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Exploring the perception of survivors on the bidirectional impact between cancer and their social contexts: A mixed-methods approach

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Abstract

Objective. The purpose of the current study was to use a mixed-methods approach to assess the perspective of cancer survivors on the bidirectional impact between cancer and their social contexts.

Method. A fixed concurrent triangulation mixed-methods survey design was used with open- and closed-ended questions that were predetermined and administered to participants. Quantitative items included demographic questions and the Life Impact Checklist. Qualitative questions were designed to explore the bidirectional impact between the patient and specific contexts including spirituality/faith, the spousal/partner relationship, and the family. A cross-sectional descriptive approach was used to evaluate the quantitative items and the constant comparative method guided the analysis of open-ended questions.

Result. Among 116 participants (mean age 58.4 years), the majority were female (66.7%) with breast cancer (27.9%). Nearly one-half the respondents endorsed a positive impact of cancer on their spirituality/faith, but qualitative results suggested less of a bidirectional impact. The importance of the spouse/partner during the cancer experience was emphasized, including the subthemes of instrumental and emotional support; however, there was often a negative impact of cancer on the spouse/partner relationship, including sexual functioning. Survivors indicated family members provided instrumental and emotional support, but not as regularly or directly as a spouse/partner.

Significance of results. Social contexts are important among cancer survivors, with many cancer survivors relying more on their spouse/partner than other family members for support. The cancer experience is stressful not only for survivors, but also for individuals in their social contexts and relationships.

Introduction

Cancer is among the leading causes of death worldwide, but cancer survivorship in the United States is on the rise. It is estimated that the number of cancer survivors will increase by 31% by 2026. Cancer survivors are also living longer than before; in 2016, 67% of survivors had survived five years or more after their diagnosis (American Cancer Society, 2016). Despite these promising statistics, the cancer experience is still uniquely and profoundly stressful because of the multiple ambiguities that can accompany the disease, including uncertainty of treatment-related decisions, recurrence, when death will occur, and how the disease experience will affect survivor overall well-being and quality of life (Johnson et al., 2016; Li et al., 2014; Weeks et al., 2012; Winner et al., 2017). These biopsychosocial side effects can serve as a consistent and persistent reminder of cancer status for survivors across their lifespan (Kornblith & Ligibel, 2003).

A cancer diagnosis not only affects the survivor; it can affect different social contexts, including spousal, familial, friendships, and work (Siminoff et al., 2008). Survivors have to adapt to physical and emotional changes at multiple points across the cancer experience, which may alter their relationships (Bellizzi et al., 2010; Montazeri, 2009; Sammarco, 2001). These relationships and interpersonal contexts are crucial to cancer survivorship. Specifically, there is a strong body of research that social support is a significant factor for improved quality of life and overall well-being among cancer patients (Balogh et al., 2011; Ell et al., 1992; Roland et al., 2013). Importantly, social support is not defined by the number of individuals in the social network of a cancer survivor, but a multifactorial concept that includes different types of support (e.g., emotional) at different levels (e.g., formal vs. informal). Previous research has demonstrated that survivor perceptions of the “right” type and level of support offered by the “right” person in their social network is associated with more optimal outcomes than simply measuring

perception of support (Fife et al., 2013; Nausheen et al., 2009). For example, a survivor may desire higher levels of emotional support from a spouse/partner, but prefer informational support from a member of their healthcare team.

A better understanding of who or what contexts affect cancer survivors may help researchers and clinicians provide better care for cancer survivors throughout the cancer experience. The Institute of Medicine advocates for a patient-centered approach to cancer care (McCormack et al., 2011). Patient-centered care promotes a more holistic view of the patient that includes consideration of health outcomes important to the patient, as well as consideration of their social contexts (Orom et al., 2018). Measuring unilateral concepts such as “support” may fail to capture the complexity of individual-level variance in support preferences and, thus, inhibit the ability to tailor care to the needs and goals of the survivor. Indeed, research shows cancer patients perceive some support efforts as ineffective, excessive, or unwanted (Li et al., 2013; Shin et al., 2013).

