Original Article

Understanding the Type of Support Offered Within the Caregiver, Family, and Spiritual/Religious Contexts of Cancer Patients

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Abstract

Context/Objectives. We sought to characterize patterns of social support types (i.e., emotional, informational, appraisal, and instrumental) within the caregiver/spouse, family, and spiritual/religious contexts for patients diagnosed with cancer.

Methods. Focus groups were conducted with mixed groups of patients with cancer and caregiver/family members at a Midwestern comprehensive cancer center. Participants completed brief demographic questionnaires. Focus groups were moderated using semistructured interviews. The 90-minute discussions were audio-recorded, transcribed, and uploaded into NVivo for analysis using a deductive approach based on four social support types and the constant comparative method.

Results. Four focus groups were conducted ($n = 25$). The average age was 58.4 years (SD = 15.1, range 26.0–76.0). Patient participants reported different malignancy types, including breast, gynecologic, skin, oral, and Non-Hodgkin's lymphoma. Participants acknowledged changes within their social network across the cancer journey. Overall, the caregiver/spouse fulfilled all types of social support. Spirituality/religion was often discussed as a form of appraisal social support. Fellow survivors were sources of informational support. Across groups, nondirective/emotional support was most frequently mentioned.

Conclusion. Cancer is a unique experience, and understanding the importance of social support, including types of social support needed from different contexts to best meet the needs of the patient, may promote optimal, patient-centered care across the cancer trajectory. J Pain Symptom Manage 2019;58:56–64. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Social support, cancer, caregiver, family, spirituality/religion

Introduction

The cancer experience can be uniquely and profoundly stressful because of the uncertainty of treatment-related decisions, possibility of recurrence, fear of death, as well as concerns around overall survivor well-being and quality of life.[1–4] Furthermore, a cancer diagnosis can impact multiple of aspects of a patient's life, or "patient contexts," including social relationships and spiritual/religious beliefs and practices.[5] These challenges often serve as a consistent and persistent reminder of cancer status for survivors across their life span.[6]

Patient-centered care (PCC), defined as "providing care that is respectful of and responsive to individual

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Accepted for publication: March 6, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.03.003

patient preferences, needs, and values and ensuring that patient values guide all clinical decisions," promotes a holistic view of the patient across the cancer care continuum.[7] The Institute of Medicine has advocated PCC as a fundamental approach to provide high-quality cancer care. As such, cancer care should not only focus on the physical symptoms of the patient but also attend to patient social and spiritual needs.[8] The experience of cancer can impact other individuals in social relationships with the patient and the overall patient dynamic. For example, the partner of a patient diagnosed with cancer may experience equal, or greater, psychological distress during treatment.[9] This experience of the partner can then impact the care given to the patient and their overall relationship quality. As such, interventions have been developed to support the coping of the patient but also the caregiver and the dyadic patient-partner relationship.[10–12]

Social relationships, including spouse/caregiver and family members and spiritual/religious well-being, are important resources for patients. Social support can be defined as a "transactional communicative process, including verbal and/or nonverbal communication that aims to improve an individual's feelings of coping, competence, belonging, or self-esteem."[13] Although there are multiple interpretations of social support in the literature, one of the most frequently cited frameworks distinguishes four types of social support: 1) emotional, 2) informational, 3) appraisal, and 4) instrumental (Table 1).[14,15]

Although there is evidence for the positive impact of social support on the overall well-being of a patient with cancer, less is known about what types of social support are most important to patients diagnosed with cancer. Previous research has suggested that social support may be most influential when there is "optimal matching" defined as the "right" type and level of support offered by the "right" person in their social network.[16,17] For example, a survivor may expect higher levels of instrumental or tangible support from their caregiver/spouse than their spiritual/religious beliefs or community.

The objective of the current qualitative study was to characterize patterns of social support types (i.e. emotional, informational, appraisal, and instrumental) within the caregiver/spouse and family context, as well as spiritual/religious context, among patients with cancer. Such data may bridge the gap in the understanding of who and/or what social support contexts impact cancer survivors as well as help researchers design and implement targeted interventions for clinicians to provide more tailored, "matched" PCC for patients with cancer.

