Social networks of older patients with advanced cancer: potential contributions of an integrated mixed methods network analysis

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Introduction:

Patients with advanced incurable cancer do not make important health decisions in isolation. Rather, medical decisions typically are based on information, perspectives, stories, and advice from multiple sources. With the patient and health care professionals, these sources also interact, forming a dynamic relational process between the patient, his/her social networks, and health care professionals (1). However, patients rarely mention these sources to clinicians.

The influence of social networks is particularly important when it comes to discussions of prognosis. Patients unaware of their prognosis are at risk for receiving burdensome treatments with little prospect of improving quality of life (QoL). Because clinicians tend to prioritize discussions of test results and treatment recommendations, defer discussions of patients' illness beliefs, information sources, and prognosis (2), and use vague language when describing risks, benefits and outcomes, patients are left unaware or uncertain of their

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prognosis. Unsurprisingly, patients often seek counsel from social network members who might provide information that is both helpful and accurate, or might also augment misconceptions about prognosis and treatment intent (curative versus palliative) (3), leading patients to pursue cancer treatments that ultimately result in lower QoL and delay in initiating palliative measures (4).

Older adults with advanced cancer are particularly vulnerable to harms due to lack of prognostic understanding. With adequate prognostic understanding, older patients more often communicate a preference for comfort-oriented approaches and palliative care (5). Yet, in addition to reluctance to discuss prognosis, communication is further hampered by the paucity of clinical trials that include older patients and those with aging-related conditions (i.e., disability, comorbidity) (6) and high symptom burden (7), resulting in optimistically-biased discussions about the benefits and risks of treatments (8).

Older adults with aging-related conditions are more likely to depend on social networks for instrumental support and communication with clinicians, and are more likely to be accompanied at office visits, especially those with low health literacy, higher symptom burden and with functionally limitations (9). Caregivers typically accompany older patients when important information is divulged (1); they were present in 86% of oncology visits when "bad news" was delivered about prognosis or lack of treatment options (1). As health and function declines, older patients increasingly defer decision-making to caregivers (10). While caregivers can be strong advocates, ensuring the accuracy of information exchange and understanding (11), sometimes they selectively filter information, overshadow patients' perspectives (12), or act as spokespersons for a larger social network (13).

The nature of social networks:

Older patients' networks are diverse and complex, including friends and family, cancer survivors, and other groups (such as clergy and acquaintances), all of whom might provide some kind of medical advice. Frequency of contact or length of relationship are not necessarily associated with influence on understanding and decision-making (14). While close relatives might be expected to provide support (15) they might be sources of tension and hinder communication and self-management of the disease (16), leading older patients to rely primarily on weaker social connections and anonymous online networks (17). Those weaker connections may also be important, for example, by raising issues that close relatives are reluctant to discuss.

Social networks evolve dynamically over time. In response to a stressful life event (e.g. diagnosis of a severe disease) older patients activate relationships within their networks that they perceive as best supporting their particular needs at the time, selecting from among a larger group of potential network members taking into account availability and potential costs (18). On the other hand, unprecedented medical conditions may result in shrinkage of social networks, as individuals' roles and expectations and the older patient's capabilities for social interactions change (19). Older patients may change the network compositions, for example, preferentially affiliating with those who reinforce over-optimistic prognoses (20), and those who are less likely to stigmatize their illness (19).

Studying social networks:

A common approach to study social networks, particularly in the field of social support is assessing the change in the size of personal networks (21), or individuals' assessment of social support (22). Existing tools, such as the Berkman Syme Social Network Index (23), typically aggregate the number of individuals in particular social groups (family, friends, colleagues, etc.) into a single score to study associations between these indices and important health outcomes. Yet, this approach may not take into account the context-dependent nature of these relationships (24). Here, we describe a methodologic approach that lends insight into these diverse and nuanced structures, content and processes that characterize social networks of older patients with advanced cancer.

