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ORIGINAL ARTICLE

Assessing structure and characteristics of social networks among cancer survivors: impact on general health

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Abstract

Purpose Robust social networks are associated with improved health and quality of life for cancer survivors. Certain cancer diagnoses are associated with higher levels of stigma than breast cancer. However, little is known about the differences in social networks depending on the type of malignancy. This study aims to assess the differences in social networks and general health between breast cancer and more stigmatized cancers.

Methods Cancer survivors were recruited to participate in a cross-sectional online survey study. Social network size and satisfaction was measured using the Cancer Survivor Social Networks Measure. General health was measured with a five-point-Likert-style item.

Results The average age of the sample ($n = 99$) was 57.6 years old (SD = 13.4) and the majority were female (67.7%). Breast cancer survivors had an average of 1.39 more members in their social network than other cancers ($t(94) = 2.28$, $p = 0.025$). There were no significant differences between groups in network satisfaction. Results of a binary logistic regression model explained 26.9% of the variance in general health ($x^2(5) = 18.35$, $p = 0.003$). There was a significant association among formal support network satisfaction ($\beta = -1.23$, $p = 0.021$), formal support network size ($\beta = -0.36$, $p = 0.019$), malignancy type (breast vs. other) ($\beta = 1.05$, $p = 0.05$), and better general health.

Conclusions The results suggest breast cancer survivors had more formal social supports then other malignancy types. An association among greater formal social network size and satisfaction, a diagnosis of breast instead of other cancers, and better general health was noted. Emphasizing formal support sources for all cancer survivors may improve their overall health.

Keywords Social network size · Social network satisfaction · Social support · General health · Stigma

Introduction

The number of cancer survivors in the United States is estimated to increase by 31% to approximately 20.6 million by 2026 [1]. Survivors have a unique set of psychosocial needs as a result of inherent emotional and physical stresses associated with the experience of cancer. Social networks, defined as the ties through which social support is provided, have a significant impact on individual-level psychosocial outcomes for patients across the survivor trajectory [2]. These social networks include both formal (e.g., support groups, other survivors, healthcare providers, employers, and religious officials) and informal (e.g., family, friends, and spouses) supports. In turn, robust social networks may be correlated with improved health outcomes, including increased quality of life and a reduced risk of mortality [2–5]. Cancer can, however,

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be especially powerful in evoking negative feelings among individuals in the social network of survivors, which can result in these individuals socially distancing themselves [6]. In turn, survivors may experience social rejection and isolation that can lead to social stigma [7]. Feelings of fear within the survivor's social network can also cause family and friends to become overly protective of the survivor [6]. Both scenarios may lead to cancer survivors feeling increased levels of stigma and decreased satisfaction with their social network, experiences which may be more strongly correlated with a patient's rating of somatic symptoms than physical assessments by a physician [8].

Although there are similarities across cancer diagnoses, different malignancy types may elicit various reactions and challenges within the social network of the cancer survivor. This variance in reaction can be attributed in large part to differences in societal stigma around various malignancy types. For example, patients with lung cancer face higher levels of stigma than other malignancy types because many people consider personal habits (e.g., tobacco use) as the etiology of the diagnosis [9–11]. Similarly, cancers associated with sex organs (e.g., vulvar, penile) can carry high levels of stigma due to societal taboos around sex/sexuality and an association of the diagnosis with sexual behavior and transmitted infections (e.g., human papilloma virus) [12–14]. Many cancer-related treatment side effects can also increase the risk of stigma. For example, outcomes associated with cancer-directed surgery, such as a colostomy after a bowel resection, can result in increased societal stigma and lower feelings of self-worth for the cancer patient. Other malignancy types, particularly breast cancer, have become less stigmatized overtime. Breast cancer is one of the most common cancers in the United States, and survivors are less likely to be blamed as the cause of their disease compared with other cancers [1, 15]. This perception is often echoed in the societal narrative that breast cancer survivors are "fighters" or "brave." Additionally, many formal supports exist to expand awareness of the disease such as Breast Cancer Awareness Month and the Pink Ribbon Foundation [16].