Methods

Focus groups were conducted with mixed groups of patients with cancer, caregivers, and family members. Focus groups are the ideal analytic approach to collect an in-depth, rich understanding of support patterns. Conversations among study participants within the groups can facilitate more comfort among participants and lead to deeper reflection of study questions.[18,19]

Participants

Participants enrolled in the present study were recruited from the members of a patient advisory program developed at a comprehensive cancer center at a large Midwestern academic medical center. The patient advisory program was developed so patients and their families could share their perspectives on the overall health care experience of their cancer journey through multiple means including patient advocacy, staff education, quality improvement projects, and research. Members of the advisory group are current/former patients or caregiver/family members at the medical center, were at least 18 years of age, completed a prescreening protocol (i.e., background check, orientation), and agreed to participate in five hours of service per year for the center. Members of the advisory group were e-mailed information about the focus groups. Individuals who were interested were invited to sign-up to participate. There was no formal incentive offered for participation, but refreshments and parking validation were provided. Focus groups were scheduled and recruited on an ongoing basis. Participants were not segmented into groups based on individual-level demographic or cancer variables, and therefore, each discussion had multiple viewpoints on the cancer experience. Based on previously published studies, it was estimated that four to six focus groups would be needed with each group containing between four and 12 participants.[19]

Procedure

The focus groups were held at the medical center. For each focus group, participants were handed a

Table 1
Types of Social Support (as Described in House, 1981)

Emotional/nondirective guidance	Sharing life experience; offering empathy, love, trust
Informational/directive guidance	Giving advice and making suggestions that are useful to a patient
Appraisal	Providing information that is needed for self-evaluation
Instrumental/tangible	Physical labor or tasks to directly assist a patient

packet to complete before the focus group began. The packet contained the consent and a brief demographic form. All participants answered questions about individual-level sociodemographic factors (e.g., age, education, relationship status). Participants were asked to answer a few questions based on their role as a patient or a caregiver/family member. Participants who self-identified as patients were asked questions regarding their diagnosis and treatment. Caregivers were asked questions related to their involvement in patient care. The packets were collected by research personnel and stored in separate envelopes to ensure patient confidentiality before the focus group conversation began.

The focus groups were moderated by two members of the research team (E. P. K. and A. M.) using a semi-structured interview format to ensure consistency in conversations across the focus groups while allowing for a more organic discussion to occur (Appendix 1).[19] Before the focus group began, the moderators answered any questions and reminded participants that the discussion was not connected to their medical file and the research team was not in contact with any of their treating physicians. The focus groups were recorded with a digital audio recording device; each group discussion lasted approximately 90 minutes. Demographic information was logged into IBM SPSS (IBM Corp., Armonk, NY), whereas the audio recordings were uploaded onto a password-protected, encrypted computer. The audio files were transcribed and fully deidentified before analysis. After each transcription, data were uploaded into NVivo, version 11 (QSR International, Melbourne, Australia), for qualitative analysis and the audio recordings were destroyed. The study was approved by the OSU Institutional Review Board (IRB protocol #2017c0203).

Four focus groups were conducted with 25 participants. The mean age of participants was 58.4 years (SD = 15.1, range 26.0–76.0). Most participants were female and were current or former patients with cancer. Participants who self-identified as patients reported different malignancy types, including breast, gynecologic, skin, oral, and non-Hodgkin's lymphoma. One participant who identified as a patient had not been diagnosed with cancer but was high-risk BRCA 1 positive. Participants were on average 11.2 years after diagnosis (SD = 7.9, range 1.0–32.0). At the time of the study, five participants were receiving chemotherapy, whereas other participants reported receiving other or no treatments. Among participants who identified as caregivers/family members, all these individuals said that they were involved with the patient with cancer at the time of diagnosis and during the treatment course; only one caregiver participant indicated that they were not engaged in making treatment-related decisions. Participant demographic variables are summarized in Table 2.

After each focus group, the moderators debriefed with other research team members to identify initial impressions and critical points of the conversation. After data collection was complete, the transcribed data were uploaded and analyzed using a deductive approach and the four types of social support (i.e., emotional/nondirective, informational/directive guidance, appraisal, and instrumental/tangible) were defined as the analytic framework using the constant comparative method. The research team read through the transcripts multiple times to gain familiarity with the data and made comments in the margins of the transcripts to develop key code words that captured

