



Associations between a sense of connection and existential and psychosocial outcomes in gynecologic and breast cancer survivors

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Abstract

Background A cancer diagnosis may lead to existential despair but potentially also to perceived inner growth. This growth may be fostered through meaningful connections with others. We sought to describe existential and related psychosocial outcomes and their association with a sense of connection with others in individuals with gynecological and breast cancers.

Methods We used cross-sectional data from two ongoing cohort studies of gynecologic ($N = 236$) and breast ($N = 62$) cancer survivors at the University of Minnesota. We summarized self-reported post-traumatic growth (PTG), sense of meaning, peace, spirituality, hopelessness, loneliness, and three exploratory measures of sense of connections with others, and used multivariate linear regression models to describe the associations between them.

Results Hope, sense of meaning, peace, and spirituality were generally high among participants, but PTG and loneliness scores varied more. Sense of connection with others was consistently associated with greater PTG and decreased loneliness with medium effect sizes: for example having positive interactions with most/all versus nobody on one's medical team, PTG (coefficient 10.49, 95% CI: 4.10, 16.87, Cohen's D 0.44); loneliness (coefficient -0.85 , 95% CI: -1.36 , -0.34 , Cohen's D 0.43). Those who knew someone in a similar life situation felt a strong sense of connection with such a person; however, 28% of participants had not met anyone in a similar situation.

Conclusions There may be untapped opportunities to nurture beneficial existential outcomes in cancer survivors. Potential interventions include connecting survivors with one another and creating opportunities for more authentic patient-provider relationships, for example, within palliative care.

Keywords Cancer survivorship · Existential outcomes · Psychosocial outcomes · Sense of connection · Post-traumatic growth

Introduction

Cancer is a crisis of one's physical and emotional health and also encompasses an existential dimension by highlighting one's inevitable mortality and often shattering core assumptions about one's place in the world [1, 2]. Conceptualized as existential disruption, cancer can lead individuals to reexamine their lives and values, which, for some, can result in unresolved suffering and despair [3, 4]. However, for others, suffering may eventually lead to positive change and personal growth, which might be considered a desirable side effect of the cancer experience: doubts may lead to insight, despair to poise, and search for meaning to sense-making and purposeful living [5, 6]. Such growth trajectories toward existential maturity, especially after a cancer diagnosis, are described in existential psychology,

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philosophy, and literature [6, 7]. Ideas of existential maturity build on theories of eudaimonia, which stand in contrast to ideas of hedonist well-being [8]. The latter focuses on happiness and minimized suffering, whereas eudaimonic well-being is believed to be achieved through growth and living up to one's authentic self, even if such living entails suffering [5, 8]. Medical practice and research, with their focus on longevity and reduced physical and emotional hardship, typically pay less attention to eudaimonic and existential outcomes and how we might foster them.

One way of facilitating existential maturity might be through meaningfully connecting with others. This hypothesis broadly draws from philosophies on human relationships such as Buber's "I and Thou," Yalom's concept of existential isolation, and narrative hermeneutics, [6, 9–12] with the underlying idea that meaningful connections with others, beyond companionship, make one feel understood and seen through shared vulnerability [13] and peer connection as a pillar of the agency [14, 15]. Building on these ideas, it was the aim of this study to describe existential outcomes (post-traumatic growth [PTG], sense of meaning, peace, and spirituality) and related social/emotional outcomes (loneliness, hopelessness) among individuals with breast and gynecologic cancers and to explore whether these outcomes might be associated with self-reported measures of sense of connection with one's medical team or individuals in similar life situations.