A novel approach to address this topic is to examine the bidirectional influence between a cancer survivor and their social context. Bidirectional, or mutual, influence is a recursive concept that cuts across multiple ecologically oriented theoretical approaches, including family systems theory, ecological systems theory, and the transactional model of development (Bowen, 1966; Bronfenbrenner, 1992; Sameroff & Mackenzie, 2003). Bidirectional influence in the context of the current study suggests the experience of cancer influences the social contexts and relationships of the survivor and vice versa: the social contexts and relationships of the survivor influence the experience with cancer. The concept of bidirectional influence is present within the current body of published research on social contexts of cancer survivors. For example, Hagedoorn et al. (2000) conducted a meta-analysis and reported a moderately strong association in emotional distress among cancer survivors and their spouse/partner ($r = .29$). These data suggested a more interdependent, mutually influential emotional reaction instead of two independent reactions. Most research fails, however, to directly examine the bidirectional relationship between social contexts and the effect of cancer. Focusing on these bidirectional relationships are important to understanding the social contexts that affect the adjustment to cancer across the illness trajectory and how the experience of cancer impacts social contexts and relationships of the survivor (Bellizzi et al., 2007).

The purpose of the current study therefore was to use a mixed-methods approach to assess the perspective of cancer survivors on the bidirectional impact between cancer and their social contexts. A fixed concurrent triangulation mixed-methods survey design was used with open- and closed-ended questions that were predetermined and administered to participants (Creswell, 2003). Quantitative questions were used to assess the magnitude of cancer impact in each context. Qualitative questions were designed to understand in greater depth the bidirectional effect between patients and their environment regarding specific contexts, specifically spirituality/faith, spousal/partner relationship (if applicable), and family. Qualitative and quantitative data were collected simultaneously, analyzed separately, and then merged for cross-validation and interpretation (Figure 1).

Methodology

To accomplish the goals of the current study, an online retrospective survey of cancer patients was conducted. Participants were

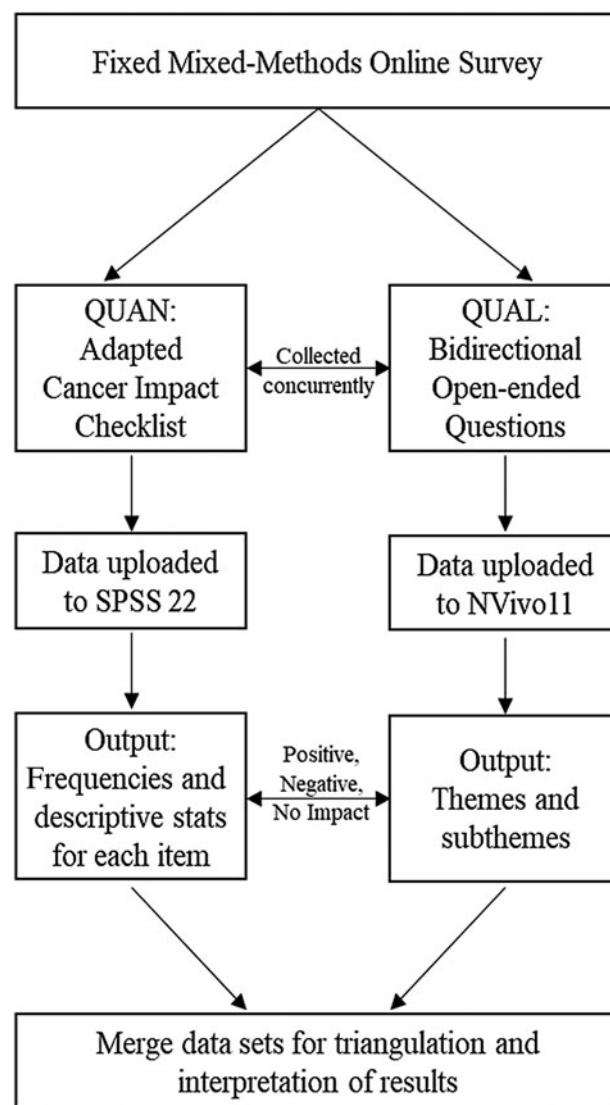


Fig. 1. Study design.