Mixed-Methods Social Network Analysis (MMSNA) can be particularly useful in shedding light into the complexity of older patients' networks. MMSNA is an approach to study the patterns of relationships between "actors" in a network by integrating quantitative information about network structures with qualitative insights about perspectives of network actors (25). MMSNA addresses structure (e.g., How well connected is the patient?; Who are the influential actors?; Are there clusters or structural gaps?) and process (e.g., What information, advice and stories are shared?; What information is withheld?; When and with whom are decisions made?). In a fully-integrated MMSNA, quantitative and qualitative data are collected and analyzed simultaneously (in contrast to conventional mixed methods approaches that collect and analyze quantitative and qualitative data in parallel or sequentially) (26). In semi-structured interviews, respondents provide data about members of their social network, display inter-relationships among network members graphically, and comment on the nature, meaning and impact of those relationships. Interviews also reveal important information about targets for intervention by illuminating how older patients reconcile competing perspectives on their illness (e.g. when family's beliefs conflict with doctors', or when patients hesitate to communicate in burdensome family networks).

An application of MMSNA:

In this paper we use the experience of a pilot study of social networks of older patients with advanced cancer to introduce an integrated mixed-methods approach to study personal networks of older patients with advanced cancer. In this study, we sought to clarify ways in which social network members informed older patients' understanding of their disease, prognosis, and treatment choices.

After ethics approval and informed consent, we interviewed 16 older patients, collecting quantitative and qualitative network data simultaneously using network maps (27). The patient (ego) lists social contacts (alters) with whom they have discussed health-related issues, and marks the strength of their relationships on a chart comprised of concentric circles with ego at the center and radial sections representing various social categories (Figure 1a). After placing all alters on the map, the older patient draws lines connecting alters to show connections between pairs. The older patients then elaborate on the quality, content, and dynamics of each social relation.

Our integrated mixed-method analysis was exploratory, inductive, and iterative, aiming to identify and score main dimensions that distinguished networks from one another. The analytic procedure included:

Framing:

In order to find a graphical presentation that represent the complexities and patterns of social relations in personal networks, we restructured the interview maps using force-directed algorithms (28) (Figure 1b), to redistribute the nodes based on their connection patterns.

Pattern Detection:

This process involved identification of network dimensions, and then sorting the maps. The multi-step qualitative coding process (29) included: *holistic coding* (exploring the overall shapes of network maps; such as resemblance to star network, segregated clusters, etc; see table 1 for results), *structural coding (*using conventional network analysis measures such as density, reciprocity, centralization etc (30)), *attribute coding* (using compositional and personal attributes as codes, such as position of health care professionals, main caregiver or other significant social roles in the network), and *exploratory coding (i*dentifying emergent non-*a priori* features). After identification of main dimensions, we sorted the maps, and identified extreme cases (two ends of the continuum) and typical cases (middle of the continuum). Team members worked independently, then reconciled their differing insights in regular consensus meetings.

Labeling:

In consensus meetings, we discussed the meaningful labels for identified dimensions. This process resembles mixed methods 'qualitization' (31), a set of procedures aiming to transform patterns and numbers into words and narrative profiles.

As shown in Table 1, we identified three structural dimensions and 5 membership dimensions. The four networks in Figure 2 are organized around the structural dimensions, while also presenting membership dimensions; dimensions are not mutually exclusive. Figure 2a shows a network with a prominent Core member (here the spouse) who is connected to the majority of the ego's network, and also to some extent resembling a star network of unconnected network members. Figure 2b presents a cohesive circle of tightly-knit family and friends, characterized by family dominance. Figure 2c shows segregated clusters with weak connections across clusters. Figure 2d exemplifies embeddedness of healthcare professionals (pink), embeddedness of other social contacts (blue; neighbors and co-workers), and role diversity.

Next steps of the analysis will include further integration of quantitative and qualitative data. Networks could be scored along the dimensions and resulting variables could be used in statistical models to assess the relationship between dimensional scores and clinical and prognostic variables. The network dimensions can also inform further purposeful sampling for qualitative assessments to learn about specific social dynamics that happen in each network type.

Discussion:

Even with our small sample size in this pilot study, we identified three thematic structural dimensions, corresponding to: a) segregated clusters, b) star-shaped, and c) core. While linking network structure and care outcomes is premature from our data, others have showed important associations between network structures and important outcomes, such as self-management in long-term illness (32), physical functioning following stroke (33), injurious falls and functional decline (34). For example, among older cancer survivors, adding two new relationships exhibited protective effects against functional decline, and declines in frequency of contacts were associated with greater functional impairment (35).

