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ARTICLE



Social support in cancer: How do patients want us to help?

Brittany D. Korotkin, MA^{a,b} , Michael Hoerger, PhD, MSCR^{a,b}, Sara Voorhees, MS^c, Chynna O. Allen, BS^b, William R. Robinson, MD^a, and Paul R. Duberstein, PhD^d

^aTulane Cancer Center, Tulane University, New Orleans, LA, USA; ^bDepartment of Psychology, Tulane University, New Orleans, LA, USA; ^cDepartment of Clinical and Health Psychology, University of Florida, Gainesville, FL, USA; ^dDepartment of Health Behavior, Society, and Policy, Rutgers School of Public Health, Piscataway, NJ, USA

ABSTRACT

Objective: Social support is fundamentally important to the well-being of patients with cancer, and informal caregivers often wish they had better insight into how to help. The aims of this study were to quantify the types of social support that patients qualitatively expressed as important, and examine whether demographics and mental health symptoms explained the type of support desired.

Methods: A sample of 82 patients with cancer (Gender: 65.9% Male, Age: M = 57.5, Race/Ethnicity: 90.2% White, non-Latino/a) completed measures of demographics, health, anxiety, and depression, and responded to an open-ended question asking them to list three types of support that they desire from their caregivers. These responses were then reliably coded into 18 different categories.

Results: Most commonly, participants expressed a desire for companionship (45%). Other common requests included empathy (33%), home care support (28%), information support (16%), being treated the same (15%), and help with appointments (13%). Patients who were more anxious were more likely to desire companionship (OR = 4.41, $p = .033$), and younger patients were more likely to desire home care support (OR = 7.24, $p = .016$).

Conclusion: Findings have implications for providing individually-tailored social support to patients with cancer.

KEYWORDS

Age factors; anxiety; caregivers; depression; empathy; home care; precision medicine; social support

Unquestionably, social support is vital for patients with cancer. In particular, perceived social support mitigates cancer-related stress,¹ is associated with greater well-being and improved quality of life,² and may even benefit longevity.³ While important, the social support needs of individuals with cancer are not always met.⁴ Given limited information on how to most effectively tailor social support to individual patients, this paper aims to describe the types of social support that are commonly requested by

CONTACT Brittany Korotkin, MA  bkorotkin@tulane.edu  Tulane University, 3073 Stern Hall, New Orleans, LA 70118, USA.

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patients with cancer and summarize key individual differences in preferences for social support.

While there has been a great deal of research on the importance of social support, prior studies may have missed some types of support that patients themselves deem crucial. For example, many studies have focused on documenting the benefits of a single type of social support, such as emotional support⁵ or group support interventions,⁶ but have rarely asked patients about how they could best be supported by family and friends. Other studies have established self-report measures of social support, rather than asking patients open-ended questions to self-identify their preferences for particular forms of social support.^{7,8} For example, the well-established MOS Social Support Survey^{9,10} uses a theoretical model conceptualizing social support across five domains: emotional, tangible, informational, positive social interaction, and affectionate. Yet, there may be additional domains that patients themselves deem as important. As acknowledged in national priority statements that were built on a foundation of input from patients and caregivers,^{11,12} the greater inclusion of patient and caregiver “stakeholder” perspectives in research can ensure that the right questions are being asked, help make results more meaningful to the public, and inform the direction of future research. Additionally, there is a movement in medicine toward a more patient-centered approach to improve health outcomes.¹³ This approach, known as precision (or personalized) medicine, is broadly defined as taking individual differences into account to create personalized treatment plans.¹⁴ Precision medicine often focuses on tailoring care based on the identification of biomarkers¹⁴ but can include the identification of psychosocial factors, such as care preferences, that can also help guide clinicians and caregivers in providing supportive care.^{15,16}

Moreover, while prior studies have made a valuable contribution to identifying the importance of some types of social support,^{17,18} research is needed to determine whether there are individual differences in support preferences, as this could help individuals with cancer receive their preferred form of social support. Research suggests that individualizing care according to the specific characteristics of the patient can help to improve quality of life by giving patients the care and support that they need most.¹⁹ Specifically, prior research has documented the importance of tailoring healthcare based on patient gender,²⁰ age,^{21,22} and mental health symptoms, such as anxiety and depression.^{23,24}

Differences in age and mental health symptoms may also be relevant to social support, as the types of support that are relevant to one patient may be unimportant or even undesirable to another. For example, supportive care is often designed with older patients in mind,²⁵ so younger patients with cancer may have unique needs related to informational and

instrumental support.^{22,26,27} In addition to age differences, many individuals with cancer experience symptoms of depression and anxiety²⁸ and may have different support needs.