recruited from ResearchMatch®, which is designed to match researchers and potential participants for study recruitment (Harris et al., 2012). Among the volunteers enrolled in ResearchMatch®, 71% are female, 29% are male, and 0.4% are transgender. Volunteers reside in all 50 states across the United States, with Ohio having the densest population of volunteers (~16,000) followed by New York (~10,300), California (~10,200), and Tennessee (~9,300). For purposes of the current study, volunteers who indicated a cancer diagnosis were recruited. Additionally, participants had to be older than 18 years of age, able to read and write English, more than four months postdiagnosis, and currently receiving treatment or follow-up care related to their cancer. This study was approved by the institutional review board (protocol #2017E0678).

Measurement

Demographics

Sociodemographic variables related to the individual participants were collected, including age, race, income, and current

relationship status. Cancer demographics were also assessed, including diagnoses, treatment history, and current cancer status.

Bidirectional impact between cancer and social contexts

To assess the impact of cancer on participants, questions were adapted from the “Impact of Cancer” section of the Adolescent & Young Adult Health Outcomes and Patient Experience Study (Bellizzi et al., 2012). This section of the survey consisted of an 18-item Life Impact Checklist to assess the negative and positive effects of cancer across multiple social contexts (Bellizzi et al., 2007; Ganz et al., 2002). For each item, participants indicated the overall effect of their cancer diagnosis for each social context on a 5-point scale from 1 (very negative) to 5 (very positive). Participants could also select “not applicable” for social relationships and contexts that did not exist in their life.

Using a mixed-methods approach, the breadth of inquiry was expanded as quantitative methods only measured the linear relationship of cancer on social contexts. As such, qualitative questions were designed to explore in greater depth the bidirectional impact between the patient and specific contexts that were indicated as important in previous research including spirituality/faith (e.g., Cohen et al., 2017; Holland et al., 1998, 1999), the spousal/partner relationship (e.g., Kayser, Watson, & Andrade, 2007; Wintre & Gates, 2006), and the family (e.g., Edwards & Clarke, 2004; Milberg, Wählberg, & Krevers, 2014). Each topic area had two open-ended questions to assess the bidirectional impact of cancer. For example, the question “What impact did cancer have on your family?” was followed by “How did your family impact your cancer experience?” Each participant had the opportunity to respond to all open-ended questions unless they were not in a committed relationship during their cancer experience. These participants were not presented with open-ended questions related to a partner/spouse.

Analytic plan

A cross-sectional descriptive approach was used to evaluate the quantitative survey items. Data were analyzed using SPSS, version 24 (IBM, 2016). The listwise deletion procedure was used to manage missing data for the analyses. Data were collapsed and categorized as positive (responses of 4, somewhat positive, and 5, very positive), negative (ratings of 1, very negative, and 2, somewhat negative), and no impact (3) based on the literature (Bellizzi et al., 2007). Qualitative data from open-ended questions were imported into NVivo 11 (QSR International, 2012). The authors read responses to the open-ended questions multiple times to orient themselves to the data. Similar to the format of the quantitative measure, the data were first categorized as “positive,” “negative,” or “no impact.” These three categories served as the three major themes for each question. The authors used the constant comparative method to guide the development of subthemes under the positive and negative categories (Glaser & Strauss, 1967). Similar codes were discussed until a consensus was reached and key subthemes were collectively determined. If there were no patterns in response or a small response size under a positive or negative theme, no subthemes were created.