In our sample, health care professionals were rarely included in older patients' networks, suggesting reasons why older patients often do not understand, accept, or heed information that they receive from clinicians. Recognizing that the clinician is only a node in a more complex and dynamic information-sharing network (36) can enable them to intervene to enhance communication and strengthen relationships by engaging influential network members (with patient consent) to provide information and facilitate decision-making (36). Providing older patients' personal care maps to health care providers may help them better understand the "person-in-context" (37), enabling more productive and effective communication about treatment choices and prognosis, and ultimate foster shared mind between older patients and health care professionals (38).

Network maps are graphical representations of social worlds that influence health care, and are particularly useful when older patients are seriously ill, symptomatic, and facing uncertainty and seeking information to guide important decisions regarding their care. Our approach to MMSNA is a novel analytic method that can help us simultaneously analyze graphical representations of older patients' social worlds (network maps), and rich personal stories about illness experiences and perspectives obtained through qualitative inquiry with older patients and their key network members, yielding insights not possible by considering these data sources separately. These insights can help health professionals engage older patients' social networks in ways that ultimately improve older patient understanding, agency, and QoL.

Acknowledgements:

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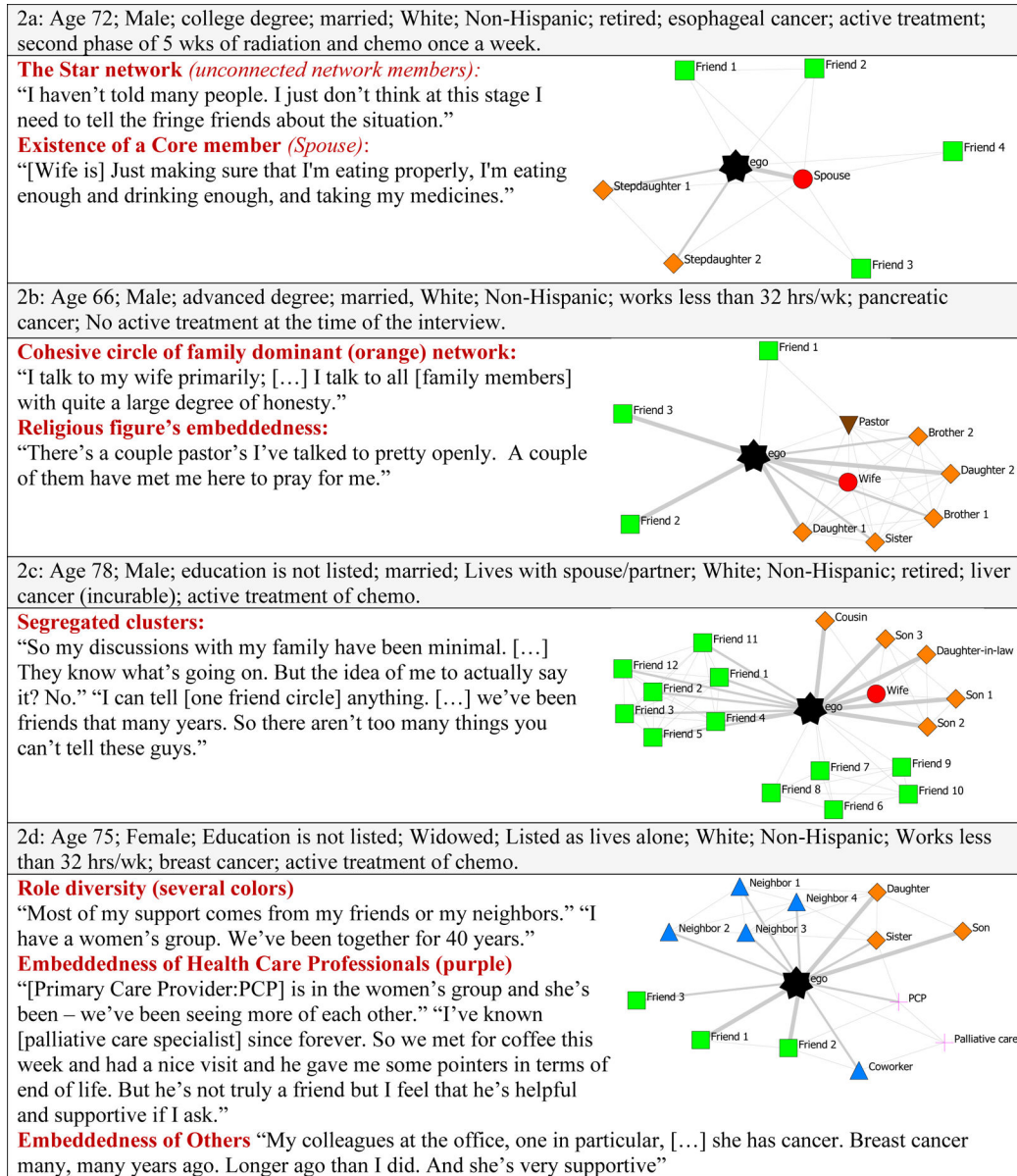6. Mohile SG, Dale W, Somerfield MR, Schonberg MA, Boyd CM, Burhenn PS, et al. Practical Assessment and Management of Vulnerabilities in Older Patients Receiving Chemotherapy: ASCO Guideline for Geriatric Oncology. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2018;36(22):2326–47. [PubMed: 29782209]

