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Social support for older adults with cancer: Young international society of geriatric oncology review paper

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Abstract

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Author Contributions

All authors have contributed significantly to this work.

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Older adults with cancer have increasing needs in physical, cognitive, and emotional domains, and they can experience decline in all domains with the diagnosis and treatment of cancer. Social support plays a key role in supporting these patients, mitigating negative effects of diagnosis and treatment of cancer, and improving cancer outcomes. We review the importance of social support in older adults with cancer, describe the different components of social support and how they are measured, discuss current interventions that are available to improve social support in older adults, and describe burdens on caregivers. We also highlight Dr. Arti Hurria's contributions to recognizing the integral role of social support to caring for older adults with cancer.

1. Introduction

Social support, as defined by the National Cancer Institute (NCI), is a network of family, friends, neighbors, and community members that is available in times of need to provide psychological, physical, and financial help to patients with cancer [1]. Studies have demonstrated that social support has a direct impact on the physical health, emotional adjustment, well-being, and overall survival of patients with cancer [2,3]. Patients with high levels of social support and social connectedness (presence of social ties without support exchange) have improved health and decreased mortality while those who lack social support and social connectedness have inferior oncologic outcomes such as increased prevalence of cancer progression and decreased overall survival [4–8].

Older adults account for >62% of cancer survivors and represent a growing population with unique psychosocial needs [9,10]. Dr. Arti Hurria recognized the importance of social support in the care of older adults with cancer and incorporated social support measurements into a cancer-specific geriatric assessment (GA). Her work on the topic focused not only on measuring social support of older adults with cancer, but also on understanding its relationship to outcomes. Throughout her career, Dr. Hurria extensively collaborated with national and international researchers to study social support and caregiving in geriatric oncology, creating a new body of literature [11–13]. These collaborations led to the development of a multidisciplinary and multi-institutional network of investigators, which is represented in Fig. 1 utilizing bibliometric analyses.

In this review, we describe social support needs of older adults with cancer and its protective effects, discuss the relationship between social support and outcomes, describe how to measure social support, list unmet social support needs in older adults with cancer, describe interventions that have been explored to improve social support in older adults and patients with cancer and discuss the important role of caregivers in providing social support. We also highlight the contributions to the field made by Dr. Hurria and her network of collaborators.

2. Older Adults With Cancer and their Need for Social Support

A diagnosis of cancer may lead to physical and emotional stress regardless of age; however, the unique needs of older adults compound the stresses resulting from a cancer diagnosis. Compared to their younger counterparts, older adults have more pre-existing chronic diseases, impaired physical and cognitive function, and decreased physiologic reserve, making the physical and emotional demands of cancer and cancer treatment more difficult

[14]. Older adults with cancer are especially vulnerable to short- and long-term treatment toxicities [15,16]. As a result, older adults with cancer are more likely to require assistance with activities of daily living (ADLs; such as bathing, dressing and toileting) and instrumental activities of daily living (IADLs; such as doing housework, taking transportation and making phone calls) [17]. Following a cancer diagnosis, older adults with cancer are more likely to experience depressive symptoms and anxiety as well as reduced quality of life (QOL) [18]. The presence of distress in older adults with cancer is common and can be associated with worse function. Dr. Hurria and colleagues identified significant distress (defined as a distress score ≥ 4 using the Distress Thermometer) in 41% of patients [19]. Increased distress scores were significantly associated with needing increased assistance with IADLs and lower Medical Outcomes Survey (MOS) physical function score. These negative effects can persist long after cancer treatment is completed, and older adults continue to report high distress, depression, anxiety, and poor QOL [20,21].

With advancing age, older adults experience a reduction of their social support structure due to life events, such as widowhood and retirement. This in turn leads to isolation and loneliness, which may exacerbate their emotional response to cancer. Combined, these biopsychosocial factors can limit an older adult's ability to cope with and manage their disease, and negatively impact QOL [22].

