi commands created 50 imputed data sets and averaged results across these data sets for final estimates. All analytic variables were included in the imputation model. Sensitivity analyses with and without the imputed data were conducted. The results of the analyses with and without the imputed data were not qualitatively different; therefore, results from the analysis of the full sample with the imputed data are presented. A p-value of < 0.05 was considered statistically significant.

Results

Table 1 displays the characteristics of the 403 participants included in the analyses. The average age was 58.8 years (range 25 to 82 years), and 78% self-identified as women. Approximately half of the individuals had received or were receiving cancer treatment from a large academic or comprehensive cancer center (47%) and were diagnosed within the last 5 years (54%). The most common cancer types for which participants reported most recently being diagnosed were breast (43%), colorectal (20%), prostate (7%), lung (7%), and gynecologic cancer (6%). Of the 403 participants, 85% were non-Hispanic non-Latino White, 66% received at least a college degree, and 62% were married. Nearly all (96%) of the participants reported having at least one moderate-to-severe cancer-related concern across the five domains; 88% reported a moderate-to-severe concern on at least two separate domains; 76% reported a moderate-to-severe concern on at least three separate domains. Figure 1 conveys the prevalence of self-reported moderate-to-severe survivorship concerns within each domain.

Emotional well-being

The most common moderate-to-severe survivorship concerns were related to emotional well-being: 76% of participants reported moderate to very serious concerns about cancer progressing or recurring, and 60% about the future and what lies ahead (see Fig. 1). Furthermore, 53% of respondents were concerned about family, children, and/or friends, and 51% were concerned about health insurance or money worries. Multivariable analyses indicated that the average rating across emotional well-being concerns was significantly higher among those individuals who were unmarried (β = 0.24, p = 0.037), were unemployed due to a disability (β = 0.37, p < 0.001), were privately insured compared to on a government insurance plan (β = 0.30, p = 0.012), were 2 or fewer years (β = 0.38, p = 0.003) since their cancer diagnosis compared to more than 5 years, or

Table 1 Sample characteristics of individuals with metastatic cancer in the Cancer Experience Registry, October 2021-March 2023 (n=403)

Characteristic	n	%
Age, years (range 25–82)	M = 58.8	SD = 11.9
Age Group		
18–39 years	28	7%
40–64 years	242	60%
65 or more years	133	33%
Gender Identity		
Man	89	22%
Woman	314	78%
Marital Status		
Married	249	62%
In relationship/dating	28	7%
Divorced or separated	68	17%
Widowed	15	4%
Single, not in a relationship	36	9%
Missing	7	2%
Sexual Orientation		
Straight or heterosexual	366	91%
Lesbian, gay, or homosexual	11	3%
Other	17	4%
Missing	9	2%
Race/Ethnicity		
NHNL White	342	85%
NHNL Black	16	4%
Hispanic or Latino, any race	19	5%
NHNL AIAN	2	<1%
NHNL Asian	9	2%
NHNL Other	1	<1%
NHNL, multiple races selected	6	1%
Prefer not to share	8	2%
Annual Household Income		
<$60K	153	38%
$60K or more	166	41%
Missing	84	21%
Region		
Urban	288	71%
Rural	46	11%
Suburban	47	12%
Missing	22	5%
Education		
Less than college	136	34%
College degree	172	43%
Graduate degree or higher	92	23%
Prefer not to share	3	1%
Employment Status		
Employed (full-time, part-time, or temporary)	116	29%
Retired	129	32%
Unemployed, due to disability	127	32%
Unemployed, other reason	26	6%
Prefer not to share/missing	5	1%
Insurance Coverage		
Private	161	40%
Government	160	40%
Private and government	41	10%
Not insured	7	2%

Table 1 (continued)