Results

Approximately 2,500 ResearchMatch volunteers >18 years of age registered as having a cancer diagnosis and received an e-mail containing information related to the survey study. A subset of

Table 1. Demographic variables

	<i>n</i>	<i>M (SD)</i>	Min-max
Age	56	58.43 (12.05)	27.0–86.0
Relationship length, years	79	22.20 (15.43)	1.5–68.0
	<i>n</i>	Valid %	
Gender	111		
Male	36	32.7	
Female	74	67.3	
Annual income, \$	78		
<50,000	17	21.7	
50,000–99,999	34	43.7	
100,000–149,999	13	16.7	
>150,000	14	17.9	
Relationship status	77		
Partnered	54	70.1	
Not partnered	23	29.9	
Education level	90		
<College degree	28	40.0	
Bachelor degree	21	14.4	
Postgraduate degree	41	45.6	
Race/ethnicity	107		
White	83	77.6	
Not white	24	22.4	
Cancer free	92		
Yes	68	73.9	
No	16	13.8	
Don't know	8	6.9	

participants ($N = 242$) met inclusion criteria and expressed interest in participating in the survey and were contacted for more information. Potential participants received an anonymous link to complete the survey, with 119 individuals initiating the survey. After reviewing the data, three participants were excluded because of lack of consent ($n = 1$) or failure to complete the questions after consenting ($n = 2$). The final sample size for the study was 116 participants.

Sample characteristics

The average age of the study participants was 58.43 years ($SD = 12.05$, range 27.0–86.0). Approximately 32.4% were male and 66.7% were female; more than one-half of the sample had a college or postgraduate degree (60.0%) and made >\$50,000 annually (78.3%). Among the 116 participants, 86% indicated a religious/spiritual belief, with the majority stating they were Christian (49%), followed by Catholic (19%). Other religious/spiritual practices reported included Judaism (9%), Buddhism (1%), and other (5%). Last, 16% of participants identified as atheist or agnostic. **Table 1** summarizes participant demographic variables.

Many participants indicated a diagnosis of breast cancer (37.9%) or prostate cancer (16.5%). The average length of

survivorship for participants was 8.36 years ($SD = 6.65$, range 1.0–42.0). Most participants reported receiving multiple cancer treatments, with the highest percentage undergoing surgery (81.1%), chemotherapy (54.7%), or radiation (56.8%). Of note, 73.9% of participants described themselves as currently cancer free at the time of data collection versus 13.8% and 6.9% of individuals who responded that they either had recurrent disease or were unsure, respectively.

Quantitative results

After combining and transforming the items on the Adolescent & Young Adult Health Outcomes and Patient Experience Study, the social context that participants perceived to be affected most positively by the experience of cancer was their relationship with their spouse/partner (55% positive, 30% negative, and 13% no impact). The social context most frequently rated with a negative effect was sexual functioning and intimate relations (5% positive, 75% negative, 20% no impact). Table 2 summarizes the frequency statistics for each item. Descriptive statistics for each scale item are noted in supplemental Table 1.

Qualitative results

The qualitative analysis procedure revealed subthemes associated with both positive and negative effects for each topic area. Tables 3–5 summarize the qualitative results, including counts associated with the organizing themes related to each topic area, subthemes, and exemplar quotes. Subthemes were described and presented with quotations.

Spirituality/ faith

Effect of spirituality/faith on the cancer experience

For participants who reported an impact of spirituality/faith beliefs on their experience with cancer (either positive or negative vs. no impact), the majority were positive. The most dominant subtheme was putting trust in God or a higher power.

“I knew God would not give me anything I could not handle...”

Participants that cited a negative impact on their cancer experience reported anger toward God or their higher power.

“Actually, I was pretty angry at my higher power when going through treatment...”

Effect of cancer on spirituality/faith

When participants reported a positive impact, they discussed a strengthening of their beliefs.

“I found myself praying more and thinking in a spiritual way more often.”

Similar to the previous question, participants who reported a negative impact discussed anger and doubts with God or a higher power.

“Took a long time... for my trust to come back.”