3. Protective Effects of Social Support

Adequate social support is necessary for older adults to navigate sudden life changes and emotional responses associated with cancer from diagnosis through survivorship. Broadly speaking, social support is composed of four defining attributes: emotional, instrumental, informational, and appraisal support (Fig. 2) [23]. All of these attributes of social support interact in order to protect the supported person, and each may exert unique beneficial effects.

Several theoretical frameworks have been postulated to explain the multidimensional effects social support has on the well-being and health of older adults; the two most widely accepted are the *buffering hypothesis* and *direct effect model*. The *buffering hypothesis* suggests that support reduces harms from stressful events by preventing the individual from appraising a situation as threatening or demanding [24]. In contrast, the *direct effect model* suggests that social support is beneficial regardless of the amount of stress perceived by the individual [25]. In this model, the perception that others are willing to help increases self-esteem and provides the individual with a sense of control over their situation. Furthermore, belonging to a social network could impact treatment outcomes directly by positively influencing treatment adherence and illness-management behaviors [26]. An individual's social circle is critical to participation in and optimization of all aspects of cancer treatment including symptom management, care coordination, assistance with ADLs and IADLs, and emotional support.

4. Association of Social Support With Patient Outcomes

The benefits of social support on survival and physical and emotional health have been studied in older adults as well as patients with cancer. In a meta-analysis of 87 studies in the general geriatric population, higher levels of perceived social support, a larger social network, and being married were associated with decreased mortality risk [7]. Higher levels of perceived social support were also associated with better mental health outcomes and improved QOL in older adults [27].

Studies on the effects of social support on oncologic outcomes in older adults with cancer are mixed. Earlier studies demonstrated that social support is associated with survival and that unmarried patients, those living alone or those lacking in emotional connectedness to others have an increased risk of having metastatic disease at diagnosis, are more likely to be undertreated and have poorer survival [28–30]. In a secondary analysis of a cooperative group study of older patients with breast cancer from the Cancer and Leukemia Group B (CALGB) 49907/Alliance A171301, Dr. Hurria and colleagues found a trend towards improved survival among patients who were living with someone and/or were married [13]. However, this finding was non-significant in multivariate analysis. The authors hypothesized that this may be because patients included in clinical trials may have a greater degree of baseline social support and better functional status, hence the effects of social support and survival was not demonstrated. There was no association between social support and treatment completion or development of serious adverse events.

Inadequate social support may also affect QOL and psychological state in older adults with cancer, as shown by Dr. Hurria and colleagues in several studies [11,31,32]. In a secondary analysis of the CALGB/Alliance 369901 cooperative group study of 1280 older adults with nonmetastatic breast cancer, women with higher tangible social support (i.e., having someone to take them to the doctor if needed) were less likely to experience a steep decline in health-related QOL (HRQOL) [11]. In a cross-sectional study of 1457 older adults with cancer, having emotional needs (i.e., needing someone to listen when needing to talk) and physical support needs (i.e., needing someone to help when fatigued) were also strongly associated with HRQOL [31]. Inadequate social support has also been shown by Dr. Hurria and the Cancer and Aging Research Group (CARG) to be associated with depression [32].

Social support may also affect the tolerance of older adults with cancer to cancer therapy. In a prospective study of 500 older adults starting a new line of chemotherapy, Dr. Hurria and CARG developed a risk model to predict chemotoxicity (www.mycarg.org/tools) [33,34]. In addition to patient, tumor and treatment variables, several geriatric assessment variables including decreased social activity due to physical health or emotional problems, were found to be predictive of an increased risk of chemotherapy toxicity.

5. How Social Support Affects Outcomes Through Physiological and Biological Mediators

Social stress caused by isolation, social relationship deficits, and a lack of social support have been linked to increased biomarkers of inflammation, immune system impairment,

tumor growth, and metastases [6,35,36]. Molecular studies suggest that adrenergic receptor activation is the primary pathway linking stress exposure to tumor growth and progression of disease [37]. Social stress can trigger a stress response that activates the autonomic nervous system, sympathetic nervous system, and the hypothalamus-pituitary-axis. This results in the release of cortisol, catecholamines, and neuropeptides, all of which alter gene expression to promote inflammation in the tumor microenvironment and ultimately leads to tumor growth and disease progression (Fig. 3) [38,39].