While current research demonstrates that social networks and support are very important to cancer patients' health and quality of life, little is known about the differences in social networks between breast cancer and other possibly more stigmatized cancers. Therefore, the objective of the current study was to assess potential differences between social network size and satisfaction, including formal and informal support sources among patients with breast cancer and other cancers. In addition, we sought to define the influence of social network size, satisfaction, and malignancy type (breast vs. other) on self-reported general health of the survivor.

Methods

An online survey of cancer patients was conducted among participants recruited from medical listservs like ResearchMatch©, a national health volunteer registry that is designed to bring together researchers and potential participants for research studies [17]. For the current study, participants who indicated a cancer diagnosis on their user profile were recruited. Other participant inclusion criteria included being an age of 18 years or older, at least 4 months past the initial cancer diagnosis, currently receiving treatment or follow-up related to their cancer, and ability to read and write in English. Participants agreed to participate in the survey before answering any questions through an online consent form. The study was approved by The Ohio State University Wexner Medical Center Institutional Review Board (protocol# 2017E0678).

Individual participant demographics were collected such as age, income, race, and relationship status. Cancer demographics such as diagnosis and current cancer status were also documented. Participant social networks were measured using the Cancer Survivor Social Networks Measure (CSSN), which is a self-administered, 16-item instrument evaluating social support satisfaction and network size [2, 18]. The CSSN assesses both formal and informal sources of support. Participants rated the degree of helpfulness of each support source on a four-point Likert scale from 1 "very helpful" to 4 "not helpful." If the respondent had no contact with a support source, he/she was able to indicate as such with a "no contact" option. If the respondent noted that the support source was not applicable to themselves, such as a single person evaluating spouse, the respondent could indicate "not applicable." Social network satisfaction was calculated by the average rating across all support sources for which the participant gave a rating other than "no contact." Last, general health was measured with a single Likert-style item. Respondents rated their general health on a scale from 1, "excellent" to 5, "poor."

All data were collected utilizing an online survey via the Qualtrics® survey platform [19]. A cross-sectional descriptive design was used to explore the quantitative survey items and the data were analyzed using SPSS Version 25 [20]. The listwise deletion procedure was used to manage missing data in the analyses. Data were summarized as descriptive statistics. To evaluate the social network size, individual items on the CSSN were summated if the participant did not indicate "no contact" or "not applicable." The same procedure was used to measure the size of formal/informal support types. Independent *t* tests and chi-square tests of independence were used to compare the social networks of breast cancer patients to other malignancy types. Correlations were used to explore the relationships among model variables. The general health variable was collapsed into dichotomous categories, and binary logistic regression was used to assess the influence of social network size, satisfaction, and malignancy type on general health. All statistical tests were two-tailed and considered significant when p values were < 0.05.

Data availability

The authors maintain full control of all primary data included in this article and are available from the authors on reasonable request.

Results

Two hundred forty-two volunteers from the ResearchMatch© listserv self-reported that they met inclusion criteria and expressed interest in the study. Among the 242 volunteers who were sent a link to complete the study, 119 individuals initiated the survey (response rate of 49.2%). Three participants were excluded due to failure to fill out study consent ($n = 1$) or failure to complete the survey after giving consent ($n = 2$). Participants who completed less than 50% of the target measure were also excluded ($n = 17$). The final sample size was 99.

Respondent characteristics

Participants were an average of 57.6 years old (SD = 13.4, range 27.0–86.0). The majority of respondents were female (67.7%); more than half of respondents had a college or post-graduate degree (72.8%) and reported a salary of more than $50,000 ($50–100 K, 40%; $100–150 K, 18.6%; > 150 K, 20% vs. < $50 k, 21.4%). Most participants identified their race as white (90.4% white, 9.6% nonwhite). Table 1 summarizes other participant demographic variables for the entire sample and breast versus other cancers subsamples. The most common malignancy type was breast cancer (36.5%) followed by prostate cancer (17.7%); other cancer diagnoses included thyroid/parathyroid (10.4%), lung (4.2%), skin (5.2%), gynecological (6.3%), bladder/kidney/urothelial (6.3%), gastrointestinal (1.0%), and other (12.4%). Approximately 15.2% of participants indicated