Spouse/ partner

Effect of spouse/partner on the cancer experience

Participants who reported that their spouse or partner had an impact on the cancer experience reported a positive impact only. Two themes emerged in this question that were classified as emotional and instrumental support. Descriptions of emotional

support included love, encouragement, and being “there for one another.”

“He went with my [treatment] decision and stayed by my side.”

“The encouragement my partner gave me made me confident that the decisions were the best for me.”

Instrumental support included processing, researching, and gathering information related to cancer.

“She is a retired nursing professor and was able to read and understand the research...”

“We attend all medical appointments together. My wife is a better note-taker than I am. We discussed what we heard...”

Impact of cancer on the spouse/partner relationship

Unlike the previous question, the majority of participants who discussed an impact of cancer on the spouse/partner relationship more frequently reported negative effects, including relationship strain and sexuality/intimacy challenges.

“It stressed our relationship. We separated a few times in 10 years.”

“Pretty well ended our sex life.”

“We have had some issues being intimate because sometimes sex is painful.”

Participants did report some positive impacts of cancer on their relationship, including an improved relationship and closeness.

“Wrestling with all the complexities that attend cancer strengthened us as a couple... We value each other even more than before.”

“In many ways, it brought us closer together.”

Family

Effect of family on the cancer experience

Similar to spouse/partner, respondents who indicated that their family affected their cancer experience positively said that family supported their decisions through treatment and helped them process information (instrumental support).

“My children were supportive of whatever I decided.”

“They came to appointments, listened, asked good questions, and supported my decisions.”

An additional positive subtheme emerged; family members (often in association with children/grandchildren) served as motivation and inspiration to keep going through the cancer experience.

“I want to see my grandsons grow to adulthood.”

“Because I have a young daughter, I opted for the most aggressive treatment options.”

There were a few negative experiences around poor interactions with family members. Because of limited responses, there was no subtheme and all responses were classified as “negative experiences.”

“My daughter... is disappointed that I am doing the medications that the oncologist wants me to take.”

Although it was not considered a subtheme, participants who reported that their family had no effect on their cancer treatment did note that their spouse/partner was still an exception to that rule, reemphasizing the importance of the spousal role during the cancer experience.

Impact of cancer on the family

There was a mix of positive and negative responses for participants who discussed the impact of cancer on their family

Table 2. Frequencies for AYAHOPE/Life Impact Scale ($N = 117$)

	n^*	Positive	Negative n (valid %)	No impact
Relationship with your mother	53	23 (43.4)	8 (15.1)	22 (41.5)
Relationship with your father	39	18 (46.2)	4 (10.3)	17 (43.6)
Relationship with your sibling(s)	88	46 (52.3)	10 (11.4)	32 (36.4)
Relationship with your spouse/partner	53	32 (60.4)	14 (26.4)	7 (13.2)
Relationship with your child(ren)	67	31 (46.3)	13 (19.4)	23 (34.3)
Relationship with your friends	101	51 (50.5)	14 (13.9)	36 (35.6)
Dating life	26	2 (7.7)	9 (34.6)	15 (57.7)
Plans for getting married	22	0 (0.0)	7 (31.8)	15 (68.2)
Sexual functioning/intimate relations	89	4 (4.5)	67 (75.3)	18 (20.2)
Plans for having children	23	1 (4.3)	9 (39.1)	13 (56.5)
Spirituality and religious beliefs	85	42 (49.4)	7 (8.2)	36 (42.4)
Plans for the future and goal-setting	96	36 (37.5)	35 (36.5)	25 (26.0)
Feelings about the appearance of your body	98	6 (6.1)	60 (61.2)	32 (32.7)
Confidence in your ability to take care of your health	100	29 (29.0)	39 (39.0)	32 (32.0)
Control over your life	100	21 (21.0)	53 (53.0)	26 (26.0)
Plans for education	46	5 (10.9)	12 (26.1)	29 (63.0)
Plans for work	79	13 (16.5)	38 (48.1)	28 (35.4)
Financial situation	91	6 (6.6)	48 (52.7)	37 (40.7)

*For each life impact item, there are different percentages of the sample for which the question does not apply. "Does not apply" was treated as missing.