Characteristic	n	%
Insured, other	9	2%
Missing	25	6
Currently Receiving Treatment		
No	37	9%
Yes	365	91%
Missing	1	<1%
Time Since Diagnosis (Median, IQR)	5	2, 10
Time Since Diagnosis Group		
Less than or equal to 2 years	115	29%
3 to 5 years	100	25%
6 to 9 years	78	19%
10 to 19 years	81	20%
20 or more years	29	7%
Missing	0	0%
Most Recent Primary Cancer Diagnosis		
Breast	175	43%
Colorectal	79	20%
Prostate	30	7%
Lung	30	7%
Gynecologic (endometrial/uterine, cervical, fallopian rube, ovarian, vulvar)	25	6%
Other	64	16%
Stage at Diagnosis		
Stage 0/I	50	12%
Stage II	58	14%
Stage III	57	14%
Stage IV	239	58%
Don't know	8	2%
Has a Caregiver		
No	64	16%
Yes	332	82%
Missing	7	2%
Where Received Most of Cancer Treatment		
Large Academic or Comprehensive Cancer Center	188	47%
Community Hospital or Cancer Center	100	25%
Private Oncology Practice	72	18%
Other	15	4%
Missing	28	7%

Abbreviations NHNL: Non-Hispanic / Non- Latino

Note % calculated out of n = 403; % may not total 100% due to rounding

diagnosed with breast cancer compared to colorectal cancer ($\beta = 0.33$, $p = 0.019$) (Table 2).

Symptom burden and impact

The most prevalent moderate-to-severe symptom burden and impact survivorship concerns were fatigue (57%), sleep problems (51%), and changes or disruptions to daily life activities (45%) (see Fig. 1). The average concern rating for symptom burden and impact was significantly higher among those individuals who lived in a rural compared to urban location ($\beta = 0.29$, $p = 0.030$), were unemployed due to a disability ($\beta = 0.42$, $p < 0.001$), were 2 or fewer years since their cancer diagnosis compared to more than 5 years, or diagnosed with breast cancer compared to colorectal ($\beta = 0.40$, $p = 0.003$), prostate ($\beta = 0.50$, $p = 0.024$), or lung cancer ($\beta = 0.56$, $p = 0.002$) (Table 2).

since their cancer diagnosis compared to more than 5 years, or diagnosed with breast cancer compared to colorectal ($\beta = 0.40$, $p = 0.003$), prostate ($\beta = 0.50$, $p = 0.024$), or lung cancer ($\beta = 0.56$, $p = 0.002$) (Table 2).

Body image and healthy lifestyle

Over half of the respondents reported moderate-to-severe concerns regarding exercising and being physically active (56%) as well as eating and nutrition (52%) (Fig. 1). Multivariable analyses indicated that the average rating across body image and healthy lifestyle concerns was significantly
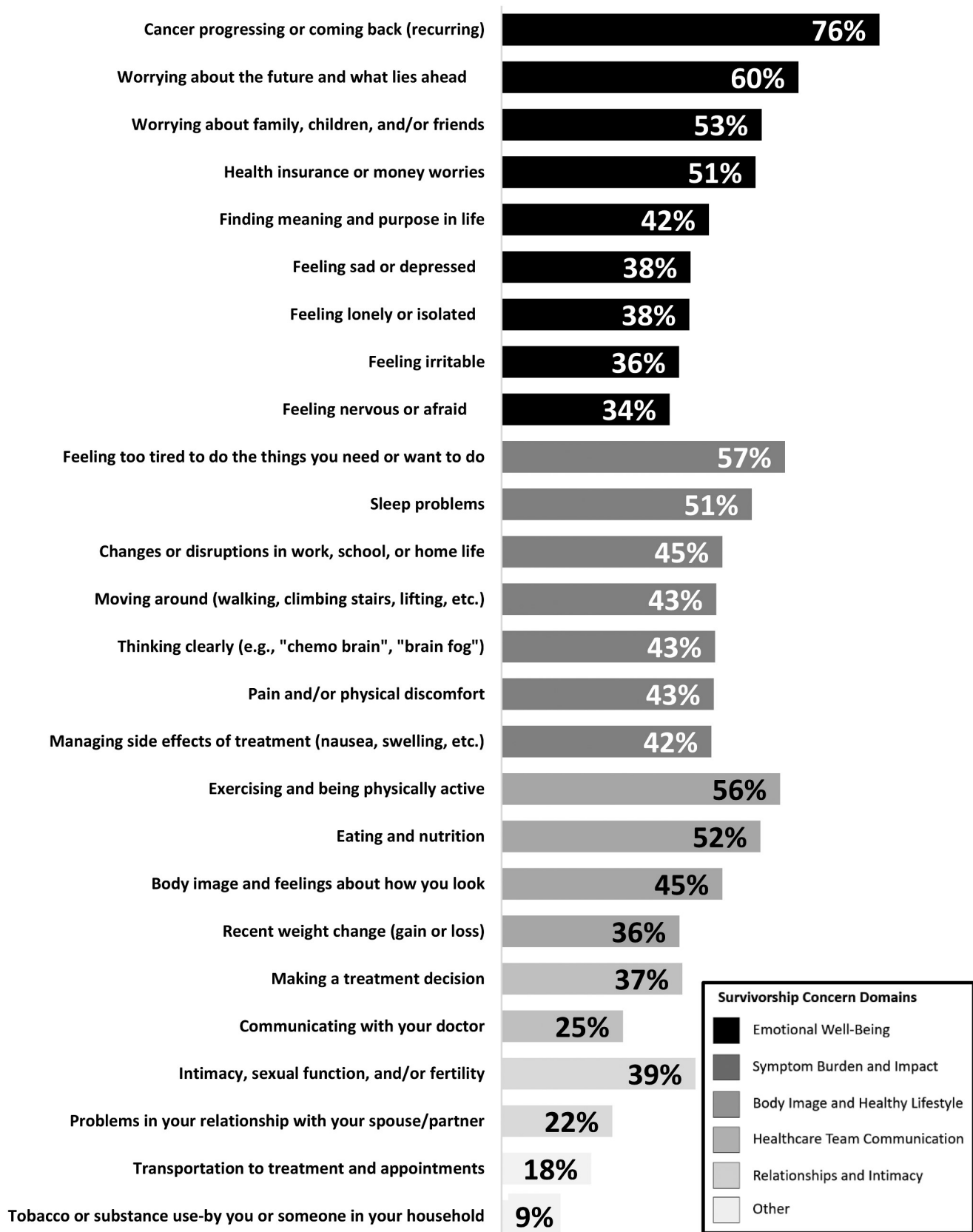
Fig. 1 Prevalence of moderate-to-very serious concerns among individuals with metastatic cancer in the Cancer Experience Registry (n=403)

