

HHS Public Access

Author manuscript *Patient Educ Couns*. Author manuscript; available in PMC 2023 April 03.

Published in final edited form as:

Patient Educ Couns. 2023 January ; 106: 135–141. doi:10.1016/j.pec.2022.10.009.

The role of social networks in prognostic understanding of older adults with advanced cancer

Veronica Yu^{a,1}, Sule Yilmaz^{b,1,*}, Jorie Freitag^c, Kah Poh Loh^d, Lee Kehoe^b, Grace Digiovanni^a, Jessica Bauer^a, Chandrika Sanapala^a, Ronald M. Epstein^e, Reza Yousefi-Nooraie^f, Supriya Mohile^g

^aUniversity of Rochester School of Medicine and Dentistry, Rochester, NY, USA

^bDepartment of Surgery, Division of Supportive Care in Cancer, University of Rochester Medical Center, Rochester, NY, USA

^cUniversity of Washington School of Medicine, Seattle, Washington, USA

^dDivision of Hematology/Oncology, Department of Medicine, James P Wilmot Cancer Institute, University of Rochester Medical Center School of Medicine and Dentistry, Rochester, NY, USA

^eDepartment of Family Medicine Research, University of Rochester Medical Center School of Medicine and Dentistry, Rochester, NY, USA

^fDepartment of Public Health Sciences, University of Rochester Medical Center, Rochester, NY, USA

^gGeriatric Oncology Research, James P Wilmot Cancer Institute, University of Rochester Medical Center School of Medicine and Dentistry, Rochester, NY, USA

Abstract

Objectives: Explore how older patients utilize their social networks to inform prognostic understanding.

Methods: In a pilot study of adults (65 years old) with advanced cancer, 16 patients completed surveys, social network maps, and semi-structured interviews exploring with whom they preferred to communicate about their illness. Interviews were analyzed using open-coding, and codes were categorized into emergent themes. Social network maps and themes were analyzed via mixed-methods social network analysis (MMSNA). Three case examples with diverse network characteristics and communication patterns were selected for further analysis.

Results: Three overarching themes (i.e., prognostic understanding, social support, and therapeutic alliance) revealed that patients' prognostic understanding was strongly influenced by the quality of the social support patients perceived from members of their social networks.

This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

^{*}Correspondence to: Department of Surgery, Division of Supportive Care in Cancer University of Rochester Medical Center, 265 Crittenden Blvd, Rochester, NY 14642, USA. sule_yilmaz@urmc.rochester.edu (S. Yilmaz). ¹Co-first authors

Conflict of Interest None.

Patients demonstrated prognostic understanding when they reported close relationships and open communication with their network members. Case examples revealed some ways that patients sought information and had better sense of their prognosis when they had supportive social networks.

Conclusion: Findings illustrate how understanding social networks may provide information on how older adults with cancer seek, share, and process prognostic information.

Keywords

Social networks; Social support; Prognostic understanding; Advanced cancer; Older adults; Therapeutic alliance

1. Introduction

Older adults with advanced cancer often rely on their social networks when making health decisions. Patients' prognostic understanding and decision-making are based on information, perspectives, stories, and advice they receive from their network members (e.g., healthcare professionals, close relatives).[1] Hence, understanding how older patients with advanced cancer utilize their social network to inform prognostic understanding is important for improving quality of care.

Older patients with advanced cancer frequently suffer from aging-related conditions (e.g., functional decline) in addition to disease and treatment related concerns. These patients become particularly vulnerable to challenging day-to-day social circumstances while having to also deal with multiple physical symptoms, a range of emotions, spiritual issues [2], and yet they try to stay connected and preserve their quality of life.[3] They often need additional support from their social networks to overcome these challenges and to navigate through the complex healthcare system to ensure all of their care needs are met.[4] Only a fraction of older patients have prognostic communication with their oncologists.[5] Hence, older patients often end up having inaccurate beliefs about cure and their prognosis [6], [7] With adequate prognostic understanding, older patients more often communicate a preference for comfort-oriented approaches and palliative care [8,9].

Social networks are becoming extremely important for communication, collaboration, and information gathering and sharing in healthcare spaces.[10] Because older adults are more likely to depend on social networks for instrumental support and communication with healthcare professionals, knowledge about the role of social networks is especially important [11].