In the present study, a sample of patients with cancer completed measures of demographics and mental health characteristics and responded to an open-ended question about the types of social support they considered important. Goals of this study were to identify types of social support commonly identified as important and examine associations with age, anxiety, and depression. The present investigation has the potential to contribute toward building knowledge that can help informal caregivers support patients with cancer.

Methods

Participants and procedures

Participants completed an Internet-mediated survey study funded in part by the National Institute of Mental Health.²⁹ The parent study consisted of two waves, first recruiting patients diagnosed with prostate cancer, and then opening up the study to other diagnoses.²⁹ Participants were recruited for the study via health education websites, discussion forums/listservs, search engines, and the ResearchMatch recruitment tool,³⁰ established by the National Institutes of Health (NIH) Clinical and Translational Science (NCATS) program. ResearchMatch provides a database of more than 136,000 volunteers and gives researchers from 162 research institutions the opportunity to recruit participants. This was an open-access study; therefore, we could not track the survey's response rate. The present analyses focused on a subset of participants (82/376) who were allocated to respond to an open-ended question about their social support needs. The study was conducted with ethical approval from the Institutional Review Board at the University of Rochester Medical Center, Wilmot Cancer Institute in Rochester, NY, USA, and adhered to necessary ethical and technical guidelines for Internet-mediated research.³¹

Measures

Demographics

Participants reported their age, gender, education, marital status, geographic location, ethnicity, race, and health insurance status. Additionally, participants completed a 4-item financial strain checklist³² that asked about difficulties affording food, housing, medicine, and other expenses; participants were classified as low strain (no strain) or high strain (strain in any area).

Social support needs

Participants responded to an open-ended question: “What are three ways that people in your life might help provide you with support in dealing with your cancer?” Using procedures established in prior research,³³ a team of five raters (four doctoral-level psychologists and one trainee) identified common themes, ultimately yielding 18 domains (e.g. Companionship, Empathy, Home Care Support). Domains were not mutually exclusive. Using a coding manual each rater independently classified each participant’s qualitative response into as many of the 18 domains as relevant. Raters classified responses solely based on the text in the open-ended responses without trying to make educated guesses about other categories that may be relevant. For example, if a participant responded, they desire people to “Make frequent visits to provide companionship,” raters did not intuit that they necessarily desire empathy. Participants’ responses were a median of 21 words (*IQR* = 11 to 32 words). Inter-rater reliability was strong (intraclass correlation coefficient, *ICC* = .93) across 7380 ratings (18 ratings per participant \times 82 participants \times 5 raters). After raters coded the responses, two of the authors conducted an additional *post-hoc* classification scheme to group our 18 domains hierarchically under the five factors of the MOS Support Survey model^{9,10} with a sixth grouping for “other” domains that did not fit reasonably within the MOS framework.

Mental Health

Symptoms of anxiety and depression were assessed using the 7-item subscales from the DASS-21,³⁴ rated using a scale from 0 (Not at all) to 3 (Most of the time). Several studies have documented the reliability and validity of the DASS-21.^{35–37} The anxiety subscale contained items such as “I felt scared without any good reason,” and measured symptoms with acceptable internal-consistency reliability (Cronbach’s α = .71). The depression subscale contained items such as “I felt I wasn’t worth much as a person,” and measured symptoms with excellent internal-consistency reliability (Cronbach’s α = .91).

Statistical analyses

Analyses summarized the frequency of participants reporting desired support across each of the 18 categories. Analyses were powered to examine individual differences in the three most common types of preferred social support (companionship, empathy, and home care support). Logistic regression analyses were conducted examining individual differences predictive of each of these types of support. First, unadjusted models were conducted, using single independent variables (e.g., anxiety symptoms) to

Table 1. Demographics of participants.

| Variable | <i>n</i> | % |
|-----------------------------------|----------|------|
| Age | | |
| <50 | 14 | 17.1 |
| 50–59 | 36 | 43.9 |
| 60–69 | 24 | 29.2 |
| 70+ | 8 | 9.8 |
| Gender | | |
| Female | 28 | 34.1 |
| Male | 54 | 65.9 |
| Race/Ethnicity | | |
| White, non-Latino/a | 74 | 90.2 |
| Other, diverse | 8 | 9.8 |
| Marital Status | | |
| Married | 62 | 75.6 |
| Unmarried | 20 | 24.4 |
| Geographic region | | |
| South | 22 | 26.8 |
| West | 15 | 18.3 |
| North | 13 | 15.9 |
| Midwest | 11 | 13.4 |
| International | 21 | 25.6 |
| Education level | | |
| High school or less | 7 | 8.5 |
| Some college or Associates degree | 23 | 28.0 |
| Bachelor's degree | 23 | 28.0 |
| Masters or Doctoral degree | 29 | 35.4 |
| Health insurance | | |
| None | 8 | 9.8 |
| Medicare | 16 | 19.5 |
| Medicaid | 1 | 1.2 |
| Private | 51 | 62.2 |
| Other | 17 | 20.7 |
| Financial strain | | |
| No strain | 54 | 65.9 |
| Strained | 28 | 34.1 |