Table 2 Sociodemographic and clinical characteristics associated with survivorship concerns by domain (multivariate analyses)

Characteristic	Emotional well-being		Symptom burden and impact		Body image and healthy lifestyle		Healthcare team communication		Relationships and intimacy	
	β	p	β	p	β	p	β	p	β	p
Age, years (range 25–82)	-0.008	0.099	-0.004	0.343	<0.001	0.848	-0.009	0.093	**-0.026**	**<0.001**
Gender Identity										
Man	REF		REF		REF		REF		REF	
Woman	-0.03	0.843	-0.07	0.582	0.01	0.933	-0.07	0.687	-0.28	0.096
Married										
Yes	REF		REF		REF		REF		REF	
No	**0.24**	**0.037**	0.20	0.085	0.22	0.071	0.17	0.240	**-0.39**	**0.006**
Race/Ethnicity										
NHNL White	REF		REF		REF		REF		REF	
Other	0.08	0.558	0.19	0.138	0.20	0.163	0.15	0.348	-0.03	0.860
Annual Household Income										
$60K or more	REF		REF		REF		REF		REF	
<$60K	0.24	0.052	0.21	0.085	0.11	0.413	0.19	0.224	-0.17	0.263
Region										
Urban	REF		REF		REF		REF		REF	
Rural	0.18	0.196	**0.29**	**0.030**	0.25	0.084	0.12	0.500	0.16	0.336
Suburban	0.04	0.788	0.005	0.971	0.09	0.527	0.16	0.342	0.03	0.842
Education										
College degree or higher	REF		REF		REF		REF		REF	
Less than a college degree	0.19	0.058	0.18	0.057	0.18	0.091	0.18	0.147	0.23	0.059
Unemployed, due to disability										
No	REF		REF		REF		REF		REF	
Yes	**0.37**	**<0.001**	**0.42**	**<0.001**	0.16	0.145	**0.32**	**0.011**	**0.39**	**0.002**
Insurance Coverage										
Private	REF		REF		REF		REF		REF	
Government	**-0.30**	**0.012**	-0.17	0.147	**-0.25**	**0.049**	-0.07	0.627	0.08	0.582
Private and government	0.01	0.943	0.02	0.920	-0.19	0.241	0.14	0.481	0.08	0.691
Not insured	-0.04	0.915	-0.38	0.251	-0.34	0.342	0.19	0.653	0.06	0.888
Insured, other	0.06	0.832	-0.11	0.713	-0.21	0.521	-0.23	0.544	0.40	0.290
Currently Receiving Treatment										
No	REF		REF		REF		REF		REF	
Yes	-0.17	0.267	-0.12	0.424	-0.01	0.940	-0.26	0.176	0.009	0.961
Time Since Diagnosis										
More than 5 years	REF		REF		REF		REF		REF	
3 to 5 years	0.23	0.057	**0.26**	**0.024**	0.19	0.135	0.27	0.062	**0.31**	**0.034**
<=2 years	**0.38**	**0.003**	**0.33**	**0.007**	0.18	0.192	**0.46**	**0.003**	0.04	0.797
Most Recent Primary Cancer Diagnosis										
Breast	REF		REF		REF		REF		REF	