Methods

Study design, study population, and data collection

Data for this cross-sectional analysis came from two ongoing cohort survey studies of gynecologic and breast cancer survivors receiving oncology care at the University of Minnesota Masonic Cancer Center. Methods of the ongoing Gynecologic Oncology—Life after Diagnosis (GOLD) study have been described elsewhere [16]. Briefly, English-speaking individuals aged 18 or older with a previous diagnosis of cancer of the ovary, uterus, cervix, vagina, or vulva were enrolled from spring 2017 to 2020. The ongoing prospective Breast Oncology – Life after Diagnosis (BOLD) study followed similar recruitment (English-speaking individuals with breast cancer aged 18 or older since 2018). The GOLD and BOLD studies are similar in study design, with overlapping self-report survey instruments; however, each study includes unique measures as well. The studies differ in frequency of follow-up assessments (every 4 months in the BOLD study; every 6 months in the GOLD study). Both studies were originally longitudinal; however, the GOLD study transitioned to a cross-sectional study design after recruitment ended in spring 2020, with ongoing but

unrelated cross-sectional surveys going forward. A total of 457 individuals were recruited in GOLD, of which 338 were still alive and remained in the study to complete the summer 2020 cross-sectional survey which was used for this study. A total of 244 (72.2%) participated in the survey, of which 236 (96.7%) completed the outcome instruments used in this study. In BOLD, 175 individuals had been recruited at the time of the study (recruitment is continuing). Of those, 65 had completed the 16-month survey used in this study, with 62 (95.4%) completing the outcome instruments for this study. All participants provided written informed signed consent, and both studies were approved by the University of Minnesota Institutional Review Board (protocol numbers 1612S01581 and 00002747).

Measures

The measures used in this analysis were collected in the 16-month follow-up survey in the BOLD study and the summer 2020 cross-sectional survey in the GOLD study. Our primary outcomes of interest were continuous scores of validated instruments of existential outcomes: hopelessness (Kuopio Ischemic Heart Disease (KIHD) study hopelessness scale), [17] sense of meaning, sense of peace, and spirituality (the three subscales of the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being; FACT-SP 12), [18] PTG (Post-traumatic Growth Inventory Short Form; PTGI-SF), [19] and loneliness (The Direct Measure of Loneliness) [20].

As primary exposures, we created three exploratory measures of participants' sense of connection with others who they have met in the specific context of their cancer experience: (1) connection with individuals in similar life situations: "I have met individuals in a similar life situation as mine (for example, with the same or another illness), and I feel a strong sense of connection with them." ("Not true for anyone in a similar situation" vs. "True for one or several people in a similar situation" vs. "True for most or all people in a similar situation" vs. "Not applicable – I have not met anyone in a similar situation"); (2) quality of the relationships with medical teams: "There is at least one person on my medical team with whom I have meaningful, supportive, or enjoyable interactions." ("no one" vs. "one person" vs. "a few" vs. "most or all people on my medical team"); and (3) patients' impressions of how their medical teams saw them: "The concept of "personhood" aims to capture "what makes you you" (as an individual, which includes aspects of you that have nothing to do with your cancer). Thinking about your medical team, how many people do you feel have made an effort to see you as a person and not just as a patient?" ("no one" vs. "one person" vs. "several" vs. "most or all people on my medical team").

Potential confounders in the multivariate analysis were chosen a priori: age at the survey (years), income (<\$50,000 vs. \$50,000–99,999 vs. \geq \$100,000 vs. prefer not to say), education (no college degree vs. at least a college degree), cancer stage (stage I or II vs. III or IV), and cancer site (breast vs. uterus vs. cervix vs. ovary vs. vagina or vulva).

Statistical analysis

Participant characteristics were summarized using descriptive statistics. We visualized the full outcome and exposure distributions using violin plots from the R *denstrip* package [21]. We used multivariate linear regression models to compare outcome scores between the exposure groups, adjusting for age at the survey, education, income, stage, and primary cancer site using the GLIMMIX procedure in SAS 9.4 [22], reporting adjusted score differences, 95% confidence intervals (CI), and Cohen's *D* as a standardized measure of effect sizes. *P*-values under 0.05 were considered significant. Although there were multiple comparisons, we made no formal adjustments in reporting *P*-values; however, we accounted for the possibility of randomly significant findings in our interpretation of the findings.