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1a

1b
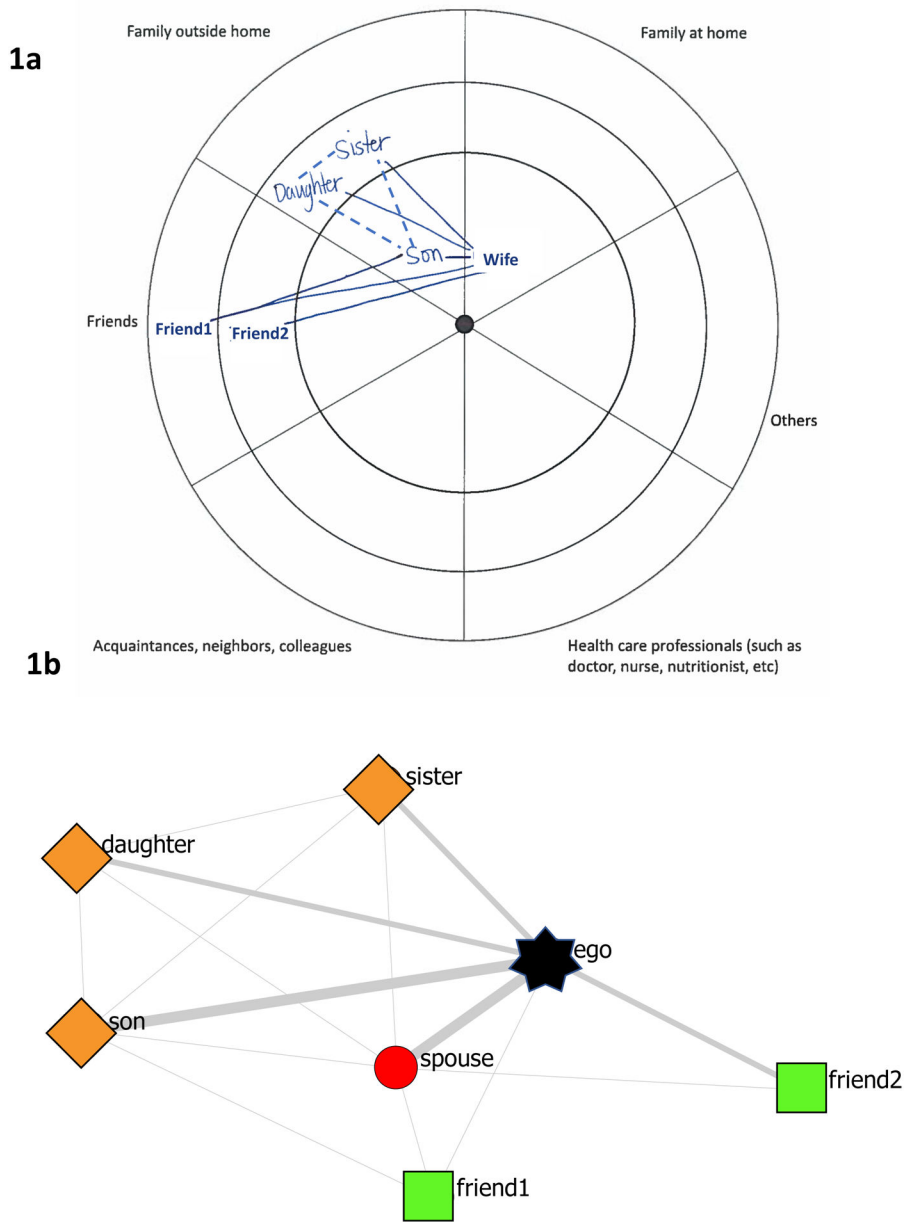
Figure 1: An example of network chart developed in social network interview of patients #24. 1a: the chart that was completed in the interview. 1b: a force-directed map created based on 1a.
1a: Solid lines were drawn by the patient. Dashed lines were added after reading the transcript. Some names were masked to preserve patient's identity. 1b: line thickness represents the actor's place on inner, middle, or outer circles. Actors are distributed using Spring embedding algorithm force-directed algorithm. Star: ego, circle: family at home, diamond: family outside home, square: friends.