Table 2 (continued)

Characteristic	Emotional well-being β	p	Symptom burden and impact β	p	Body image and healthy lifestyle β	p	Healthcare team communication β	p	Relationships and intimacy β	p
Colorectal	**-0.33**	**0.019**	**-0.40**	**0.003**	-0.28	0.056	-0.19	0.270	**-0.50**	**0.003**
Prostate	-0.36	0.109	**-0.50**	**0.024**	**-0.61**	**0.011**	-0.16	0.555	-0.17	0.548
Lung	-0.19	0.316	**-0.56**	**0.002**	**-0.47**	**0.018**	-0.15	0.506	-0.12	0.599
Other	-0.13	0.288	-0.10	0.423	-0.17	0.208	-0.10	0.537	-0.12	0.444
Stage IV at Diagnosis										
No	REF		REF		REF		REF		REF	
Yes	-0.03	0.788	< 0.001	0.997	0.06	0.567	-0.11	0.356	0.06	0.633
Has a Caregiver										
No	REF		REF		REF		REF		REF	
Yes	0.11	0.374	0.11	0.343	0.12	0.343	-0.04	0.771	-0.07	0.672
Where Received Most of Cancer Treatment										
Large Academic or Comprehensive Cancer Center	REF		REF		REF		REF		REF	
Community Hospital or Cancer Center	0.08	0.448	0.09	0.423	0.14	0.220	-0.07	0.632	0.05	0.739
Private Oncology Practice	0.04	0.759	0.09	0.447	0.06	0.651	**-0.32**	**0.035**	0.11	0.468
Other	-0.005	0.982	0.05	0.814	0.21	0.408	-0.12	0.685	0.30	0.296

Significant predictors are shown in bold

higher among respondents diagnosed with breast cancer compared to prostate ($\beta = 0.61$, $p = 0.011$), or lung cancer ($\beta = 0.47$, $p = 0.018$) compared to those diagnosed with breast cancer. Furthermore, respondents were more likely to state moderate-to-severe body image and healthy lifestyle concerns if they reported private insurance coverage compared to coverage through a government insurance plan ($\beta = 0.25$, $p = 0.049$).

Healthcare team communication

The most prevalent moderate-to-severe healthcare team communication concern was making a treatment decision (37%) (Fig. 1). One of four respondents reported moderate-to-severe concerns communicating with their doctor (25%). The average concern rating for healthcare team communication was significantly higher among those individuals who were unemployed due to disability ($\beta = 0.32$, $p = 0.011$), who were 2 or fewer years ($\beta = 0.46$, $p = 0.003$) since their cancer diagnosis compared to more than 5 years, and who were treated at an academic or comprehensive cancer center compared to a private oncology practice ($\beta = 0.32$, $p = 0.035$) (Table 2).

Relationships and intimacy

Intimacy, sexual function, and/or fertility (39%) was the most common moderate-to-severe concern regarding relationships and intimacy. Multivariable analyses indicated that the average rating across relationships and intimacy concerns was significantly higher among those individuals who were married ($\beta = 0.39$, $p = 0.006$), unemployed due to a disability ($\beta = 0.39$, $p = 0.002$), 3 to 5 years ($\beta = 0.31$, $p = 0.034$) since their cancer diagnosis compared to more than 5 years, or diagnosed with breast cancer compared to colorectal cancer ($\beta = 0.50$, $p = 0.003$) (Table 2). Furthermore, concerns about relationships and intimacy significantly decreased with increasing year of age ($\beta = -0.03$, $p < 0.001$).