In this study, we explored how social network structures and processes influence prognostic understanding of older patients with advanced cancer. Mixed Methods Social Network Analysis (MMSNA) [12] was used to study the patterns of relationships among members of a social network by incorporating quantitative information about network structures with qualitative perspectives of network members, both of which are collected and analyzed simultaneously. Hence, MMSNA can be a powerful approach to help understand the

complexities of change in networks and relations between individuals via use of both subjective and objective data [12].

2. Methods

2.1. Study design and setting

This is a secondary data analysis of a mixed-methods pilot study of older adults with advanced cancer exploring how patients' social networks influence their prognostic understanding. The pilot study was carried out in the Wilmot Cancer Institute. Patients were enrolled between November 2018 and March 2020. The study's protocol was approved by the University of Rochester's Institutional Review Board. All patients provided written informed consent prior to participating.

2.2. Study participants

Sixteen patients who completed a survey with demographic information, a semi-structured interview, and a social network map were included. Eligible patients were aged > 65 years old, within six months of diagnosis of advanced cancer (including advanced hematologic malignancies who may still have a small chance of cure). Patients have demonstrated the capacity to make decisions and the ability to understand informed consent process as verified by their oncologist. Patients were excluded from the study if they were unable to read and understand spoken English. Patients received a gift card of \$50 for completing the survey and \$50 for completing the interview.

2.3. Data collection

Patients completed a survey about their sociodemographic and cancer-related clinical characteristics. Survey questions included age (in years), sex (female or male), race, ethnicity, marital status, education, and employment status. Patient data about cancer type, stage, and treatment status were collected from electronic medical records.

Patients participated in a semi-structured interview and constructed a social network map with trained research staff (GD or JG). After listing social contacts with whom they discussed health and illness-related issues, patients were instructed to indicate the strength of their relationships by graphically placing social contacts on a network chart composed of concentric circles, with the patient at the center and radial sections representing various social categories (family at home, family outside home, friends, neighbors-colleagues, healthcare professionals, and others). Finally, patients were asked to draw lines between social contacts to depict connections among network members to indicate who knows and communicates with whom and were asked to provide details on the quality, content and dynamics of each relationship. All interviews were audio-recorded and transcribed verbatim.

2.4. Data analysis

Descriptive statistics (e.g., frequency distribution, mean and standard deviation) were computed to describe the demographic characteristics of older adults.

MMSNA was employed to characterize social networks by the following three dimensions: structural (the overall shape of the network), membership (the identity makeup of the network), and relationships. This approach was an inductive and iterative process of framing (restructuring the graphical configuration of network maps via force-directed algorithms), pattern detection (independent identification of underlying dimensions, sorting and clustering), and labelling of network dimensions based on their overarching features (collectively performed by team members in consensus meetings).[13] A preliminary set of dimensions was identified from emergent patterns: three structural dimensions included cohesive circle of tightly knitted family and friends, segregated cluster with weak connections between clusters, and star-shaped network of unconnected network members; and five membership dimensions related to certain social roles included core member (s) connected to the majority of the patient's network, family dominance (primarily includes family members), role diversity (includes other network members besides family), embeddedness of health care professionals (includes healthcare professionals as part of the social network), and embeddedness of other network members that could explain the similarities and differences among the maps.

We used constant comparative method [14] to analyze the transcribed interviews in multiple phases. First, transcripts were analyzed via line-by-line open coding by two trained research staff (VY, JF). With assistance from a third member of the research team (SY), discrepancies in codes were then reviewed, discussed, and resolved through an iterative process of interpretation and comparison to the raw data. As analysis progressed, initial codes were modified and a provisional coding scheme was developed. Codes were then categorized into emergent themes, and matrices were employed for analytic comparison of themes.

Following initial analyses, three representative case examples with diverse network characteristics and differing levels of prognostic understanding were selected from the total sample by the coding team for in-depth, juxtaposed comparison. Exemplar quotes were selected from the transcripts for each case example. Qualitative themes were integrated with social network maps into a joint display. We selected these three cases with distinct network structures to understand how communication patterns within diverse social network structures influence prognostic understanding.

3. Results

3.1. Demographic characteristics

Table 1 shows patient demographics. Majority of the sample consisted of male (81%; n =13), white (94%; n =15), married (56%; n =9), retired (69%; n = 11) patients with a mean age of 76 years (*SD* 6.66), with most being high school graduate or higher (69%; n = 11). Amongst the patients with solid tumor (62.5%; n = 10), the most common was pancreatic in origin. Amongst the hematologic malignancies (37.5%; n = 6), the most common was myelodysplastic syndromes.