predict each dependent variable (e.g., companionship). Second, covariate-adjusted models were conducted that simultaneously included the three predictors of interest (age, depression symptoms, anxiety symptoms) predicting each dependent variable (e.g., companionship), while controlling for the covariates of gender, financial strain, education (Bachelor's degree vs. less education), marital status (married vs. unmarried), stage (metastases present vs. absent), cancer site (prostate [most common diagnosis] vs. other), and time since diagnosis. In logistic regression analyses, age was scaled in decade units so that odds ratios indicated the changes in odds associated with a ten-year difference in age. Anxiety and depression symptoms were scaled by 2 standard deviation (SD) units,³⁸ such that odds ratios indicated the changes in odds associated with moving from 1 SD below the mean to 1 SD above the mean on symptom severity. These linear transformations increase the interpretability of odds ratios without affecting observed *p* values.³⁸

Table 2. Social support category definitions with example quotes.**Emotional***Empathy: Sympathy, emotional support*

"Be understanding of the impact on my life." "Empathize" "Emotional support" "Understand my concerns. Be patient with me during treatment."

Acceptance: Accept my emotions, moods, difficulties

"Cut me some slack when my mood dips down a bit but don't let me stay there for long." "Be patient with my mood swings."

Tangible*Home Care Support: Chores, physical tasks*

"Offer practical support with housework/shopping etc." "Doing the things I'm not up to doing." "Send prepared meals; do laundry; help with yard work (don't ask patient what you can do – it's uncomfortable) just do it."

Appointments: Come to appointments with me

"Come along to most of my appointments as a second pair of ears to take notes and make sure that questions we wrote down ahead of time got answered." "Accompanying to medical appointments."

Financial Needs: Provide financial support

"Give me money for expenses."

Informational*Information Needs: Help me be informed*

"Understand the disease." "Learn about the treatment side effects before advising me." "Help me research different treatments." "Providing information and a 'sounding board' to test my ideas and strategies for survival."

Discuss Health: Talk about my health

"Talk openly about it instead of feeling that they shouldn't bring the subject up." "Talk to me more about it instead of acting like it's not happening."

Decision Support: Help with decisions, respect my decision making

"Just back me up on my decisions that I make for treatment." "Support me in whatever decision I believe is best for me even if you don't agree."

External Resources: Navigating the healthcare system, counseling services, etc.

"Guide me towards groups and/or organizations with other cancer survivors." "Encourage me to seek psychological counseling if the depression or anxiety is overwhelming."

Planning: Help me plan for the future

"Plan events in the distant future to help me focus on something."

Positive Social Interaction*Positivity: Positive focus or reinterpretation*

"Share my positive attitude of my life accomplishments and success." "Encourage positive activities – like going out to dine, movies, concerts, friends, etc. instead of letting me wallow at home."

Avoid Discussing Health: Don't focus on the cancer, don't talk about my health

"Don't walk up and ask about my cancer every time you see me. If I want to enlighten you ... I'll bring it up" "Ignore the *bleep* out of it. Prostate cancer is not a car-magnet and t-shirt disease for most of us – the side effects are embarrassing as hell and I hardly want to talk about it"

Other*Companionship: Just being there, just listening, not leaving me alone*

"Be there to listen IF patient wants to talk; don't push." "Make frequent visits to provide companionship." "Letting me know that they are there for me even though there may be little they can quantitatively offer me."

Being Treated The Same: Don't change our relationship

"Do not treat me like an outsider because of the cancer." "Treat me normally. Never lower expectations." "Try to treat the person the same way as before the cancer diagnosis/treatment."

Respect Boundaries: Give me space and privacy, help only when asked

"Give you space to process your dx." "Respect need for privacy."

Tranquillity: Don't overreact or overdo it

"Don't overreact and remain emotionally stable." "Ask about it but not obsess over it."

Spirituality: Spiritual or religious support

"Pray – and put the patient on prayer rosters available to you; let the patient know you are praying; it's THE best thing you can do!" "Pray with me and for me."