Results

Of the 298 participants included in this analysis, 62 (20.8%) had breast, 25 (8.4%) cervical, 109 endometrial (36.6%), 87 ovarian (29.2%), and 15 (5.0%) vaginal or vulvar cancer (Table 1). The mean age at the time of the survey was 61.7 ± 10.9 years. The majority of participants (63.1%) had early-stage disease (stage I or II); two individuals had in situ breast cancer, and 11.5% had metastatic cancer. About half (51.1%) did not have a college degree, and 31.0% had household incomes under \$50,000; most (93.0%) were 2 or more years out from their initial cancer diagnosis.

Figures 1 and 2 visualize the outcome score and exposure distributions. With few exceptions, participants tended to have a high sense of meaning, peace, spirituality, and low hopelessness scores. There was more variation in PTG and loneliness scores: Patients' PTG scores ranged from 0 to 50; mean 27.0 ± 13.3 ; Q1 17; Q3 37; loneliness scores ranged from 0 to 4; mean 1.6 ± 1.1 , Q1 1, Q3 2). Most participants (90.5%) had positive interactions with at least one member of their medical team, and 93.8% stated that at least one member of their medical team was making an effort to see them as a person, not just as a patient. Notably, both of these measures had relatively large missingness ("I do not know" or "prefer not to say" or missing; 12.1% and 13.4%, respectively). A total of 84 (28.5%) of 295 participants stated they had not met anyone in a similar life situation; of the remaining 211 participants, 195 (92.4%) stated that they

Table 1 Demographic and clinical characteristics of the study population, *N*=298, GOLD and BOLD studies 2017–2020

Characteristic	<i>N</i>	%
Age at the cross-sectional survey, years		
<45	29	9.7
45–54	42	14.1
55–64	96	32.2
65–74	110	36.9
\geq 75	21	7.1
Primary cancer site		
Breast	62	20.8
Cervix	25	8.4
Uterus	109	36.6
Ovary	87	29.2
Vagina/vulva	15	5.0
Cancer stage		
In situ	2	0.7
I	146	49.5
II	38	12.9
III	75	25.4
IV	34	11.5
Time since diagnosis at the survey		
<1 year	3	1.1
1–1.99 years	17	5.9
2–4.99 years	215	74.9
\geq 5 years	52	18.1
Education		
No college degree	146	51.1
At least college degree	140	49.0
Household income		
<\$50,000	88	31.0
\$50,000–\$99,999	94	33.1
\geq \$100,000	76	26.8
Prefer not to say	26	9.2

had a strong sense of connection with at least one person in a similar life situation.

Associations between the exploratory measures of connection and outcomes, after adjustment for potential confounders, are shown in Table 2. Given the possibility of randomly significant associations, we focus primarily on findings that were consistently significant across all exposure measures. Individuals with a greater sense of connection reported greater PTG: for example sense of connection with most/all persons in similar life situation versus none or not knowing anyone in a similar situation (coefficient 9.28, 95% CI: 5.17, 13.39, Cohen's *D* 0.55); having positive interactions with most/all members versus no one on the medical team (coefficient 10.49, 95% CI: 4.10, 16.87, Cohen's *D* 0.44); and recognizing that the medical team is making an effort to see one as a person; most/

Fig. 1 Full outcome score distributions (existential and social/emotional outcomes), $N=298$, GOLD and BOLD studies 2017–2020