Table 1 Demographic variables

	Breast cancer survivors ($n = 38$)		Other cancer survivors ($n = 58$)		Total sample ($n = 99$)	
	M (SD)	Range	M (SD)	Range	M (SD)	Range
Age	53.94 (14.31)	27.0–80.0	58.36 (12.91)	30.0–77.0	57.6 (13.40)	27.0–86.0
	n	Valid %	*n*	Valid %	*n*	Valid %
Gender	36	36.4	60	60.6	99	100.0
Male	0	0.0	29	48.3	32	32.3
Female	36	100.0	31	51.7	67	67.7
Annual income	28	35.9	42	53.8	70	100.0
< $50 K	9	32.1	6	14.3	15	21.4
$50 K–$99,999	11	39.3	17	40.5	28	40
$100 K–$149,999	3	10.7	10	23.8	13	18.6
> $150 K	5	17.9	9	21.4	14	21.4
Relationship status	29	40.8	42	59.2	71	100.0
Partnered	18	62.1	29	69.0	47	66.1
Not partnered	11	37.9	13	31.0	24	33.8
Education level	35	43.2	46	56.8	81	100.0
< College degree	9	25.7	13	28.3	22	27.1
Bachelor's degree	8	22.9	11	23.9	19	23.4
Post-graduate degree	18	51.4	22	47.8	40	49.4
Race/ethnicity	38	45.8	45	54.2	83	100.0
White	32	84.2	43	95.6	75	90.4
Non-white	6	15.8	2	4.4	8	9.6
Cancer-free	36	41.9	50	58.1	86	100.0
Yes	29	80.6	34	68.0	63	73.3
No	4	11.1	11	22.0	15	15.2
Do not know	3	8.3	5	10.0	8	8.1

multiple primary or secondary malignancies. Participants frequently reported receiving multiple treatments for their cancer including surgery (82.2%), chemotherapy (54.4%), and radiation (55.6%). Of note, the majority of participants indicated that their medical oncologist was their primary cancer doctor (52.6%), followed by their surgical (26.8%) or radiation (3.1%) oncologist.

Social network characteristics

The mean score for social support satisfaction for all items was 1.72 ($SD = 0.48$). Cancer survivor respondents reported on average 9.81 ($SD = 2.96$) members in their social network ranging from 2 to 15 members. Overall, survivors reported formal ties ($M = 5.13$, $SD = 2.07$, range: 0–9) more often than informal ties ($M = 4.69$, $SD = 1.51$, range: 1–7). The most frequently reported formal support sources were physicians (99%), nurses (89.9%), and other cancer survivors (67.7%). Informal support sources included friends (92.9%), spouses (80.8%), and siblings (78.8%). Average satisfaction ratings for formal ($M = 1.74$, $SD = 0.57$) and informal ($M = 1.71$, $SD = 0.56$) support sources were comparable.

Of note, breast cancer survivors had an average of 1.39 more members in their social network than other cancer survivors ($t(94) = 2.28$, $p = 0.025$). In addition, differences were noted in formal support network size ($t(94) = 2.25$, $p = 0.027$); specifically, breast cancer survivors had more formal support sources ($M = 5.68$, $SD = 2.07$) compared with other cancer survivors ($M = 4.72$, $SD = 2.03$). Breast cancer survivors also more often included their employers ($x^2(1) = 5.60$, $p = 0.018$) and other cancer survivors ($x^2(1) = 6.29$, $p = 0.012$) in their formal support network than other cancer survivors. Specifically, 71.1% and 81.6% breast cancer survivors included their employer and other cancer survivors, respectively; in contrast, only roughly one-half of non-breast cancer survivors included their employer (46.6%) or other cancer survivors (56.9%). Interestingly, there were no differences in the number of informal support sources among breast cancer ($M = 4.95$, $SD = 1.27$) and non-breast cancer survivors ($M = 4.52$, $SD = 1.62$; $t(94) = 1.38$, $p = 0.172$). In addition, despite the difference in overall network size, there were no differences for social network satisfaction (overall, informal and formal) comparing breast cancer survivors with other cancer survivors (Table 2).