Honesty

"Be honest with me."

Note: N = 82.

Table 3. Frequencies of requested categories of social support.

| Social support | <i>N</i> | % |
|-----------------------------|----------|----|
| Emotional | | |
| Empathy | 27 | 33 |
| Acceptance | 7 | 8 |
| Tangible | | |
| Home care support | 23 | 28 |
| Attending appointments | 11 | 13 |
| Financial needs | 2 | 2 |
| Informational | | |
| Information needs | 13 | 16 |
| Discuss health | 7 | 8 |
| Decision support | 7 | 8 |
| External resources | 3 | 4 |
| Planning | 3 | 4 |
| Positive social interaction | | |
| Positivity | 7 | 8 |
| Avoid discussing health | 5 | 6 |
| Affectionate | | |
| N/A | 0 | 0 |
| Other | | |
| Companionship | 37 | 45 |
| Being treated the same | 12 | 15 |
| Respect boundaries | 7 | 8 |
| Tranquillity | 7 | 8 |
| Spirituality | 7 | 8 |
| Honesty | 2 | 2 |

Note: *N* = 82.

Results

Participant characteristics

Participants ($n = 82$) ranged from age 32 to 79 ($M = 57.5$, $SD = 9.2$ years), 65.9% were male, 90.2% were White, non-Latino/a, 75.6% were married, 63.4% had a Bachelor's Degree, and 62.2% had private health insurance (see Table 1). The majority ($n = 48$; 58.5%) had prostate cancer, and 12 other diagnoses were represented, including breast cancer ($n = 17$; 20.7%), colon/rectal cancer ($n = 9$; 11.0%), hematologic ($n = 5$; 6.1%), and others ($n = 3$; 3.7%). The median time since diagnosis was 1.5 years, with 19 (23.2%) diagnosed in the prior six months, and 22 (26.8%) diagnosed over three years ago. Metastatic disease was reported by 18 participants (22.0%), and 51 (62.2%) reported at least one comorbid health condition, most commonly hypertension. Treatments included surgery (26.8%), radiation (23.2%), chemotherapy (22.0%), other treatments (18.3%), and no treatment (25.6%).

Social support needs

Table 2 indicates how each social support domain we identified fits into the larger structure of the MOS Social Support model. The table also indicates how each social support domain was operationally defined and provides illustrative examples. Table 3 is also organized using the MOS Social

Table 4. Individual differences in preferences for the most common types of social support.

| Social support | Significant predictor | Unadjusted model | | Adjusted model | |
|-------------------|-----------------------|-------------------|----------|-------------------|----------|
| | | OR (95% CI) | <i>p</i> | OR (95% CI) | <i>p</i> |
| Companionship | Anxiety | 2.73 (1.02–7.36) | .047 | 4.41 (1.13–17.30) | .033 |
| Home care support | Younger age | 6.44 (1.73–24.04) | .006 | 7.24 (1.45–36.06) | .016 |

Note. $N = 82$. OR = odds ratio. Age is reverse coded such that younger age is associated with increased preferences for home care support. The adjusted model controls for the covariates of gender, financial strain, education, marital status, cancer stage, cancer site, and time since diagnosis (see Statistical analyses).

Support model and describes the frequency with which participants voiced a desire for each domain of social support in our coding scheme. Participants most commonly requested companionship, empathy, and home care support (28–43%), followed by help with information needs, being treated the same, and help with appointments (13–16%). Participants also noted a broad range of relatively unique domains of social support mentioned by <10% of the sample (see Table 3). Whereas many of the requested domains of social support fit within the MOS Social Support framework (12 of 18), six of the domains participants identified did not fit reasonably within that system: companionship, being treated the same, respect for boundaries, tranquility, spirituality, and honesty. None of the domains of support participants mentioned were similar to the MOS affectionate support category. Our remaining analyses focused on identifying demographic and mental health differences in participants who voiced the three most commonly reported types of support (i.e., companionship, empathy, and home care support).

Individual differences in social support needs

Age and anxiety symptom severity were associated with social support needs (see Table 4). Participants who were more anxious were more likely to desire companionship ($p = .047$), including when controlling for gender, financial strain, education, marital status, cancer stage, cancer site, and time since diagnosis ($p = .033$). As well, participants who were younger were more likely to desire home care support ($p = .006$), also when controlling for demographic and health covariates ($p = .016$). None of the covariates nor depression symptom severity had significant multivariate associations with a desire for companionship, empathy, or home care support.