Discussion

This study examined the emotional, physical, behavioral, practical, and social survivorship concerns experienced by individuals diagnosed with metastatic cancer. Nearly all (96%) respondents reported at least one moderate-to-severe concern, with the most common survivorship concerns related to emotional well-being, particularly future-oriented, followed by symptom burden and body image and healthy lifestyle. These findings highlight opportunities to

improve care for individuals with metastatic cancer, both in clinical care and research contexts.

The consequences of common survivorship concerns with emotional well-being were suggested by a recent meta-analysis which revealed that individuals with metastatic cancer who experience emotional well-being concerns, inclusive of anxiety or depressive symptoms, were at risk of lower treatment compliance and higher risk of cancer-specific mortality [15]. Furthermore, unaddressed emotional distress can result in social isolation or constraints, poor management of physical symptom burden, and further emotional decline [16]. Of note, individuals with breast cancer were more likely to report emotional well-being concerns compared to those with other cancer types, after controlling for gender and other demographic variables. This may be due to other well documented relationships between increased reporting of survivorship concerns and body image disruption [17], social isolation and changes in interpersonal dynamics [18], as well as stigma associated with metastatic breast cancer [19] compared to other cancer types. Additional research and clinical efforts should focus on integration and delivery of psychosocial interventions in order to overcome the burden of emotional distress and its downstream consequences. It is worth highlighting that over two-thirds of respondents had concerns about fear of progression or recurrence as well as worries about the future. It will be imperative to develop and refine clinical tools to measure prognosis in metastatic cancer as well as communication tools to support patient-provider communication surrounding disease uncertainty [2, 4]. Future work should also develop education and communication skills trainings to guide mental health professionals and cancer care team members in best practices when supporting individuals with metastatic cancer [20].

From a care delivery perspective, there is limited knowledge about the impact of early adoption and consistent integration of psychosocial care on emotional well-being concerns [21]. Describing current patterns in psychosocial care utilization among metastatic populations may inform individuals of the risk of not receiving psychosocial care as well as inform potential system-level interventions to improve access. Given how interrelated the survivor and family unit are, future research may also develop and test care delivery or programmatic support that extends to the metastatic survivor's family and friends. Over 50% of respondents reported worries about family, children, and friends. Future qualitative research may explore the dyadic care concerns, from the perspectives of both the individual with metastatic cancer as well as family unit members, to optimally tailor emotional programs or care delivery interventions.

The second most prominent survivorship concern domain was symptom burden and impact. Between 20 − 30% of individuals with metastatic cancer are estimated to have been living with metastatic disease for 10 or more years [1]. Whereas novel therapies are enabling individuals with metastatic cancer to live longer, therapy-related toxicities are associated with diverse and persistent symptomatology that can decrease the quality of life among this population [22, 23]. Multi-stakeholder collaboration between pharmaceutical research, healthcare clinicians, and individuals with metastatic cancer could inform clinical benefit and utility of novel treatments in relation to symptom burden, tolerability, and quality of life [24]. Whereas payers and clinicians typically use 5-year benchmarks of overall survival or progression-free survival as key clinical endpoints, individuals with metastatic cancer may highly value alternate endpoints such as longer survival time periods, quality of life, functional independence, and manageable symptom burden. By engaging individuals with metastatic cancer in the design of treatment-related trials and guidelines, there may be greater consideration of priorities and survivorship concerns when evaluating the utility of new therapy regimes. Such a collaboration could facilitate early alignment between goals of treatment with goals of the patient (e.g., patient-centered care) [24] as well as provide greater information regarding patient-valued clinical endpoints, inclusive of symptom burden and impact, to inform treatment decision-making [25].