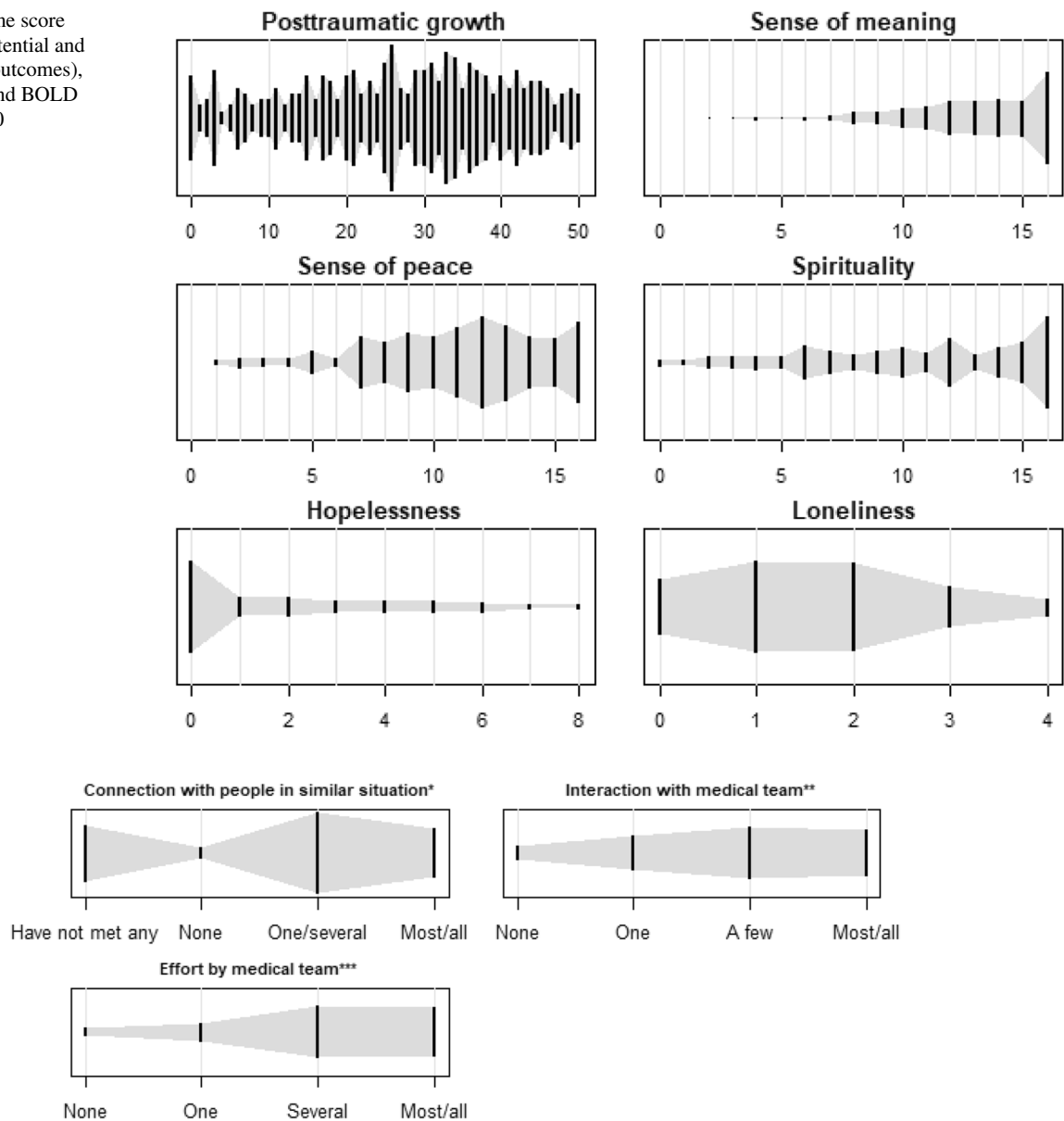


Fig. 2 Exposure distribution (measures of sense of connection), $N=298$, GOLD and BOLD studies 2017–2020. * “I have met individuals in a similar life situation as mine (for example, with the same or another illness), and I feel a strong sense of connection with them.”

all versus no one (coefficient 11.48, 95% CI: 4.17, 18.78, Cohen’s D 0.42). Individuals who had positive interactions with their medical team reported lower loneliness scores (having positive interactions with most/all members versus no one on the medical team [coefficient -0.85 , 95% CI: -1.36 , -0.34 , Cohen’s D 0.43] and recognizing that the medical team is making an effort to see one as a person; most/all versus no one [coefficient -1.16 , 95% CI: -1.74 , -0.57 , Cohen’s D 0.52]). Individuals who had positive interactions with their medical team reported greater spirituality (with most/all members versus no one

** “There is at least one person on my medical team with whom I have meaningful, supportive, or enjoyable interactions.” *** “Thinking about your medical team, how many people do you feel have made an effort to see you as a person and not just as a patient”

on the medical team [coefficient 3.60, 95% CI: 1.69, 5.73, Cohen’s D 0.48]).