Because all breast cancer survivors in the current study identified as female, the significant results (formal network size and overall network size) were further examined between female breast cancer survivors ($n = 36$), female survivors of other cancers ($n = 31$), and male survivors of other cancers ($n = 29$) to account for gender differences. Analyses revealed that the significant results remained when comparing female breast cancer survivors and female survivors of other cancers for both the formal network size ($t(66) = 1.99$, $p = 0.050$) and overall network size ($t(66) = 2.14$, $p = 0.036$). Female breast cancer survivors had a larger formal network and overall social network ($M = 5.68$, $SD = 2.07$; $M = 10.63$, $SD = 2.63$, respectively) than female survivors of other cancers ($M = 4.67$, $SD = 2.14$, $M = 9.13$, $SD = 3.15$, respectively). Significance did not remain when comparing the formal network and overall network size between female breast cancer survivors and male survivor of other cancers ($t(64) = 1.79$,$p = 0.079$; $t(64) = 1.80$, $p = 0.076$, respectively) or between female survivors of other cancers and male survivors of other cancers ($t(56) = -0.22$, $p = 0.862$, $t(56) = -0.27$, $p = 0.786$, respectively).

Impact of social network size, satisfaction, and malignancy type (breast vs. other) on the self-reported general health of the survivor

Overall, survivors reported good general health ($M = 2.71$, $SD = 1.05$). Binary logistic regression was used to examine the influence of formal/informal network size, formal/informal network satisfaction, and malignancy type (breast vs. other cancer) on self-reported general health (excellent/very good vs. moderate/poor). There were no significant correlations between model independent variables but there were significant correlations formal network satisfaction and general health ($r = 0.22$, $p = 0.045$). Together, these results suggest that multicollinearity was not a confounding issue. Overall model fit was strong ($X^2(5) = 18.35$, $p =$

Table 2 Summary of independent *T* test results between breast ($n = 38$) and other ($n = 58$) cancer survivors

	M(SD)				
	Breast	Other cancers	*t*	df	*p*
Overall network size	10.63 (2.63)	9.24 (3.10)	2.28	94	0.025
Formal network size	5.68 (2.07)	4.72 (2.03)	2.25	94	0.027
Informal network size	4.95 (1.27)	4.52 (1.62)	1.38	94	0.172
Overall network satisfaction	1.78 (.48)	1.68 (.50)	0.95	94	0.347
Formal network satisfaction	1.74 (.55)	1.74 (.60)	− 0.07	93	0.941
Informal network satisfaction	1.79 (.60)	1.65 (.55)	1.21	94	0.230

0.003) and explained 26.9% of the variance in general health (Nagelkerke $R^2 = 0.269$). Formal support network satisfaction ($\beta = -1.23$, $p = 0.021$), formal support network size ($\beta = -0.36$, $p = 0.019$), and malignancy type (breast vs. other cancer) ($\beta = 1.05$, $p = 0.05$) were associated with general health; in contrast, informal network satisfaction ($\beta = -0.31$, $p = 0.592$) and size ($\beta = 0.20$, $p = 0.316$) were not associated with general health.

Conclusions

The presence of supportive, nurturing relationships and social networks may be associated with a range of health outcomes [21–23]. Cancer survivors have a particular need for robust social support. Unique challenges such as coping with their illness, treatment side-effects, as well as the fear of recurrence can impact cancer survivor quality of life. Cancer survivors who are connected to a diverse range of individuals may experience a better quality of life, lower risk of depression, as well as increased rates of survival [24–30]. While previous work has examined the impact of social networks on behavior around cancer screening, as well as on cancer survival, few studies have investigated the impact of social networks on the general health of cancer patients [24–26, 31–35]. In addition, the characteristics and impact of social networks among cancer patients with different diagnoses have similarly not been well studied. Such data are important as societal perceptions of different cancer diagnoses can have varied effects on patient psychosocial needs. For example, breast cancer patients have reported feelings of power and strength associated with the strong community of survivors, while patients with other diagnoses may feel more stigmatized and socially isolated [36]. The current study was important because it specifically characterized differences in the social networks among patients with breast versus non-breast cancer. In addition, the impact of these social networks on the general health of cancer survivors was assessed. Of note, breast cancer survivors had more formal social supports compared with patients who had other malignancy types. Additionally, greater formal social network size and satisfaction and a diagnosis of breast instead of other cancers, were strongly associated with better general health.