Individuals with metastatic cancer commonly reported moderate-to-severe concerns regarding their lifestyle and body image. Specifically, over half of respondents reported concerns related to physical activity and nutrition. A recent systematic review found that supportive care interventions incorporating physical activity, lifestyle, and self-management approaches yielded improvements in quality of life and symptom experiences among individuals with metastatic breast cancer [26]. The interventions were, however, quite heterogenous and there was a paucity of research regarding supportive care or lifestyle interventions [27, 28]. This is partially attributed to limited inclusion of individuals with metastatic cancer in lifestyle, and more broadly, intervention trials [29–31]. Future research warrants the development of new lifestyle interventions (e.g., health behavior, physical activity, smoking cessation, nutrition) or refinement of existing interventions from other cancer stages or populations to address this prominent need as well as the inclusion of individuals with metastatic cancer in similar intervention research. Furthermore, cancer centers and community settings should consider the availability of health behavior or lifestyle intervention resources within the community that may support the concerns of individuals with metastatic cancer.

Across the survivorship concern domains, results of this study revealed modifiable and non-modifiable factors associated with greater survivorship concern. By capturing

a variety of survivorship concerns, our findings provide a foundation to develop interventions that can improve the quality of life of individuals living with metastatic disease. Similar to findings of past systematic reviews, gender was not a significant factor related to survivorship concern domains despite cancer type being a predictor [9]. This may be due to cultural differences in reporting survivorship concerns [9] or insufficient representation of men within the sample size to detect differences. Although each domain revealed different factors that placed individuals at higher or lower risk of experiencing a survivorship concern, unemployment due to disability was significantly associated with four of the five domains. Unemployment due to disability underlines the interconnectedness of survivorship concerns and its potential to modify such challenges across cancer type, time since diagnosis, and treatment setting. While many have called for research to develop and test scalable and sustainable ways to improve work-related outcomes for all cancer survivors [32], current intervention research focuses on individuals who are younger and with non-metastatic disease [33, 34]. Future interventional research should test the development of novel or the refinement of existing intervention or environmental approaches (e.g. reasonable accommodations, workplace modification, state or federal policy) that can impact job retention and return-to-work outcomes in this population [35]. Given unemployment's relation to different types of survivorship concerns (e.g., financial, relationship problems, worrying about family), developing and implementing effective work retention and return-to-work strategies, as well as understanding potential policy solutions related to those unable to work may yield valuable benefits.

The findings in this study also indicate that time since diagnosis is associated with multiple survivorship concern domains. There was a high acuity of survivorship concerns during the first five years following diagnosis. Integration of routine screening assessments during this time period will be important to intervene and manage distressing survivorship concerns. Although the findings revealed lower or less severe survivorship concerns relative to time periods further from diagnosis, there were still reports of moderate-to-severe concerns among long-term survivors. Future work may consider understanding which long-term survivors of metastatic cancer are at risk of persistent survivorship concerns to ensure access to supportive care.

This analysis captured the experiences of individuals with a variety of cancer types and time since diagnosis. Thus, the findings respond to calls to study survivorship concerns across clinically diverse metastatic cancer populations [2, 4, 30]. This study provides important information on an under-researched population; however, the results of this study should be viewed in light of certain limitations.

While this sample was drawn from a national registry, it is not considered to be a nationally representative sample. Self-identifying as having a Stage IV or currently metastatic solid tumor was not confirmed via medical chart or health records, which may introduce misclassification bias related to sample selection. Furthermore, the Cancer Experience Registry survey was only conducted in the United States using English language, limiting the generalizability of the findings to non-English speaking populations or citizens living outside of the United States. Given that the sample was primarily women and diagnosed with Stage IV cancer at diagnosis, the results may not generalize to experiences of individuals identifying as male or diagnosed with Stage IV cancer later in the cancer care continuum. Lastly, the cross-sectional study design limited our ability to identify causality between explanatory factors and survivorship concerns. Future research should leverage longitudinal data collection to explore the evolution of survivorship concerns over time and strengthen potential causal inference.

Conclusions

Survivorship concerns are prevalent and pervasive for many individuals diagnosed with metastatic cancer and highlight potential intervention and care delivery solutions. Unemployment due to disability and time since diagnosis were associated with survivorship concerns across multiple domains and emphasize the interconnectedness of survivorship concerns. As the population of individuals diagnosed with metastatic cancer lives longer, future research is warranted to systematically screen for and intervene on these distressing concerns in order to improve care experiences and quality of life for this growing population.

Declarations

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