3.2. Qualitative themes

3.2.1. Prognostic understanding—Patients expressed prognostic understanding in terms of cancer curability and estimated survival for their respective diagnoses. Describing curability, patients elaborated on the staging of their diagnosis and the goals of treatment. Patient 3 reported, "As I understand it, there's no cure because it's metastatic breast cancer, which means it's systemic." When asked about the goals of cancer treatment, Patient 9 clarified, "No, it's [the cancer] is not curable. It is just containable."

While the majority of patients acknowledged that their cancer was deemed incurable, some reported that the cancer was curable and/or that they were unsure. For Patient 8, past personal experience with cancer contributed to their view of curability: *"I can be cured. I've had cancer before and I was cured."* Similarly, optimism dictated the perception of Patient 14[']s conversations with medical providers: *"I'd like to feel like all of them have said, 'Yes, we're going to get this."* For those with an unclear understanding of curability, this was often due to the ongoing diagnostic work-up. Patient 15 reported, *"They [healthcare professionals] haven't said. They have to figure out what it is and where it is, I would guess."* Patients who reported survival estimates had personal interpretations of the estimate provided to them by their oncologist. Patient 5 stated, *"They [healthcare professionals] said the average life span to live with this is three years [.] That's the average. But I'm not average."* Patient 3 acknowledged that the inherent uncertainty of survival estimates: *"I think they [healthcare professionals] have said the usual prognosis would be two to three years. But it's - since it's in my liver it might not be that long."*

3.2.2. Instrumental social support—Involvement of social contacts with patients' medical care appeared to both facilitate and hinder prognostic understanding. In most cases, improved prognostic understanding appeared to result from increased exposure of network members to the patient's illness experience (cancer-related symptoms, treatment-related side effects) and increased network member activation in the treatment process (participation in conversations with healthcare professionals shared health-information seeking). Most patients reported that when they received support from their network members to navigate through the healthcare system, it helped create opportunities for both patients and their caregivers to explore the topic of prognosis more in-depth. Patient 15 appreciated his son accompanying him to medical appointments and said, *"He's smarter than I am. He asks questions that I wouldn't have thought of."* Patient 11 referring to his sister, stated, *"She's involved in the conversations I have with doctors - I put her on the phone so she can ask questions. Like my son, both of them check MyChart on a regular basis to see what's going on."*

3.2.3. Emotional social support—Patients reported receiving emotional social support in 'well wishes' forms (e.g., prayers and well wishes, statements of optimism or encouragement) and in-depth forms (e.g., processing of patient fears and preferences for end-of-life care). Patients receiving primarily well wishes from social contacts frequently expressed fear of burdening others with their emotions and the perception that others may not want to have tough conversations with them. On discussions with his sister, Patient 11 reported, *"[She]'s got enough on her plate. I keep it fairly general, which is safe. I don't like*

to upset her more than her life is already upset. "Although Patient 11 received significant instrumental support from family members, he hesitated to seek emotional support. He did not report any specific survival estimate for his prognosis. In comparison, some patients who were supported by social contacts to engage in in- depth conversations appeared to exhibit clearer prognostic understanding. Patient 10, who reported a survival estimate of "up to a year" from his oncologist, reported discussing with their spouse *"how I'm feeling, what I want done when the time comes, things of that nature - facing reality.* "Patient 10[']s father passed away from the same type of cancer as which the patient was diagnosed, perhaps contributing to this particular patient's willingness to discuss prognosis and end-of-life.