In patients with cancer, social stress has been associated with increased inflammatory cytokines such as vascular endothelial growth factor (VEGF) and interleukin 6 (IL-6) that mediate cancer proliferation and metastasis and have been associated with poor survival [40–42]. Conversely, social support has been associated with an increase in anti-tumor immune cells as well as a decrease in inflammatory cytokines [6]. Patients with ovarian cancer who had higher levels of social support were found to have higher levels of natural killer (NK) cells, which inhibit tumor growth, in the tumor microenvironment and the peripheral blood [43]. Higher levels of social well-being has been associated with decreased levels of metalloproteinases (MMPs) which promote cancer growth and decreased levels of pro-inflammatory cytokines IL-6, VEGF, and tumor necrosis factor (TNF)- α [8,44]. In women with breast cancer, greater satisfaction with social resources was associated with less leukocyte pro-inflammatory (i.e. cytokines) and pro-metastatic (i.e. matrix metalloproteinases) gene expression on microarray analysis [45]. These studies suggest that social support, by acting as a buffer against stress, may exert an immunoprotective effect and thus favorably impact cancer outcomes.

6. Measuring Social Support in Older Adults With Cancer

When assessing social support, a distinction between perceived and received support should be made. Perceived social support refers to the subjective evaluation of the availability and adequacy of social connections, while received social support focuses on the quantity and the quality of the actual provided help [47,48]. This distinction is essential because different methods are used to assess each type of support, and each type of support exerts differential effects on health and well-being [47]. That being said, both are closely related to the characteristics of each individual's social network, which is the set of linkages and personal contacts through which each person maintains his/her social identity and receives support [49]. Social networks are complex systems which have specific structural, functional, and interactional characteristics that define them and make them unique, including their directionality, geographic dispersion, density, and homogeneity (Table 1) [50,51].

The complicated nature and multiple dimensions of social support make measuring it extremely difficult. This is further complicated by the fact that perceptions regarding the quality or quantity of social support may vary across geographic, social, economic, racial, and ethnic groups [52]. Therefore, the effect of social support on psychological and biological stress response may vary by group being studied. In order to adequately measure social support, instruments should comprise a combination of several items, including an assessment of the structure of social networks, the availability of support (including the number of persons who can provide it), the role of each supporting individual, and

perceptions regarding the quality of the support [25]. There are several validated tools to measure social support including the Medical Outcomes Study Social Support Survey (MOS-SSS), Duke-University of North Carolina Functional Social Support Questionnaire (DUFSS), and the Multidimensional Scale of Perceived Social Support Scale (MPSSS) [53–55].

The MOS-SSS was developed as part of a two-year study, which included patients with chronic conditions, and was designed to develop practical tools for the routine monitoring of patient outcomes in medical practice [54]. The original development of the MOS-SSS was carried out among a subsample of 2987 patients and included four subscales (emotional/informational, tangible, affectionate, and positive social interaction) [56]. The survey measures perceived support, and is made up of 19 items rated on a 5-point Likert scale from “none of the time” to “all of the time.”

Two of the MOS-SSS subscales (emotional/informational and tangible support) were studied and incorporated into what is now the CARG cancer-specific geriatric assessment by Dr. Hurria [57]. Twelve of the 19 MOS-SSS items are included in the assessment. It had excellent internal consistency among older adults with cancer, with a standardized Cronbach alpha of 0.95, and high test-retest reliability (Spearman coefficient 0.86) [58]. The MOS-SSS was effective in identifying social support needs in older adults with cancer [59]. Its use in a brief self-reported questionnaire in older adults with cancer resulted in a referral to social work for 45% of patients.