Table 3. Summary of themes and subthemes for the bidirectional impact between cancer and spirituality/faith

Question	Theme*	Subtheme	Exemplar quotes
Impact spirituality/faith on the cancer journey ($n = 71$)	Positive ($n = 26$)		It makes me value life.
		Trust in God/higher power	I knew God would not give me anything I could not handle...
	Negative ($n = 2$)		I was pretty angry with God.
		Anger with God	Actually, I was pretty angry at my higher power when going through treatment...
	No impact ($n = 43$)		It didn't. But I did decide I wanted to live, so I got treatment.
Impact of cancer on spirituality/faith ($n = 70$)	Positive ($n = 24$)		I found myself praying more and thinking in a spiritual way more often. I prayed for strength and healing.
		Strengthened beliefs system	I found myself praying more and thinking in a spiritual way more often.
	Negative ($n = 7$)		It did make me question why. I guess I felt that I had led a life helping others and been a good person, why did I get cancer.
		Anger and doubts of God/higher power	I was angry with God and we didn't speak for a while.
	No impact ($n = 39$)		None...it remained the same.

*Themes are organized by a positive, negative, no impact framework.

members. When discussing the negative impact, participants most often discussed the concern or worry (emotionally taxing) of their family members.

"My son was very upset and did not tell me. He ended up with a [driving under the influence violation] three days after my surgery ; he has never been in trouble."

Participants who reflected on the positive impact of cancer discussed the concept of support and many respondents also

noted increased feelings of closeness and communication throughout the cancer experience.

"It brought us all closer. We communicate better. I see some of my family much more often than before."

Discussion

The current study used a mixed-methods approach to assess the effect of cancer across multiple social contexts (who/what) and

Table 4. Summary of themes and subthemes for the bidirectional impact between cancer and spouse/partner relationship

Question	Theme*	Subtheme	Exemplar quotes
Impact of spouse/partner on the cancer journey† (n = 50)	Positive (n = 36)	Stayed Positive	
	Emotional support		The encouragement my partner gave me made me confident that the decisions were the best for me
	Instrumental support		We attend all medical appointments together. My wife is a better note-taker than I am. We discussed what we heard...
	Negative (n = 0)	—	
	No impact (n = 11)		I made my own decisions. He did not influence me.
Impact of cancer on the spouse/partner relationship† (n = 49)	Positive (n = 18)		She went above, and beyond, in my thinking, in supporting me, and taking care of me.
	Improved relationship and closeness		Wrestling with all the complexities that attend cancer strengthened us as a couple... We value each other even more than before.
	Negative (n = 20)		...He portrayed himself as the one who was impacted the most by my cancer treatment (the inconveniences, etc.).
	Relationship strain		It stressed our relationship. We separated a few times in 10 years.
	Sexuality and intimacy challenges		We have had some issues being intimate because sometimes sex is painful.
	No impact (n = 10)		No impact on the relationship.

*Themes are organized by a positive, negative, no impact framework.

†Participants who did not indicate they were in a relationship during their cancer treatment did not receive open-ended questions about a spouse/partner relationship.

Table 5. Summary of themes and subthemes for the bidirectional impact between cancer and the family

Question	Theme*	Subtheme	Exemplar quotes
Impact of family on the cancer journey (n = 79)	Positive (n = 32)		Positive, lots of encouragement.
	Instrumental support		They came to appointments, listened, asked good questions, and supported my decisions.
	Motivation and inspiration		I want to see my grandsons grow to adulthood.
	Negative (n = 3)		My daughter... is disappointed that I am doing the medications that the oncologist wants me to take.
	No impact (n = 44)		They had no influence; I decide what happens in my medical care 100%.
Impact of cancer on the family (n = 78)	Positive (n = 15)		It increased their awareness of how prevalent the cancer is in or family and triggered contact with their doctors.
	Improved closeness and communication		It brought us all closer. We communicate better. I see some of my family much more often than before.
	Negative (n = 41)		I am unable to provide any caregiving to my 92-year-old father.
	Emotionally taxing		My son was very upset and did not tell me. He ended up with a [driving under the influence violation] I three days after my surgery, he has never been in trouble.
	No impact (n = 22)		It had little or no impact.