3.2.4. Therapeutic alliance—Most patients expressed confidence in their healthcare professionals to guide them through a process that is full with uncertainty. Patient 1 stated, *"I have confidence in the doctors here. I think they know what they're doing. They're being very careful about a lot of things and it's very difficult to manage such a serious illness. They've got a tough job and I'm going to help them do it." For Patient 2, having direct communication with their provider lead to build trust: <i>"[Doctor] was forthcoming about what was going to happen and what was happening and let us know straight up what was going on. It was really appreciated. [.] It's a trust thing, because I really trusted what she was telling me and the fact that she was really forthcoming, didn't pull any punches, didn't try to sugar coat anything, she wanted us to know exactly what was going on. "For others, non-verbal cues heavily impacted the therapeutic relationship. Patient 6 reported that the doctor <i>"always greets me with a good handshake,"* instilling feelings that *"he's a good doctor."*

Despite reports of strong therapeutic relationships, many patients either had not discussed prognosis or could not recall such a conversation with a healthcare professional. Patients described an assumption that their healthcare professional would bring up the conversation, so they did not bring up the topic themselves. *Patient 9 stated, "We've talked about [prognosis]. I don't know how deep. I'm sure there's going to be more conversations about it. [...] I just don't think I've been there yet.* "Reflecting on patient agency in prompting prognostic discussion, Patient 16 remarked, "*I haven't discussed [prognosis] with [oncologist] – what the percentage of cure is or anything like that. I just understand that it's low. [...] In fact, the next time I talk to [oncologist], I'm going to ask her to give me an idea."*

Most patients reported trusting healthcare professionals as their primary source of health information, indicating that they would consult their doctor for advice regarding health information. Patient 12 stated, *"If they (friends and family) came up with some new stuff, then it's where did you get that from? The internet? Okay. All right. I'll ask the doctor next time."* Although most patients identified healthcare professionals as trusted sources of health information, less than half of patients included any type of healthcare professional in their social network map.

3.3. Case examples

We selected three representative case examples to compare and contrast patients' social network structures and processes in relation to the emergent themes [see Table 2].

In Case One, the patient was a 91-year-old male diagnosed with hematologic cancer on active treatment with chemotherapy. He was never married, living alone, and was retired. This patient's social network structure was star-shaped, with the patient at the center connecting to each point of the star, but with limited connections between the points of the star themselves. The network structure was characterized by role diversity, lacking role dominance of any one particular member identity, such as family or friends. Neighbors and church friends offered transportation assistance, but no one was closely involved in his care or bore witness to his illness experience. Acquaintances offered words of comfort to him, but he lacked close contacts with whom to delve into serious discussions about his illness. The lack of support and engagement in care from network members, the patient acknowledged that the cancer is not curable, but he had no knowledge about survival estimates nor treatment options, suggesting that the patient had limited understanding of his poor prognosis.

In Case Two, patient was an 82-year-old male diagnosed with hematologic cancer on active treatment with chemotherapy. He was married, living with his spouse, and retired. This patient's social network structure comprised of a cohesive circle where members were densely connected to both the patient and each other. Network structure was characterized by a strong core member role (patient's spouse) and family dominance role, meaning that the patient's social network was comprised mainly by the family members. In stark contrast to Case One, the patient in Case Two had significant instrumental social support from his closely-knit network of family members as well as peripheral members with healthcare knowledge. His relationships were characterized by openness in communication and significant emotional social support from family, including one of whom had personal experience with cancer. Further, he described a close relationship with his primary care physician (PCP) which was evidenced by the inclusion of this physician in the patient's network map. With clear and shared communication among network members, this patient displayed a strong understanding of prognosis: he acknowledged that the cancer was not curable, accurately described the goals of treatment, and reported the "best-case scenario" survival estimate.

In Case Three, patient was a 75-year-old female diagnosed with breast cancer on active treatment with chemotherapy. She was widowed, living alone, and working part-time (less than 32 h per week). This patient's network structure was comprised of segregated clusters, or groups of individuals connected amongst themselves but with limited, weak connections to other groups. The network structure was characterized by role diversity (without any specific dominant role group) and embeddedness of other network members, indicating strong relationships with network members of varied identities. Despite the varied types of relationships (i.e., role diversity) in this patient's network, her main source of both instrumental and emotional social support was a pair of long-time friends. Importantly, these friends engaged the patient in discussions about the disease and her feelings about end-of-life care. The patient also reported open communication about her prognosis and treatment

options with her PCP and with a friend who is a palliative care physician. Although the clusters of this patient's network were not connected to each other, the patient effectively sought information to support her needs. She displayed clear prognostic understanding by acknowledging that the cancer was not curable, describing the goals of her treatment, and reporting a specific survival estimate.

Considered together, these case examples emphasize the utility of social support from social network members in the dissemination of illness-related information. In all three cases, while network structure alone provides clues about social support and communication, it does not comprehensively capture HOW patients are sharing and understanding information. It is respectively important to pinpoint that network structure alone also does not capture WHAT patients are sharing and understanding.