A particular strength of the current study was the investigation of both network structure (e.g., network size) and characteristics of the social network (e.g., formal vs. informal). Previous research has noted that the size of the social network, specifically the number of individuals that constitute a patient's community, correlates with overall perceived support [37]. In the current study, breast cancer patients had, on average, a larger social network size than patients with other cancers. Interestingly, the differences in social network size were attributable to formal sources of support. Specifically, breast and non-breast patients reported a comparable informal network size that included individuals such as friends, family, and spouses. However, breast cancer patients had more formal support sources such as employer or community associations than other cancer survivors. The reasons for the differences in formal network support were undoubtedly multifactorial and may relate to how breast cancer has been embraced in society and advocacy [36, 38]. Indeed, several studies have documented how breast cancer has become less stigmatized overtime with increased awareness, public advocacy, as well as widespread support for patients with this disease [16]. Data from the current study noted that—while breast and non-breast patients had comparable informal social networks—non-breast patients had fewer formal social network resources. The reason for this may relate to increased isolation and social stigma associated with non-breast cancers that may prohibit or discourage patients from seeking out social support [9–14]. In addition, formal support networks (e.g., support groups, and advocacy groups) for non-breast cancer patients are less available [39]. Guidry et al. noted the important role of both informal and formal social support networks for patients with cancer [40]. As such, data from the current study highlight the need to facilitate increase opportunities for both formal and informal social network support for all cancer patients.

Clinical implications

Despite the difference in social network size, there was no difference in social network satisfaction among breast and non-breast cancer survivors. While breast cancer patients had more sources of support than non-breast patients, they were not more satisfied with the sources of support to which they had access. These data highlight that both network structure (e.g., network size), as well as characteristics of the social network (e.g., formal versus informal, and quality of the social support) can impact patient satisfaction. Indeed, social support can be nuanced and may be a concern related to quality of support, not quantity. For example, cancer survivor perception of "matched" support, meaning the supportive behaviors of the individual matched the survivor's expectations, has been suggested to be a stronger link to positive outcomes than social network size or presence of supportive behaviors [41, 42]. The concept of "matched support" may be important for physicians and other healthcare providers to help develop strong therapeutic relationships with their patients. In addition, the concept of "matched support" may be equally important among patients in their informal social networks with spouses, family, and friends. Future research will need to elucidate multi-perspective data that assess the congruence between support given and support received, as such data will be important to understanding the concept of "matched support."

Another interesting finding of the current study was the association of network support and overall general health.

Specifically, patients with a larger network size and overall higher satisfaction with their support network were more likely to have better general health. These findings were consistent with other studies that have linked more social networks to better health outcomes in cancer patients [5, 43]. The current study expands, however, on previous work as it characterized the distinction between formal and informal support, noting that formal support sources had a greater influence on general health. It is possible that the ability to openly discuss a cancer diagnosis with formal supports may be associated with improved self-reported general health. For example, the ability of a patient to talk to their employer and receive more understanding regarding missed work or low energy in the office may lead to better feelings of general health. Furthermore, formal social support sources such as interactions with other survivors could lead to the exchange of advice (e.g., ways to reduce nausea, exercises to do after surgery) among survivors, which in turn can improve feelings of general health.

Limitations

Results of the current study should be interpreted in light of several limitations. Participants included only individuals who willingly signed up for ResearchMatch© and agreed to participate without incentive; as such, volunteer bias was possible. The survey also utilized a retrospective self-report framework, which may be subject to recall bias, acquired meaning-making memories, and the mood of the participant at the time of the survey [44]. Due to the cross-sectional nature of the survey, “true” causality could not be determined, which should be considered when interpreting the results. Finally, given that the sample set was derived largely from individuals residing in the Midwest, the results should be confirmed in a larger cohort of participants from other regions of the country.

In conclusion, robust social networks may improve health and quality of life for cancer patients. Important differences in social networks among breast and non-breast cancer survivors were identified. Specifically, breast cancer survivors had larger social networks that were characterized by more formal social supports then non-breast survivors. Greater formal social network size and satisfaction were associated with better general health. These data demonstrate that social networks play an important role in the self-reported health and well-being of cancer survivors.

Compliance with ethical standards

Conflicts of interest The authors declare that they have no conflicts of interest.

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