7. Unmet Social Support Needs in Older Adults

Because older adults experience an increase in needs and a decrease in social network as they age, they are more likely to have unmet social support needs. In the setting of cancer, however, very limited data exist in understanding unmet social support needs among older adults.

Specific social support needs of 1460 older US adults with mixed cancer types were recently evaluated in a study utilizing the MOS-SSS [60]. Social support was categorized into five domains: physical, emotional, informational, practical, and medical support. Among these patients, two-thirds had at least one social support need and 45% had at least one need that was unmet. Unmet need was highest in medical support (39%), followed by informational (35%), physical (30%), emotional (28%), and practical (20%) support. Common unmet needs included not having someone to share worries with, not having help if patient was fatigued, and not having help with daily chores when sick (8% in each). Those who had an increasing number of unmet social support needs were more likely to have lower QOL. Several subgroups were more likely to have unmet needs in one or more social support domains. These included minority patients and those who were not married, had lower household income, and had higher symptom burden. More research is needed to understand why certain subgroups are more likely to have unmet social support needs so that interventions can be specifically designed for these patients.

8. Social Support Interventions

Much of Dr. Hurria and her colleagues' work on social support in older adults with cancer were aimed at identifying patients lacking in social support so that interventions could be implemented to mitigate its negative effects. However, there has been little research on social support interventions in older adults with cancer.

Several different interventions have been investigated in the older adult population without cancer, with the majority of these aimed at reducing social isolation and promoting social connectedness in older adults [61,62]. Social interactions can be facilitated through group activities, such as engaging in shared interests and day care centers, or can be one-on-one, such as engaging individually with volunteers who are able to provide a new friendship to a lonely individual [57]. These interventions can take place in person, via telephone, or using technology-based videoconferencing and social networking. Animal-assisted therapy involving felines or canines has been used to alleviate loneliness in older adults. All of these interventions have been successful in reducing loneliness, promoting happiness, and life satisfaction in older patients without cancer [61]. Solitary interventions such as videoconferencing or solitary pet therapy are equally effective as group interventions in reducing loneliness, suggesting that effective social support interventions can be offered even to those older adults who may be housebound or unable to easily participate in group activities.

In patients with cancer, studies examining the effects of interventions targeting social isolation are limited and have either demonstrated small or no effects of reducing loneliness. Two studies that provided 13 months of telephone social support as well as educational information to patients with cancer found significant but very small differences in loneliness scores [63,64]. In a study of 42 patients with head and neck cancer who were starting multimodal concurrent chemoradiation, animal-assisted therapy consisting of a visit from a certified therapy dog team at each treatment visit increased social well-being and emotional well-being scores [65].

Patient navigation programs which involve individualized assistance by cancer survivors, nurses, social workers and other health workers to patients with cancer have also been developed. These programs were initially developed to advocate for minority and low-income patients with breast cancer in a medically underserved urban community but now have widespread use [66]. The patient navigator is viewed as a proactive patient representative distinct from the social worker, who focuses on the concrete needs of the patient and guide the patient from cancer diagnosis through treatment. Patients in a patient navigation intervention program, Breast CARES (Cancer, Advocacy, Resource Education and Support), reported that it helped them overcome financial barriers (73%), transportation needs (60%), improved communication with medical providers (73%) and helped them access additional support (i.e. support groups) [67]. Although patient navigation improves emotional well-being and patient self-efficacy, the few studies that have evaluated its effect on social well-being found no significant effects [67,69].