4. Discussion and conclusion

4.1. Discussion

Our findings from this MMSNA study confirmed that patients' prognostic understanding is often influenced by the quality of the social support and therapeutic alliance patients perceived from members of their social networks. Patients demonstrated clearer understanding of their prognosis when they reported close relationships and open communication with their network members, including their healthcare professionals. Case examples showed that patients sought information and had better sense of their prognosis when they had wider cluster of supportive social networks.

Research shows that patients identify connectedness with family and friends and others (e.g., oncologists) as important element of their quality of life.[15] Particularly, having close network members serve as a potential buffer and can minimize the psychological distress that patients face due to cancer-related concerns. There is substantial evidence that patients with cancer benefit from having supportive network structures— as the patients depend on family caregivers for emotional, financial, and material support. Nissen and colleagues [16] mentioned that among families of patients with cancer, poor family functioning has been associated with increased risk of psychological distress and existential crisis. In addition, studies have highlighted the importance of the role physicians play in providing emotional support to patients with terminal cancer and treating them as a "whole person" rather than just focusing on the disease processes.[17] For this reason, understanding the role of network members in facilitating patients for accurate prognostic understanding is an important aspect of research aimed at enhancing QOL of patients with cancer [18].

Our findings confirmed social support as a key facilitator of prognostic understanding for patients and their network members. More specifically, in-depth emotional support influenced patient prognostic understanding. Amongst all of the participants, the few that reported in- depth emotional social support also acknowledged that their cancer was not curable and were able to report a specific survival estimate. In contrast, majority of the patients receiving primarily 'well wishes form' emotional support acknowledged that their cancer was not curable, but tended not to be aware of prognostic estimates. These patients also expressed fear of burdening others with their emotions and indicated that others might

not want to have tough conversations with them. Instrumental social support on the other hand had varied influence on prognostic understanding. In most cases, improved prognostic understanding was associated with increased exposure of network members to patient's illness experience (cancer-related symptoms, treatment-related side effects) and increased patient and social network member engagement in the treatment process (participation in conversations with healthcare professionals, health-information seeking).

While having supportive interactions and connections with members of a social network can reduce burden both from diagnosis and treatment of cancer,[19–21] social support at the same time can produce negative effects if the type of support provided is not concordant with patients' needs.[22] Hence, as much as the provision of support is crucial for patients' QOL, providing the right type of support is essential. [22] In this study, we observed the negative influence of social support in cases where the social support hindered patient prognostic understanding. In the first, social contacts took on such a significant portion of responsibility that patients, in turn, were allowed to disengage completely from their care. In the second mechanism, social contacts and patients directed shared attention to the details of illness management as a coping mechanism, and this focus deflected from potential in-depth conversations about prognosis. This variability in the experience and effects of social support echoes the inconsistency in findings of prior studies [23–25] on social support across studies.[26,27].

Patients' connection with their oncologist is a crucial aspect of their care,[28] especially to ensure that patients have clear prognostic communication with their oncologists. Particularly, in this connection, oncologists' attentiveness to the emotional needs of patients becomes increasingly important [17] for the oncologists to accurately assess whether patients are emotionally ready to have prognostic communication and be able to understand their poor prognosis. Hence, having a strong connection between patients and oncologists has been associated with better QOL, and adjustment to illness among patients.[29] Patients with cancer often report feeling isolated from their social network. Thus, the alliance between patients and oncologists become an important source of support for patients. [29] In a mixed methods study, Mako and colleagues. [30] revealed that the issue of 'presence' comes up frequently. This suggests that patients report a desire to spend time with oncologists who listen and talk to their patients.[31].

Patients in our study generally reported positive rapport with their healthcare professionals but did not routinely include healthcare professionals in their social network maps. More importantly, majority of the patients reported a wish for direct communication about prognosis with their healthcare professionals [32] highlighting a need for ongoing research into the timing, content, and communication styles of effective prognostic conversations.

4.2. Strengths and limitations

This is one of the few studies that includes older patients with cancer aged 65 years. We included patient perspectives on prognostic understanding using semi-structured interviews. Moreover, we captured social network structure, dimensions, and relationships with various network members (e.g., pastors, healthcare professionals, neighbors, etc.) and not only

close family and caregivers. This allowed us to gather rich data about how social network members influence prognostic understanding of patients with advanced cancer.