Table 2
Participant Demographic Variables

Variable	Mean	SD	Range
Age	58.84	15.14	26.0–76.0
Years from diagnosis[a]	11.19	7.88	1.00–32.00
Years from last operation (n = 15)[a]	6.93	4.22	1.0–16.0
	n	%	
Role			
Patient	16	64.0	
Caregiver/family	9	36.0	
Gender			
Male	4	16.0	
Female	21	84.0	
Work status			
Full-time	9	36.0	
Part-time	2	8.0	
Retired/Unemployed	14	56.0	
Education			
Some college	5	20.0	
College graduate	13	52.0	
Post graduate	7	28.0	
Race			
White	21	84.0	
Asian	2	8.0	
Native American/White	2	8.0	
Relationship status			
Single	5	20.0	
Married	12	48.0	
Other	8	32.0	
Had cancer-directed surgery[a]			
Yes	15	93.8	
No	1	6.3	
Current treatments[a,b]			
Chemotherapy	3	18.8	
None	11	68.8	
Other	4	25.0	
Follow-up care[a,b]			
Surgeon	13	81.3	
Medical oncologist	9	56.3	
Radiation oncologist	7	43.8	
Primary care doctor	8	50.0	
Other	10	40.0	
Malignancy type[a,b]			
Breast	9	56.3	
Other	3	18.8	
Gynecologic	4	16.0	
High-risk (BRCA 1+)	1	6.3	

[a] Question only asked to participants that identified as patients diagnosed with cancer (n = 16).
[b] A multiple response question.

participant quotes and experience. Members of the research team also examined and compared classification of text by social support types and discussed exemplary quotes. This process continued until all researchers agreed on the classification of the text within each social support type.

Results

Participants in the study made statements about the changing nature of their social network during their cancer journey during their cancer care. All four types of social support were identified within the data related to the role of their caregiver/family and spirituality/religion. Overall, the caregiver/spouse fulfilled all four types of social support (i.e. emotional, informational, appraisal, and instrumental), whereas spirituality/religion was most often discussed as a form of appraisal social support. Other cancer survivors were seen as an important source of informational support. Across groups, nondirective or emotional support was most frequently mentioned. Findings were stratified according to social support type accompanied by descriptive quotes from the participants after all identifying information was removed to protect participant confidentiality.

Informational or Directive Guidance Social Support

Participants most often discussed reaching out to other survivors via support group or social media to receive information related to the cancer experience. Often, this information was not related to a treatment decision. Rather, interaction with other cancer survivors offered the opportunity to corroborate the experience of treatment side effects/symptoms such as neuropathy and decreased salivation.

> I tell my ladies [in chemotherapy treatments], I have neuropathy in my feet. And sometimes after a very long day on my feet, especially over, my feet just kill me. We talk about that a lot.

Spouse/caregivers were not often considered sources of informational social support for new cancer information; rather, spouse/caregivers were more often involved in helping the patient process information related to cancer treatment within the dyad. Spouse/caregivers were also often described as providing informational support and guidance outside of the dyad (e.g., to the oncologist), especially when the spouse/caregiver was acting as a patient proxy.

> … and for me my husband asked a lot of questions because I was kind of in and out of consciousness. So he relied on the doctors to answer his questions and he was very persistent.

A subset of participants discussed reaching out to friends and family within the medical field for informational guidance on how best to select a treatment facility/physician, get medical advice, or ask the provider to be more involved in their care. One caregiver participant commented that she asked a previous employer to attend her husband's cancer appointments with her to help her process and understand the information.

> I was very lucky in that my old boss, he was a retired critical care physician, came with us, and he didn't come to take care of my husband or to give the … doctors advice… I called my old boss and he said,'I'll be there with you,' and we told them he can see anything, He looked in and the computer lab work and we just said,'He can look at anything, everything is open to him.' But he was there for us, he was really there for us.

Appraisal Social Support

Other cancer survivors were also crucial for participant appraisal social support. Participants suggested that seeing another survivor, especially individuals with a similar diagnosis, gave them hope and reminded them that they could persevere through their treatment.

> … there was a man right in front of us… talking about his treatment. He had cancer too. And I think it was calming that you saw someone, and he was very thin, but he was chugging along, but I think that was one of the more calming things.

Discussions about spirituality and religion were most often classified as appraisal social support. Participants discussed finding inspirational quotes or bible verses that gave them the motivation and strength during their cancer journey.

> But um I remember… I really felt like God was saying, 'you're going to walk through … the valley of the shadow death. You're going to go through this and come out the other side.' So, I think gave me a different perspective of everything knowing that I was going to get through it. And so, it was, we just I think looked at it differently, we're like, 'this too shall pass'.

Instrumental/Tangible Social Support

Tasks related to instrumental and tangible support most often were taken on by the caregiver/spouse. Participants discussed the caregiver role in terms of their home/family life ("family logistics") and cancer treatment ("cancer logistics").

> So almost the family planning that comes adjacent to treatment planning. Like you're gonna make a decision … for treatment but then there's all these other small paths you have to walk down as well.