*Themes are organized by a positive, negative, no impact framework.

explore the bidirectional impact of cancer on specific contexts in greater depth (how). The specific contexts that were examined included spirituality/faith, spousal/partner relationship (if applicable), and family. Herein, we provide an integration, triangulation, and interpretation of the quantitative and qualitative results. Specifically, within the quantitative part of the survey, almost one-half of respondents endorsed the positive impact of cancer on their spirituality/faith; in contrast, within the qualitative responses, most participants suggested that there was no impact of spirituality/faith on their cancer experience ($n = 43$) or that the cancer diagnosis had an effect on their spirituality/faith ($n = 39$; Table 3). To this point, there is a growing body of evidence in the literature that has suggested a relationship between religious/spiritual beliefs and the way patients experience illness and disease (Koenig, 2012;

Puchalski, 2012, 2013; Savel & Munro, 2014). Within the open-ended responses, participants did not mention finding or abandoning a spiritual/religious practice as a result of their cancer experience; thus, a cancer diagnosis may deepen the importance, through bidirectional influence, of spirituality/faith among patients who already possess these beliefs, spirituality/faith may not become an important factor in the cancer experience of patients who did not identify with a particular spiritual/faith practice.

Within the subset of respondents who did report an effect (either positive or negative) between cancer and spirituality/faith, the majority said the effect was positive. A positive subtheme that emerged from the question examining the impact of faith spirituality on the cancer journey was putting trust in a higher power. Putting trust in God or a higher power may have

supported positive coping and adjustment that strengthened the patient's belief system, which was a positive subtheme that emerged from the effect of cancer on spirituality/faith. Indeed, spirituality/faith can be an important resource for patients diagnosed with cancer that facilitate positive coping, psychosocial adjustment, acceptance of prognosis, and meaning-making across the cancer trajectory (Pargament *et al.*, 2004; Peteet & Balboni, 2013; Wright *et al.*, 2008). Defining mechanisms by which spirituality/faith influences the cancer experience and how healthcare providers can engage with patients to assess the importance spirituality/faith may facilitate optimal, supportive patient care.

Another interesting finding of the current study was the positive effect of a spouse/partner on the cancer experience relative to emotional and instrumental support. Within the quantitative data, survivor perceptions of the impact of cancer on the spouse/partnership were rated the most positive among all items. Cancer did have a negative impact on some aspects of the spouse/partnership. For example, respondents noted that cancer had a negative impact on sexual functioning and intimate relations. In fact, in the qualitative results, challenges with sexual functioning and intimacy was a substantial subtheme. Previous data have noted that most cancer diagnoses can affect sexual functioning via biological and/or psychological pathways (Christie *et al.*, 2015; Kornblith & Ligibel, 2003; Li & Loke, 2014; Roland *et al.*, 2013); this effect can be particularly pronounced when the malignancy affects areas related to sexual functioning (Morreale, 2011). Within the current study, breast and prostate cancer survivors were overrepresented, so it is possible there were physical/anatomic challenges related to intimacy in addition to the negative biological and psychosexual side effects of cancer. The data serve to highlight that healthcare providers should not overlook emotional, informational, and sexual needs/concerns of the spouse/partner.