Discussion

Understanding patient preferences for how informal caregivers, such as family and friends, can help them adapt to their illness is important for improving cancer care. Previous research has shown patients' support needs

are left unfulfilled.⁴ By identifying types of social support patients commonly express as important, the present study aimed to provide guidance for informal caregivers and professionals working with cancer patients and their families. Additionally, the present study showed that demographic and mental health characteristics were related to the types of social support requested, which may inform efforts to tailor support to individual patients with cancer.

We identified common types of social support patients viewed as important and the most commonly requested type of social support was companionship (45% of patients). This finding suggests that caring for patients may not necessarily involve extensive effort, as merely being present for patients was valued by nearly half of the patients with cancer in our study. Additionally, about 1 in 6 participants stressed the importance of being treated the same. Empathy was the next most commonly requested type of support, providing additional evidence for the importance of emotional support.³⁹ While the five domains identified by the MOS Social Support Survey,^{9,10} emotional, tangible, informational, positive social interaction, and affectionate support, provide a framework for examining social support, this study captures additional areas of social support that are important for patients in the context of cancer. This builds on prior research that suggests that tangible and emotional support are important for patients but adds additional components that are not fully captured by previous conceptualizations of social support. Notably, the presence of an individual, regardless of whether that person is providing assistance or if it is a positive interaction, seems to be important to patients. Patients also identified ways that friends and family can provide cognitive empathy, by treating them the same, being honest, and respecting boundaries. Interestingly, affectionate support was not endorsed by patients in this context, although it has been previously established as one of the five domains of social support.

Drawing upon the perspective of precision medicine where the goal is to provide tailored care based on individual differences, we identified variation in social support requests based on demographic and mental health characteristics (see [Table 4](#)). One of our main findings was that younger patients were more likely to desire home care support than older patients. This observed age difference may be due to older patients already receiving more support at home since they may have adult children as informal caregivers,⁴⁰ and echoes recent calls for precision medicine⁴¹ and attending to the unique needs of younger adults with cancer.⁴² We also found that patients with higher anxiety were more likely to request companionship as a desired form of social support. As signs of anxiety (e.g., verbally expressing worries and fears, tremulous hands, panic attacks) may be readily

apparent, these findings could provide caregivers and professionals with greater certainty in how to tailor and personalize support for some patients.

There were both strengths and limitations to this study. The study capitalized on the recruitment infrastructure of the NIH NCATS ResearchMatch program,³⁰ involved reliably quantitatively coding open-ended responses that used a patient-centered approach to provide a window into the perspectives of patient stakeholders,^{11,12} and was sensitive to key individual differences. Despite these strengths, this was a small open-access internet-mediated study and patients were more often white and college educated, so future research should recruit more diverse samples. Patients with prostate cancer were also more likely to participate in the study than patients with other diagnoses, and while we could detect no significant differences in findings based on cancer site, this might be a fruitful area for future research involving large samples. This study was also observational; therefore, no firm conclusions can be made about the direction or causal nature of the observed effects.

This research has implications for future studies aimed at assessing and improving social support. There are several survey measures of social support preferences,^{9,43,44} though these are not specific to cancer. Additionally, the National Comprehensive Cancer Network's Distress Thermometer⁴⁵ assesses a few social support needs (e.g., home care support, physical problems, and emotional problems), but not all of those are noted here. Our results provided additional evidence for some of the domains included in the MOS Social Support Survey, a widely used measure, but did not capture other components including cognitive empathy and just being there. Thus, it could be useful to develop and validate a brief cancer-specific self-report survey of social support needs, drawing upon the types of social support patients identified as important (see [Table 2](#)). As well, in this study, we did not assess whether patients prefer different types of support from different people. Future studies could further improve certainty in how to support patients with cancer by identifying whether the source of support (e.g., spouse, adult child, friend, coworker) influences support preferences or interacts with patients' demographic and mental health characteristics. Perhaps, we might have observed a desire for more affectionate support if asking specifically about a spouse. Additionally, intervention studies might examine whether patients can be screened to identify support needs and whether that information can be utilized to mobilize caregivers (companionship, empathy, assistance with information needs) or route patients to supportive services (navigators, health coaches, mental health clinicians).

Overall, this study described common types of social support, such as companionship, that patients expressed as important, and identified

individual differences in support preferences. This study helps to build knowledge that may reduce uncertainty in caregiving and can assist caregivers in tailoring their support to meet the needs of individual patients.

Disclosure statement

No potential conflict of interest was reported by the authors.

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ORCID

Brittany D. Korotkin  <http://orcid.org/0000-0001-9967-4360>

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