We reran our models restricting to individuals with stage III or IV cancer—unadjusted for cancer site because of reduced degrees of freedom—because existential outcomes and associated factors may differ in this group. We found that most associations between the sense of connection and existential and psychosocial outcomes were weaker in this subpopulation than in our main analysis (Supplementary Table 1). However, those who felt seen by their medical team as a person reported improved outcomes (except

Table 2 Multivariate linear regression model estimates of associations between connectedness with others and existential outcomes, *N* = 298, GOLD and BOLD studies 2017–2020

Connection with others in similar life situation			Meaningful, supportive, or enjoyable interactions with my medical team			My medical team made an effort to see me as a person, and not just as a patient					
Value	Coefficient (95% CI)	<i>P</i>	Effect size [‡]	Value	Coefficient (95% CI)	<i>P</i>	Effect size [‡]	Value	Coefficient (95% CI)	<i>P</i>	Effect size [‡]
Post-traumatic growth											
None/have not met any	0 (Ref.)	0.0001		None	0 (Ref.)	0.003		None	0 (Ref.)	0.007	
One/several	3.42 (−0.23, 7.07)	0.07	0.23	One	9.15 (2.54, 15.77)	0.007	0.37	One	9.21 (1.11, 17.31)	0.03	0.30
Most/all	9.28 (5.17, 13.39)	< 0.0001	0.55	A few	11.91 (5.57, 18.24)	0.0003	0.50	Several	12.78 (5.48, 20.08)	0.0007	0.47
		0.39		Most/all	10.49 (4.10, 16.87)	0.001	0.44	Most/all	11.48 (4.17, 18.78)	0.002	0.42
Hopelessness											
None/have not met any	0 (Ref.)			None	0 (Ref.)			None	0 (Ref.)		
One/several	0.12 (−0.48, 0.71)	0.70	0.05	One	−1.25 (−2.29, −0.22)	0.02	0.31	One	−1.13 (−2.38, 0.13)	0.08	0.23
Most/all	−0.33 (−0.98, 0.33)	0.34	0.12	A few	−1.20 (−2.18, −0.21)	0.02	0.32	Several	−0.93 (−2.05, 0.19)	0.10	0.22
		0.10		Most/all	−0.86 (−1.85, 0.14)	0.09	0.22	Most/all	−0.61 (−1.74, 0.52)	0.29	0.14
Sense of meaning											
None/have not met any	0 (Ref.)			None	0 (Ref.)			None	0 (Ref.)		
One/several	0.58 (−0.21, 1.36)	0.15	0.18	One	1.13 (−0.23, 2.50)	0.1	0.22	One	0.92 (−0.74, 2.59)	0.28	0.14
Most/all	0.94 (0.05, 1.83)	0.04	0.26	A few	1.83 (0.53, 3.13)	0.006	0.37	Several	1.03 (−0.46, 2.52)	0.16	0.18
		0.25		Most/all	2.01 (0.70, 3.32)	0.003	0.40	Most/all	1.16 (−0.34, 2.65)	0.12	0.20
Sense of peace											
None/have not met any	0 (Ref.)			None	0 (Ref.)			None	0 (Ref.)		
One/several	0.24 (−0.72, 1.20)	0.62	0.06	One	0.87 (−0.82, 2.56)	0.31	0.13	One	0.43 (−1.64, 2.50)	0.68	0.05
Most/all	0.90 (−0.18, 1.98)	0.10	0.20	A few	1.40 (−0.21, 3.01)	0.09	0.22	Several	1.12 (−0.73, 2.98)	0.23	0.16
		0.14		Most/all	1.71 (0.08, 3.34)	0.04	0.27	Most/all	1.73 (−0.13, 3.59)	0.07	0.24
Spirituality											
None/have not met any	0 (Ref.)			None	0 (Ref.)			None	0 (Ref.)		
One/several	0.49 (−0.76, 1.73)	0.44	0.10	One	3.61 (1.49, 5.73)	0.0009	0.44	One	1.74 (−0.87, 4.36)	0.19	0.17
Most/all	1.41 (0.00, 2.81)	0.05	0.24	A few	3.71 (1.69, 5.73)	0.0004	0.48	Several	1.44 (−0.89, 3.77)	0.22	0.16
		0.12		Most/all	3.60 (1.56, 5.64)	0.0006	0.46	Most/all	2.40 (0.06, 4.73)	0.04	0.27
Loneliness											
None/have not met any	0 (Ref.)			None	0 (Ref.)			None	0 (Ref.)		
One/several	−0.09 (−0.39, 0.22)	0.80	0.07	One	−0.56 (−1.09, −0.03)	0.04	0.27	One	−0.61 (−1.26, 0.04)	0.07	0.24
Most/all	−0.36 (−0.71, −0.02)	0.05	0.25	A few	−0.65 (−1.15, −0.14)	0.01	0.33	Several	−0.82 (−1.40, −0.23)	0.006	0.37
				Most/all	−0.85 (−1.36, −0.34)	0.001	0.43	Most/all	−1.16 (−1.74, −0.57)	0.0001	0.52