The integration of the qualitative and quantitative data further illustrated the importance of the spouse/partner during the cancer experience. Subthemes within the qualitative data delineated how the spouse/partner was important, including emotional and instrumental support. Although this subtheme was reflected in the qualitative data for the effect of the family, "no impact" was more frequently reported by participants, suggesting that family was not as regularly or directly involved with the cancer experience as a spouse/partner. In fact, many participants who indicated "no impact" of the family added the exception of their spouse/partner. Although family very often is important to patients diagnosed with cancer, there may be differences in family involvement resulting from differences in the developmental stages of the family members or patient, as well as varying cancer treatment factors (Laidsaar-Powell *et al.*, 2013; Northouse, 1984; Rolland, 2005; Weihs *et al.*, 1996). For example, the spouse/partner may be highly involved in treatment decision-making, whereas young children may not; thus, the positive effect of cancer on these relationships may be occurring through different processes. The positive impact on the relationship with family members (e.g., children) may be explained by a more passive role, such as motivation and inspiration, whereas the spouse/partner has a more active role in the cancer experience through emotional and instrumental support. Overall, it is important for providers to assess patient preferences for family involvement across the cancer experience.

Limitations

The mixed-methods survey design allowed for the contextualization of results and improved validity. There were limitations,

however, that should be considered when interpreting the results (Creswell, 2003). Volunteer bias may be evident in the sample, because individuals who participated in the study needed to willingly sign up for ResearchMatch® and agree to participate in the study. Social desirability bias may also have affected participant survey responses, particularly about negative feelings within familial relationships (Krumpal, 2013). Retrospective perspectives are subject to bias for many reasons, including difficulty of recall, acquired meaning-making of memories, and the current mood of the participant (Hassan, 2005). The mix of open- and closed-ended questions affected the response rate among the different question types, because participants in web-based surveys may answer closed-ended questions more frequently than open-ended questions (Reja *et al.*, 2003).

Finally, the sample was also not nationally representative; thus, the results of this study may not be generalizable. For example, the majority of the sample identified as breast and prostate cancer survivors, which have higher five-year survival rates in the general population (89.7% and 98.6%, respectively; National Cancer Institute, 2016). Additionally, almost three-fourths of the sample identified as being currently cancer free, so the data may more accurately represent long-term cancer survivors. The homogeneity of the participant sample limited the ability to examine the influence other contextual variables, such as race and socioeconomic status, which can affect the cancer experience (Williams *et al.*, 2008).

Clinical implications

The current study highlights the important role of partner/spouse relationships to cancer survivors. By integrating a spouse/partner in the medical decision-making process, providers can minimize conflict and emotional distress associated with the cancer experience, but providers often neglect the influence of the spouse/partner in treatment-related conversations (Shin *et al.*, 2013). Failure to recognize the bidirectional influence between the spouse/partner and the cancer experience may lead to delay in identifying unmet biopsychosocial needs of survivors. In addition, caregivers may be an important source of information for treating physicians regarding patients' day-to-day symptom levels (Shin *et al.*, 2013).

Similarly, current research shows that both patient and caregiver participants perceived family involvement in medical decision-making as helpful without compromising patient autonomy, whereas physicians were only comfortable with family involvement until caregiver influence appeared to conflict with the physician perception of patient values (Laidsaar-Powell *et al.*, 2017). Healthcare providers should intentionally incorporate spouse/partners and other family members in different stages of the cancer experience. For example, goal setting can be guided by an awareness of the components of family functioning most relevant to particular phases of an illness. Sharing this information with the family and deciding on specific goals can provide a better sense of control and hope for the family. Enabling healthcare providers to think about the patient within the context of their family system and the bidirectional impact of a cancer diagnosis will be an important skill to examine patterns and anticipate psychosocial needs with patients over the course of the cancer experience (Rolland, 2005).

In conclusion, cancer is a unique experience and understanding the bidirectional impact between cancer and social contexts of the survivor will promote patient-centered care throughout the cancer experience. Relationships and social contexts are important to patients diagnosed with cancer and the central role of

relationships will only grow as the survivorship continues to lengthen. More research is needed to better understand what relationship or social context is important and how understanding these processes may assist in providing more optimal patient-center care.

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