While the study used mixed methods approach to highlight patient perspectives – there are several limitations worth noting. Potential limitations include selection bias as we enrolled specific population of older patients with cancer and are underrepresented in research studies. In addition, we enrolled predominantly white male participants and so the study findings may not be generalized to other populations of patients with cancer. Recognizing the importance of diversity, equity, and inclusion for representation and participation of different groups in research studies, it is our goal to include more female and patients of color in our follow up research with larger samples.

4.3. Conclusion

We found that when patients have diverse structured, supportive social networks, they are more apt to seek information and have discussions about their prognosis with their network members.

The findings will be used to determine the directions of future work to leverage on the structure, dimensions, and relationships with social network members of patients with cancer to improve prognostic communication and understanding for better quality of care and decision-making. Future longitudinal cohort studies with larger samples are needed to better identify how social networks influence prognostic understanding – in addition to understanding why networks are the way they are and how they shift when patients are diagnosed.

4.4. Practice implications

Our findings may help a) inform family members of cancer patients on how to be more proactive in providing instrumental and emotional social support (i.e., through patient advocacy) and b) stimulate patients to make use of social networks for instrumental and emotional social support.

Acknowledgements

All persons who have made substantial contributions to the work reported in the manuscript (e.g., technical help, writing and editing assistance, general support), but who do not meet the criteria for authorship, are named in the Acknowledgements and have given us their written permission to be named. If we have not included an Acknowledgements, then that indicates that we have not received substantial contributions from non-authors.

Funding

NCI-funded postdoctoral T32 Fellowship Program in Cancer Control (T32 Grant # T32CA102618). This study also received funding from the National Institute on Aging (K24AG056589 to SGM). Dr. Loh is supported by the National Cancer Institute (R00CA237744), Wilmot Research Fellowship Award, and Conquer Cancer American Society of Clinical Oncology Career Development Award. The investigators were independent in the conduct and analysis of the results. Funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Practice Implications

Findings may stimulate and inform network members on how to facilitate instrumental and emotional social support circles.

References

- Yousefi Nooraie R MSG, Yilmaz S, Bauer J, Epstein RM. Social networks of older patients with advanced cancer: potential contributions of an integrated mixed methods network analysis. J Geriatr Oncol 2021;12:855–9. [PubMed: 33342721]
- [2]. Krikorian A, Limonero JT, Maté J. Suffering and distress at the end-of-life. Psycho-Oncol. 2012;21:799–808.
- [3]. Breitbart W Existential isolation. Palliat Support Care 2017;15:403. [PubMed: 28641587]
- [4]. Austin P, MacLeod R. Finding peace in clinical settings: a narrative review of concept and practice. Palliat Support Care 2017;15:490. [PubMed: 27919306]
- [5]. Epstein RM, Duberstein PR, Fenton JJ, Fiscella K, Hoerger M, Tancredi DJ, Xing G, Gramling R, Mohille S, Franks P, Kaesberg P, Plumb S, Cipri CS, Street RL, Shields CG, Back AL, Butow P, Walczak A, Tattersall M, Venuti A, Sullivan P, Robinson M, Hoh B, Lewis L, Kravitz RL. Effect of a patient-centered communication intervention on oncologist-patient communication, quality of care, and health care utilization in advanced cancer. The VOICE randomized clinical trial. J Amer Med Assoc Oncol. 2017;3:92–100.
- [6]. Weeks JC, Catalano PJ, Cronin A, Finkelman MD, Mack JW, Keating NL, Schrag D. Patients' expectations about effects of chemotherapy for advanced cancer. N Engl J Med 2012;367:1616– 25. [PubMed: 23094723]
- [7]. Loh KP, et al. Association of prognostic understanding with health care use among older adults with advanced cancer: a secondary analysis of a cluster randomized clinical trial. J Am Med Assoc Netw Open 2022;5. 2200–18.
- [8]. El-Jawahri A PL, Eichler AF, Plotkin SR, Temel JS, Mitchell SL, Chang Y, Barry MJ, Volandes AE. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. J Clin Oncol 2010;28:305–10. [PubMed: 19949010]
- [9]. Wittink MN MK, Meoni LA, Ford DE, Wang NY, Klag MJ, Gallo JJ. Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins Precursors Study. Arch Intern Med 2008;168:2125–30. [PubMed: 18955642]
- [10]. Keckley PH, Hoffmann M. Social networks in health care: communication, collaboration and insights. Deloitte Cent Health Solut 2010:1–9.
- [11]. Tomini F, Tomini SM, Groot W. Understanding the value of social networks in life satisfaction of elderly people: a comparative study of 16 European countries using SHARE data. BMC Geriatr 2016;16:203. [PubMed: 27905902]
- [12]. Froehlich DE, Martin R, Rienties BC. Mixed Methods Social Network Analysis: Theories and Methodologies in Learning and Education. Routledge; 2019.
- [13]. Yousefi Nooraie R, et al. Social network analysis: an example of fusion between quantitative and qualitative methods. J. Mixed Methods Res. 2020;14:110–24.
- [14]. Green J Commentary: grounded theory and the constant comparative method. Brit Med J 1998;316:1064–5. [PubMed: 9558994]
- [15]. Tarakeshwar N VL, Paulk E, Pearce MJ, Kasl SV, Prigerson HG. Religious coping is associated with the quality of life of patients with advanced cancer. J Palliat Med 2006;9:646–57. [PubMed: 16752970]
- [16]. Nissen KG, Trevino K, Lange T, Prigerson HG. Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer. J Pain Symptom Manag 2016;52:841–9.
- [17]. Wenrich MD, Curtis JR, Ambrozy DA, Carline JD, Shannon SE, Ramsey PG. Dying patients' need for emotional support and personalized care from physicians: Perspectives of patients with terminal illness, families, and health care providers. J Pain Symptom Manag 2003;25:236–46.