Boldface indicate *P*-values < 0.05

[†]All models adjusted for age at baseline, annual household income (<\$50,000 vs. \$50,000–\$99,999 vs. ≥\$100,000 vs. prefer not to say), education (no college degree vs. at least a college degree), cancer stage (in situ/II vs. III/IV), and cancer site (breast vs. cervix vs. ovary vs. uterus vs. vagina/vulva)

[‡]Cohen's *D*

spirituality) with stronger associations and effect sizes than in our main analysis; for example increased PTG (one versus no one on the medical team perceived to make an effort; coefficient 16.72, 95% CI: 6.30, 27.14, Cohen's *D* 0.65), and reduced hopelessness (one versus no one on the medical team perceived to make an effort; coefficient -3.42 , 95% CI: -5.77 , -1.08 , Cohen's *D* 0.65).

Discussion

In our study, individuals with breast and gynecologic cancers reported overall high hope, sense of meaning, peace, and spirituality but mixed PTG and loneliness scores. Most of our measures of connection were associated with greater PTG and decreased loneliness with medium effect sizes. The associations were weaker in individuals with advanced cancer stage, except efforts of the medical team to see one as a person which were more strongly associated with most outcomes. We also found that almost everyone who knew someone in a similar life situation felt a strong sense of connection with such a person; however, more than a quarter of participants reported not having met anyone in a similar situation.

Our study adds to a growing body of literature on existential outcomes in serious illness [3]. Based on Victor Frankl's writings, Breitbart et al. developed meaning-centered psychotherapy for individuals with advanced cancers, which has been successfully rolled out to multiple populations and settings [5, 23–25]. Other existentialist theory-based approaches have further confirmed the effectiveness of similar interventions among individuals with serious illness, [26, 27] including among individuals with early cancer [28]. Our findings also add to a small number of studies on the role of close relationships with others for psychosocial outcomes during serious illness. For example, two studies in Germany found associations of less favorable communication with providers [29] with greater demoralization and of perceived relatedness with others [30] with lower demoralization among patients with cancer.