Peer support, which is support from a cancer patient or survivor, may help to compensate for unmet social support needs of patients with cancer and help them cope with the illness. Patients with cancer are more likely to participate in peer support groups when they feel their family and friends do not understand their cancer experience [70,71]. Through mutual identification and shared experiences, peers can provide experiential empathy, as well as emotional, informational and appraisal support for patients with cancer [72]. In patients with cancer, peer support interventions increase perceived social support and sense of belonging and improve psychosocial outcomes by providing both informational and emotional support [73]. Peer discussion groups were particularly helpful for women who lacked social support compared to those who reported adequate social support [74]. Conversely a small number of studies have also found that patients who reported adequate social support and peer counselors were negatively impacted by peer group interventions with decreased physical function outcomes, dissatisfaction with the medical team and increased emotional suppression [69,74]. A meta-analysis of peer-led interventions for patients with cancer found that effects on social support, emotional health, coping, and quality of life were stronger interventions when delivered face-to-face (versus on the telephone) and when peers had counseling experience [75]. This suggests that patients must be carefully selected for peer support interventions and patient counselors carefully trained and supervised to facilitate them.

Internet based peer-support programs and social media platforms may increase social support in patients with cancer who may not have access to face-to-face peer support or patient navigation. Both allow patients to create social networks to exchange information and personal stories regarding their illness and get social support from their peers [76]. A 5-month, home-based computer intervention for women aged 60 years with breast cancer that included informational content, discussion groups, decision support and answers from cancer experts on found improvements in patient-reported emotional and instrumental social support compared to controls [77]. Other studies of online peer-support group interventions, conducted mostly in patients with breast cancer, have not shown a clear benefit in social support, psychosocial measures or QOL [78,79]. However, these studies were small and of low quality.

Social media platforms (i.e. blogs, Twitter, YouTube, and Facebook) are different from internet-based support groups in that they are they offer user-friendly interfaces, easy access, fast communication and actively engage users [80]. However, compared to internet-based support groups created by and maintained by health professionals, social media platforms are largely not curated or moderated by experts and can contain negative information [81]. Harassment of participants has also been an issue compared to internet-based support groups generated by health professionals. Studies of social media interventions in patients with cancer are limited but have been shown to be feasible [80]. Attai *et al.* found that patients who participated in a Twitter support community for patients with breast cancer (Breast Cancer Social Media tweet chat #BCSM) reported increased knowledge and decreased anxiety with 67% of patients who initially reported “high/extreme” anxiety reporting “low/no” anxiety after participation. Effects of the intervention on social support was not evaluated.

Many of these interventions could also help meet unmet social support needs in older adults with cancer. In a study of older adults with advanced stage cancer, telephone monitoring significantly decreased anxiety, depression and overall distress compared to provision of educational material alone [82]. Patient navigators may be of particular use to frail or vulnerable older adults to help them navigate complex decision making and treatment and provide tangible support such as transportation to the hospital and provision of healthy meals. Videoconferencing, internet-based and social media interventions may be beneficial for older adults who are unable to access in-person support groups due to geographic, transportation or physical mobility constraints. Comfort and competency with the internet, however, are important considerations when considering the utility of these types of interventions. A 2012 Pew Research Center report found that 53% of Americans aged 65 years use the internet or email, and 33% use social networks, both of which represented a significant growth from previous years but lower than younger adults [83]. Internet adoption among older adults 75 years remains low (34%). Older adults continue to have concerns over online privacy and many do not understand online social networks [84]. As a result, older adults may have difficulty with using technology and may have difficulty in accessing online resources. Studies are needed to determine if these interventions can be tailored to older adults with cancer.

9. Impact of Caregiving on Social Supports

Informal caregivers, typically family and friends, represent the main source of social support for patients. They are increasingly relied upon to provide support with cancer treatment and symptom management, medical and nursing tasks, ADLs, and IADLs [86]. While social support is critical in helping older adults with cancer through the stages of the cancer continuum, caregiving can have significant physical, emotional, and financial impacts on the caregivers. Older caregivers, the majority of whom are spouses, are usually older themselves with an average age of 63 and have similar vulnerabilities as those they care for [87]; 36% had fair/poor health or a serious health condition [88].

Caregiving can cause emotional distress, including depression and anxiety. The level of distress among caregivers is increased when the care recipients have poor functional status and increased symptom burden [89]. Greater emotional distress in-turn leads to increased caregiver burnout, fatigue, and sleep disturbance [90]. Concerningly, older caregivers who experience caregiver burden have an increased risk of mortality [91].