- [18]. Heijer MD, Seynaeve C, Vanheusden K, Duivenvoorden HJ, Vos J, Bartels CC, Menke-Pluymers MBE, Tibben A. The contribution of self-esteem and self-concept in psychological distress in women at risk of hereditary breast cancer. Psycho- Oncol 2011;20:1170–5.
- [19]. Helgeson VS, Cohen S. Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. Health Psychol 1996;15: 135–48. [PubMed: 8681922]
- [20]. Koopman C, Hermanson K, Diamond S, Angell K, Spiegel D. Social support, life stress, pain and emotional adjustment to advanced breast cancer. Psycho-Oncol 1998;7:101–11.
- [21]. Cohen S Social relationships and health. Am Psychol 2004;59. 676–84. [PubMed: 15554821]
- [22]. De Leeuw JRJ, De Graeff A, Ros WJG, Hordijk GJ, Blijham GH, Winnubst JAM. Negative and positive influences of social support on depression in patients with head and neck cancer: a prospective study. Psycho-oncol. 2000;9:20–8.
- [23]. Chochinov HM, et al. Prognostic awareness and the terminally ill. Psychosomatics 2000;41:500–4. [PubMed: 11110113]
- [24]. Fisher K, et al. Patient characteristics associated with prognostic awareness: a study of a Canadian palliative care population using the InterRAI palliative care instrument. J Pain Symptom Manag 2015;49:716–25.
- [25]. Loh KP, et al. Willingness to bear adversity and beliefs about the curability of advanced cancer in older adults. Cancer 2019;125. 2506–13. [PubMed: 30920646]
- [26]. Sjolander C AG. The meaning and validation of social support networks for close family of persons with advanced cancer. Brit Med J Nurs 2012:11–7.
- [27]. Loh KP MS, Epstein RM, McHugh C, Flannery M, Culakova E, Lei L, Wells M, Gilmore N, Babu D, Whitehead MI, Dale W, Hurria A, Wittink M, Magnuson A, Conlin A, Thomas M, Berenberg J, Duberstein PR. Prognostic understanding in hematologic malignancies: a multicenter longitudinal study. J Clin Oncol 2019;37. 11524–11524.
- [28]. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Peace of mind and sense of purpose as core existential issues among parents of children with cancer. Arch Pediatr Adolesc Med 2009;163:519–24. [PubMed: 19487607]
- [29]. Trevino KM, Fasciano K, Block S, Prigerson HG. Correlates of social support in young adults with advanced cancer. Support Care Cancer 2013;21:421–9. [PubMed: 22790223]
- [30]. Mako C, Galek K, Poppito S. R, Spiritual pain among patients with advanced cancer in palliative care. J Palliat Med 2006;9:1106–13. [PubMed: 17040148]
- [31]. Boston, Bruce Anne, Schreiber Rita. Existential suffering in the palliative care setting: An integrated literature review. J Pain Symptom Manag 2011;41:604–18.
- [32]. Hagerty RG BP, Ellis PA, Lobb EA, Pendlebury S, Leighl N, Goldstein D, Lo SK, Tattersall MH. Cancer patient preferences for communication of prognosis in the metastatic setting. J Clin Oncol 2004;22:1721–30. [PubMed: 15117995]

Table 1

Participant Demographics.