> … but it was a very traumatic time for my family and we don't have other family in the area so it was just the nuclear family so to get additional family, we had to arrange for family to come up from Florida, for example, to come stay with me for a while … but there are all kinds of, even trips to the doctor or trips to rehab I would say the same thing that you need to have all this coordination going on, and that's hard for patients.

Some participants reflected on their desire to be autonomous and independent during their treatment and the need to communicate that with their spouse/partner.

> … he wanted to take me to radiation and I went, 'I don't think I need it.' I would just rather not have somebody pampering me when I feel like I don't need pampering. I want to be up. Now if I get to the point where I can't drive myself, I'll let you know but, I didn't want that extra treatment, it made me feel sicker, someone's over me doing that.

Participants also acknowledged that this process was very complicated and often did require additional support from other members of their social network. Participants most often cited friends or other extended family members who played a smaller role in providing instrumental social support (e.g. siblings). A few participants mentioned that their children participated in the logistics of their cancer care, but other participants made a point to say they did not want to involve their children in this support modality. In particular, several participants suggested it would be too much of a burden or interfere with their children's own family lives.

> so that whole process of trying to coordinate care and aftercare and having to have someone be with you all the time for a month after my transplant it's like, you know that's a lot of interconnectedness. Interconnected things that you have to arrange. And it's a very complicated process for patients many times for them and their families. It's very stressful for their families.

Emotional/Nondirective Social Support

Emotional/nondirective social support was the most frequently mentioned mode of social support. Participants reflected on the importance of feeling loved, supported, cared for, empathized with, and the importance of compassion. Most often, participants talked about receiving this support from their significant other or caregiver. Participants highlighted different ways they felt emotionally supported during their cancer journey. One participant stressed a moment with her husband that demonstrated more implicit emotional support:

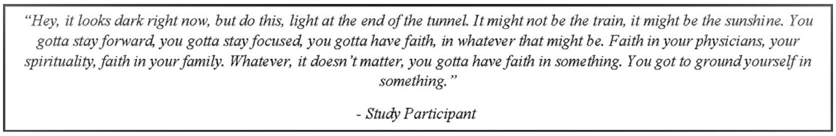
> So, you know what my husband did, he took me to [a department store] at the time he says, 'here, you buy your makeup over here, would you please show her how to draw her eyebrow.' He said that to the lady that was at the counter, 'show her the right way to put the eyebrow on.' I mean I was, I loved my husband more after when he did that.

Other participants discussed moments when their significant other was more explicitly emotionally supportive in conversations and often reflected on their significant other as the "anchor" or "rock" during their treatment.

> … I remember at one point during the first ovarian cancer I could barely walk down the hallways, tubes are coming out of me every which way, and I said I don't want to do this anymore. And I get emotional every time I talk about it because it was probably the one moment where I took a turn. And he said, walking next to me, we don't know how to do anything in life except go forward and keep moving. And we're going to keep moving … he's been the strength.

Other family members, like children and siblings, were mentioned in the conversation as sources of emotional/nondirective support, however, less often than the significant other/spouse. Participants did discuss the critical role of spirituality/religion in providing emotional/nondirective support, but the support was derived from established spiritual/religious communities instead of from their individual beliefs and behaviors.

> I go to a women's bible study once a week, and when I told them I wouldn't be there next week because I was going to be having surgery for breast cancer, oh it was great! They were very accepting and understandable, ya know understanding, and were there if I needed help.



"Hey, it looks dark right now, but do this, light at the end of the tunnel. It might not be the train, it might be the sunshine. You gotta stay forward, you gotta stay focused, you gotta have faith, in whatever that might be. Faith in your physicians, your spirituality, faith in your family. Whatever, it doesn't matter, you gotta have faith in something. You got to ground yourself in something."

- Study Participant

Fig. 1. Exemplary participant quote.

Discussion

Social support is a significant factor for improved quality of life and overall well-being among patients with cancer Figure 1.[7,20,21] The present study used a focus group methodology and a social support typology framework to describe the types social support within the contexts of the caregiver/spouse, family, and spirituality/religion for patients diagnosed with cancer. Overall, all participants acknowledged that there were some changes in their social network, with the cancer experience bringing some relationships closer and driving other relationships further apart. Across all social contexts, nondirective or emotional support was most frequently mentioned by participants. This finding was in line with recent research that has suggested that patients receive emotional support from many social contexts, both related to (e.g., support groups) and not related to (e.g., church) the cancer diagnosis and treatment.[22,23] Within the present study, specific support contexts provided the three other types of support (i.e., informational, appraisal, and instrumental), with the exception of the caregiver/spouse who fulfilled all four types of social support.