2a: Age 72; Male; college degree; married; White; Non-Hispanic; retired; esophageal cancer; active treatment; second phase of 5 wks of radiation and chemo once a week.

The Star network *(unconnected network members):*
"I haven't told many people. I just don't think at this stage I need to tell the fringe friends about the situation."
Existence of a Core member *(Spouse)*:
"[Wife is] Just making sure that I'm eating properly, I'm eating enough and drinking enough, and taking my medicines."

2b: Age 66; Male; advanced degree; married, White; Non-Hispanic; works less than 32 hrs/wk; pancreatic cancer; No active treatment at the time of the interview.

Cohesive circle of family dominant (orange) network:
"I talk to my wife primarily; […] I talk to all [family members] with quite a large degree of honesty."
Religious figure's embeddedness:
"There's a couple pastor's I've talked to pretty openly. A couple of them have met me here to pray for me."

2c: Age 78; Male; education is not listed; married; Lives with spouse/partner; White; Non-Hispanic; retired; liver cancer (incurable); active treatment of chemo.

Segregated clusters:
"So my discussions with my family have been minimal. […] They know what's going on. But the idea of me to actually say it? No." "I can tell [one friend circle] anything. […] we've been friends that many years. So there aren't too many things you can't tell these guys."

2d: Age 75; Female; Education is not listed; Widowed; Listed as lives alone; White; Non-Hispanic; Works less than 32 hrs/wk; breast cancer; active treatment of chemo.

Role diversity (several colors)
"Most of my support comes from my friends or my neighbors." "I have a women's group. We've been together for 40 years."
Embeddedness of Health Care Professionals (purple)
"[Primary Care Provider:PCP] is in the women's group and she's been – we've been seeing more of each other." "I've known [palliative care specialist] since forever. So we met for coffee this week and had a nice visit and he gave me some pointers in terms of end of life. But he's not truly a friend but I feel that he's helpful and supportive if I ask."
Embeddedness of Others "My colleagues at the office, one in particular, […] she has cancer. Breast cancer many, many years ago. Longer ago than I did. And she's very supportive"

Figure 2: Four examples of networks prominently present the structural and membership dimensions

Star: ego, circle: family at home, diamond: family outside home, square: friends, up triangle: neighbors and acquaintances, down triangle: others, plus: healthcare professionals

Table 1:

Structural and membership dimensions identified through analysis

Domain	Definition
Structural dimensions	
Cohesive Circle	existence of a densely connected circle/cluster in the network (most people are connected to each other) usually family and friends
Segregated	existence of separate (weakly connected) clusters, usually identified by different social roles: family, friends, colleagues, etc.
Star	a network resembling a central actor (ego), with most people connected to it, with no (rare) connections between those partners. A network that looks like a cartwheel
Membership dimensions	
Core	one (or more) central actor who is connected to almost everybody that ego is connected. The main caregiver. Often the spouse
Health Care professional's inclusion / embeddedness	your judgment of how strongly/frequently health care professionals are connected to ego and other network members
Others' embeddedness	your judgment of how strongly/frequently members of OTHERS group (e.g. religious figures, patient experts, etc.) are connected to ego and other network members
Family Dominance	the overall picture of network, how dominantly the network is shaped by the family (number, strength of ties to ego, connections with each other) in comparison to other groups
Role Diversity	the overall picture of network, how diverse the network is in terms of multiplicity of social roles. The extreme low is a network that is only made of family