Patient Characteristics	N (%), N = 16
Age (SD)	76, SD = (6.66)
Sex (Female) (Male)	3 (19%) 13 (81%)
* Race (White)	15 (94%)
Ethnicity (Non- Hispanic)	16 (100%)
* Marital Status (Separated, Widowed, Divorced) (Never Married) (Married)	3 (19%) 3 (19%) 9 (56%)
* Education (HS graduate) (>HS graduate)	1 (6%) 11 (69%)
Employment (Retired) (Employed) (Part-time Student, Other)	11 (69%) 3 (19%) 2 (12%)
Cancer Type (AML) (Breast) (Esophageal) (Hypopharynx) (Liver) (MDS) (Multiple Myeloma) (Pancreatic) (Prostate)	$\begin{array}{c} 1 \ (6.25\%) \\ 1 \ (6.25\%) \\ 1 \ (6.25\%) \\ 1 \ (6.25\%) \\ (6.25\%) \\ (12.50\%) \\ (18.75\%) \\ (25.00\%) \\ 2 \ (12.50\%) \end{array}$
Active Treatment (Yes)	13 (81.25%) 3 (18.75%)

Abbreviations: SD = standard deviation; HS = high school; AML = acute myeloid leukemia; MDS = myelodysplastic syndromes

Author Manuscript

Table 2

Yu et al.

\geq
È
5
2
_
\leq
a
5
õ
_⊒.
9

Integrated mixed methods analysis of case examples illustrates how communication patterns within diverse social network structures influence prognostic understanding.



Cohesive circle network with family dominance: "So I have a big family, I've been successful in life and my kids are very nice kids. So, if I pass on I've given something to this planet in a positive way and I don't feel that terrible about it."[29,30]

we get a tour test user territies about it. Leaved fore member: "We're (patient and wife) married 57 years. We know everything about each other." [264]

Case C: 75yo female, working < 32hrs/week, solid cancer on treatment	Initiates discussions about future	Acknowledges curability: "No.
	plans from various parties: "Well,	There's no - as I understand it
	as soon as I was diagnosed, I got all	there's no cure because it's
A Neighbor 1	my paperwork together for my kids. I	metastatic breast cancer which
Daughter Daughter	did my health care proxy. It was	means it's systemic." [34,35]
	signed by a friend who is going to be	Reports survival estimate:
	the health care proxy. And also, my	"I think they have said the usual
A Neighber 2 A Neighber 3	primary care. I saw my financial	prognosis would be two to three
PIDE THE T	advisor. And when my son came	years. But it's - since it's in my liver
	home and he and I went over	it might not be that long. [] On the
	everything. And then my daughter	other hand, I know that nobody
	came home in October and she and I	really knows and depending on how
100	went over everything." [56-59]	I respond to Taxol that will have an
Televit 1	Social support (emotional):	impact on how long I live." [46-50]
	"With [Friend 2] I've talked a fair	
	amount about the disease and end of	
	life care. And my fears. And I've	
Pallative care	discussed that also with [Friend 1]."	
	[321,322]	
	Utilizes contacts in healthcare:	
RATEN	"I've known [Palliative Care	
	Physician] since forever. So we met	
Segregated cluster network with role diversity and others embeddedness	for coffee this week and had a nice	
"I have a women's group. We've been together for 40 years. The same group. One of the members	visit and he gave me some pointers in	
died of colon cancer ten years ago but the rest of it has been friends for a long time. So we've been	terms of end of life." [188-190]	
to weddings and our kids' weddings and funerals and divorces and remarriages." [82-85]		

Legend: Ego: respondent; Red: family at home; Orange: family outside home; Green: friends; Blue: colleagues/neighbors; Brown: others. Line thickness indicates strength of relationship.

Author Manuscript

Author Manuscript

Page 16