Dr. Hurria recognized the importance of caregiver health in the care of older adults with cancer. Among older adults with cancer seen in the ambulatory setting, Dr. Hurria's team found that 75% of caregivers reported some burden and 15% reported high caregiver burden [12]. Employed caregivers and caregivers of patients who required help with IADLs were more likely to experience high caregiver burden. Caregivers noted greater IADL needs of patients compared to the patient's own report and this difference in patient-caregiver assessment was also associated with an increased likelihood of high caregiver burden [92]. Another group also identified that caregivers of older patients who had a higher number of impairments on the geriatric assessment were more likely to experience depression and lower caregiver QOL [93].

In caregivers of hospitalized older adults with cancer, Dr. Hurria and colleagues found that caregivers have relatively good QOL [94]. Most caregivers (79%) reported excellent or good health and had no major comorbidities. However, 22% reported a decline in their health as a result of caregiving. Those with poorer mental health, less social support, and who cared for patients with poor function were more likely to experience poorer QOL. These results suggest that in addition to assessing the patient's social support, understanding the caregiver's social support may be necessary.

It is equally important to consider that older adults with cancer may themselves be caregivers and caregiving responsibilities may impact patient treatment decisions and health management [95,96]. Patients with cancer who are caregivers have been found to have poorer social outcomes and depressed mood [97,98]. For example, in a study of patients with colon cancer, a majority of whom were > 65 years of age, 20% stated that they had caregiver responsibilities [97]. These patients were found to have more social distress on the Social Difficulties Inventory (SDI-21) than patients without caregiver responsibilities, particularly in the financial and emotional subscales. Identifying patients with caregiver roles early is also necessary in order to provide them with adequate social support.

Dr. Hurria strongly advocated that the geriatric assessment should be utilized early in the management of older adults with cancer to identify those with increased needs and increased risk of treatment toxicity, both of which may affect patient and caregiver outcomes. Once identified, early mobilization of community resources to provide assistance and remove some of the burdens should be considered. By identifying those individuals at increased risk for negative outcomes and implementing early interventions, both patient and caregiver health and QOL may be improved.

10. Conclusion

Older adults with cancer have significant physical, emotional, informational, practical, and medical support needs. Dr. Hurria's work has expanded the literature on the effects of social support on outcomes among older adults with cancer and the importance of identifying social support needs using the geriatric assessment. Existing interventions for social support are primarily tested in the general geriatric population and research is needed to understand if and how these translate to older adults with cancer and whether adaption is needed. To support a growing population of older adults with cancer, it is also imperative to recognize the burdens on caregivers and provide them with additional support.

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Fig. 1.

Dr. Arti Hurria's social support and caregivers research bibliometric network. A: Dr. Hurria's Bibliometric Network on social support* Panel B: Bibliometric Network of work done by Dr. Hurria on caregivers** Each color represents a "cluster" of authors who worked on common papers. *Articles by Dr. Hurria with the terms "social" and "support" in the title and/or abstract obtained from PubMed Central database (22 documents). **Articles by Dr. Hurria mentioning the terms "caregivers" in the title and/or abstract obtained from PubMed Central database (9 documents). Authors with two or more co-authorships have been included. Created using VOSviewer (<http://www.vosviewer.com/>).

Fig. 2.
Attributes of social support.

Fig. 3. Effects of social stress on tumor microenvironment, cancer growth and progression. Used with permission from Lutgendorf et al. [46].

Table 1

Characteristics of social networks.

Adapted from Heaney et al. [51].

Construct	Definition
Directionality	Extent to which members share equal power and influence (power dynamics between patient/caregiver)
Geographic dispersion	Extent to which the network's members live in close proximity to the patient
Density	Extent to which network members know and interact with each other
Homogeneity	Extent to which network members are demographically similar (in age, race/ethnicity, marital status, etc.)