Instrumental/tangible support often was the responsibility of the caregiver/spouse as the one to handle the "logistics of cancer." These instrumental tasks varied in gravity—ranging from helping the patient get to the bathroom to change jobs/moving to be closer to the treatment facility. Within the U.S., approximately five million people have a caregiver role for someone with cancer at home; most often the spouse/partner.[24] For patients without a spouse or partner, there may be a member(s) of their social network that fulfills a caregiver role, but it is also possible that a patient may lack social support. Similarly, the needs of the patient may vary depending on the desired involvement and availability of a partner/spouse.[25] This is potentially problematic as patients who lack social support have a higher risk for negative outcomes across the cancer trajectory, including poor psychosocial adjustment.[26] Future research efforts should aim to assess patient sources of support to determine if a patient is at a higher risk of adverse outcomes.

Spirituality and religion were often discussed relative to appraisal/feedback support as participants often looked to their faith for strength and inspiration. The benefits of spirituality/religion have been previously reported with data suggesting that spirituality and religion may facilitate "meaning-making" or searching for purpose around the experience of cancer.[27] The role of spirituality and religion may be more as a means to cope with the cancer diagnosis and treatment, rather than as a functional means to support positive psychosocial adjustment.[28] Also, patient spirituality/religion may play different supportive roles across the life span of a patient with cancer. To date, most studies have focused on meaning-making through spirituality/religion among patients with cancer at the end of life care[29]; however, several reports have examined spirituality/religion as a coping means around diagnosis and treatment.[21,30] In the future, it will be essential to investigate how spirituality/religion needs evolve throughout the cancer experience relative to different patient contexts.

Clinical Implications

Spouse/caregivers also played an interesting role by offering directive guidance support. This support occurred both within and outside of the couple dyad. Within the dyad, the spouse often did not provide new information; rather, the spouse frequently helped the patient reprocess information as related to treatment decisions. The spouse was often also responsible for acting on behalf of the patient, as well as advocating for their spouse's preferences when the patient was unable to do so. These findings emphasize the important supportive role of the caregiver/spouse as a "patient-centered proxy" instead of a medical proxy. In turn, providers may benefit from intentionally integrating the caregiver/spouse into essential aspects of cancer treatment, including shared decision-making, to minimize decisional conflict and regret.[31] When partner support does not match the patient expectation or need, patients can experience higher levels stress and lower perceptions of control over their choices.[32,33] In addition, the experience of cancer can have a negative impact or burden on the caregiver/spouse (e.g., increase in affective disorders) and quality of life, which could then influence the care of the patient.[34] Therefore, providers need to explore the desired level of initial involvement of the caregiver/spouse with each patient, as well as across the course of cancer care.

Study Limitations

Certain limitations should be considered when interpreting the results of the present study. Participants were part of a service group at a large academic cancer center, and thus, volunteer bias could have affected the results.[35] The focus groups varied in size, with most of the participants being female. Therefore, the results may not be generalizable to all patients with cancer, care facilities, or environmental contexts. The participants in the present study reflected on their entire survivorship, so it is possible that the support types from each context may change naturally or necessarily at key points across the cancer trajectory. In addition, the methodology for the present study led to a variance in conversation across groups, as some groups spent more time on specific topics or explored different subtopics. The focus group format and semistructured interview did allow, however, for a breadth and depth of many experiences to be explored.

In conclusion, cancer is a unique experience and understanding both the role of social support, as well as the type of social support based on the context of the patient will be important to promote patient-center care. Relationships and social contexts are essential to patients diagnosed with cancer. For that reason, understanding the relationships and social networks of patients across the cancer trajectory will only grow in importance as the number of cancer survivors increase.

Disclosures and Acknowledgments

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The authors have declared no conflicts of interests.

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Appendix 1
Focus Group Question Guide

What are the most important components of the relationship between a cancer doctor and their patient?
How did you and your physician make decisions together?
What was the experience like making your decision for your cancer treatment?
In what ways were your family, including your spouse/partner, impacted by your cancer journey?
If this applies to you, specifically for your spouse/partner, what type of involvement did they have in your cancer treatment?
If applicable, how did your cancer doctor discuss the impact of cancer on your familial relationships?
In what ways were your spiritual and religious practices present in your cancer journey?
If you align with a religious/spiritual belief, how did that belief influence your cancer journey?
If their ways that you hoped your religion/spirituality was more present during your cancer treatment, could you describe that further?