Overall, our findings suggest potential areas of opportunity with regard to patients' PTG and loneliness. Almost everyone who knew at least one person in a similar life situation stated that they felt a strong sense of connection with such peers. However, 28% of participants did not know anyone in a similar situation. A shared cancer experience may create unique bonds, building on a mutual understanding that is not found in the same way in individuals who do not have cancer or another serious illness. Such bonding experiences may facilitate eudaimonic outcomes such as inner growth and reduce loneliness. A simple step to foster improved existential outcomes in those with cancer may therefore be connecting individuals with cancer with one

another. Barriers to such interventions exist—for example, HIPAA laws protecting patient information and difficulties to reach vulnerable populations such as individuals of color, individuals with limited English proficiency, or individuals with lower socioeconomic status [31]. However, clinicians can proactively encourage participation in cancer support groups, and many peer-support interventions have overcome existing barriers [31–33].

The associations of patient-provider relationships with PTG, loneliness, and other outcomes highlight their potential importance. The manner and quality of patient-provider relationships may especially matter for those with advanced cancer, since we found that in this group, feeling seen as a person, and not just as a patient, was more strongly associated with improved existential and psychosocial outcomes. This suggests that patients with advanced cancer want to be seen for who they are—and not primarily as someone who may die as prognosis worsens. Attempts to change relationships between providers and patients toward more authentic connections have been made within the field of narrative medicine. Briefly, narrative medicine integrates humanist and narrative methods into clinical practices, hypothesizing that such approaches will result in clinical benefits, encourage reflection, nurture empathy, and provide means to deal with the pain and losses of serious illness [34, 35]. In getting at “what really matters,” shared personal narratives may create bonds, give words to concerns, and help patients make sense of their illness and feel seen by those who listen [36, 37]. While it may be challenging to implement narrative approaches within oncological care given time constraints and competing cancer care issues, there may be untapped opportunities for this approach within palliative and survivorship care. The need for expanded palliative care services has been widely recognized [38, 39]. Future research should establish whether narrative medicine might also hold potential benefits for clinicians to decrease burnout: anecdotally, residents have reported perceiving narrative medicine approaches as more authentic than their usual medical training [40].

This study has limitations. We used cross-sectional data and hence cannot speak to the direction of the observed associations. For example, it is possible that those who previously experienced greater PTG or spirituality would judge connections with others more positively; and some associations may be bidirectional: stronger connections with others may benefit existential outcomes, but greater existential maturity may also influence how one perceives connections with others. Our measures of connection with others have not been previously validated. The vast majority of study participants were ≥ 2 years out from cancer diagnosis, and among those diagnosed more recently, associations may differ. Our study population came from one academic institution, and the vast majority of participants

were self-identified White women, which limits our ability to generalize to other populations. It is possible that social desirability bias was introduced in the answers on the quality of interactions with medical teams. Further, the data on the patients with gynecologic cancers were collected in summer 2020, and the SARS-CoV-2 pandemic might have impacted existential outcomes during this time.

Conclusion

While most participants in our study had high existential and related psychosocial outcome scores, PTG and loneliness scores varied more and were associated with a sense of connection with others. There may be untapped opportunities to foster improved existential outcomes in individuals with cancer, and paying closer attention to these patient outcomes captures an important but underutilized dimension of cancer. The existential dimension of cancer should be the subject of future work, including a focus on the potential role of meaningful connections with others in nurturing existential growth, from patients', and possibly even from clinicians' perspectives.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-021-06784-8>.

Author contribution Conception/design: Jewett, Blaes, Vogel, and Galchutt; data analysis: Jewett and Vogel; interpretation of the data: all authors; writing—first draft: Jewett; writing—review and editing: all authors; all authors read and approved the final manuscript and agreed to be accountable for all aspects of the work.

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Availability of data and material Data are not shared due to HIPAA restrictions. Aggregated and de-identified versions of the dataset are available upon request to the corresponding author (Jewett).

Code availability Coding was done in SAS and R. Coding can be made available upon request to the corresponding author (Jewett).

Declarations

Ethics approval The data for this analysis come from the University of Minnesota GOLD and BOLD studies. Both of these studies were approved by the University of Minnesota Institutional Review Board (protocol numbers 1612S01581 and 00002747).

Consent to participate All study participants provided written informed signed consent.

Consent for publication Not applicable. Only aggregated, deidentified results are presented.

Competing interests The authors declare no competing interests.

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