

A little help from my friends: social support in palliative rehabilitation

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ABSTRACT

Background Social support has been shown to buffer some difficulties of living with advanced cancer. The Palliative Rehabilitation Program (PRP) was an interdisciplinary outpatient program offering post-treatment palliative rehabilitation to patients with advanced cancer. Social support was directly integrated into the program. The aim of the present study was to examine the types and sources of social support that patients found most beneficial.

Methods Twelve patients participated in 30-minute semi-structured interviews. Thematic content analysis was used to explore the social support experiences of those patients in the PRP. Patients were eligible to participate in the interview if they had completed the 8-week PRP, spoke English, and did not have cognitive or auditory impairments affecting their ability to participate.

Results The main sources of support reported by participants were team members and spouse, family, or close friends; peers attending the program; and spiritual beliefs. Social support varied based on sex and age, such that, compared with women, men reported relying less on social support, and the supportive needs of younger (≤ 50 years of age) and older participants differed. Team members were endorsed as frequently as family as social support.

Discussion Emotional support was endorsed with the greatest frequency. The members of the interdisciplinary care team were also providers of emotional and informational support for patients, bolstering the support received from caregivers. Widowed or divorced women might rely on health care providers more readily than do married men, who chose their wives as support. Future rehabilitation programs might consider the importance of an interdisciplinary team, the formal integration of caregivers, and the incorporation of spirituality to meet the unique supportive needs of patients with advanced cancer.

Key Words Advanced cancer, social supports, palliative care, rehabilitation, qualitative studies, interdisciplinary care

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INTRODUCTION

Patients with advanced cancer are living extended months or years^{1,2}. Despite a lack of curative therapies, palliative cancer care can, at this stage, focus on quality of life (QOL), symptom management, and both psychosocial and social support³⁻⁵. The literature describes 3 main categories of social support (ss) that can be integrated into the care of patients with advanced cancer, including instrumental support (the provision of tangible aid or assistance, such as transportation), informational support (guidance or advice provided at a time of need or stress), and emotional support (a sense of personal belonging, value, and acceptance)^{6,7}.

Instrumental and emotional support have been found to be the most important types of support when an individual is facing a life-altering event such as cancer⁶⁻⁸.

The existing literature suggests that the 3 categories of ss can be gleaned from family and friends⁹, peers¹⁰, and religious or spiritual communities¹¹. Health care providers could be an additional and potentially important source of support in cancer care^{9,12}.

The availability and quality of ss has been found to decline considerably 1 year after diagnosis^{13,14}, resulting in a unique challenge for patients with advanced cancer who continue to require strong support systems. Further, living with advanced cancer can restrict participation in

social activities, resulting in isolation and reduced social networks⁸. Accordingly, a palliative rehabilitation program providing interdisciplinary intervention and encouraging social participation was offered to help meet the supportive needs of patients with advanced cancer.

The Palliative Rehabilitation Program (PRP), 2009–2015, was developed in Ottawa, Ontario, and was modelled after a similar program in Montreal, Quebec¹⁵. Consistent with the palliative approach to care¹⁶, the PRP used an interdisciplinary approach to help meet the distinct needs of patients with advanced cancer^{17–20}. More specifically, the PRP targeted post-treatment patients who were experiencing loss of function, fatigue, malnutrition, psychological distress, or other effects of cancer and its treatment²¹. The team had 6 members: an oncologist, a nurse, an occupational therapist, a physiotherapist, a social worker, and a dietitian. Preliminary evaluations of the PRP demonstrated improved patient outcomes on a variety of self-reported and clinical measures of functioning and QOL, including fatigue, mobility, endurance, nutrition, mood, and general activity, among others^{21–23}. Such findings are promising, given that the existing palliative literature has not found similar improvements without rehabilitation²⁴.

Multiple components of ss were integrated into the PRP framework. Examples of instrumental support included the social worker assisting with finances and transportation, the dietitian helping with nutrition supplements, and the physiotherapist providing resistance bands for home exercise. Examples of informational support included the nurse or occupational therapist providing education about energy conservation, the social worker or nurse providing information about community resources, or the dietitian providing strategies for appetite augmentation. Examples of emotional support included integrating caregivers into aspects of the program (with the patient's permission), the social worker providing cognitive-behavioural therapy for those with higher levels of distress, any clinician providing empathic listening while patients expressed their difficulties, and group members providing peer support in the gym. This unique program's element of ss has not yet been examined.

The present work reports a qualitative examination of ss. We specifically examined beliefs about the availability of ss and the perception of support received by patients in the PRP²⁵. The goal of the study was to examine the types and sources of ss that the participants found most beneficial.

METHODS

The study was approved by the Bruyère Research Ethics Board (Bruyère REB protocol M16-13-060) and the Ottawa Health Science Network Research Ethics Board (OHSN-REB protocol 20130887-01H). All participants provided written informed consent before taking part in the interview (details of the consent process are outlined in the Procedure subsection).

The PRP

The logistics of the PRP have previously been described^{21,22,26}. Briefly, patients underwent an initial assessment with each member of the team to obtain clinical

information and measurements and to establish goals. At that point, patients had the option to consent to being informed about future research studies. If admitted to the program, patients were offered an interdisciplinary care plan. Interventions included group physiotherapy sessions twice weekly for 8 weeks and appointments with other team members as requested or advised by the care plan. Group exercise sessions included 2–5 patients. A sitting area outside the gym was available to family and friends. Upon program completion, a completion interview was conducted to reassess the initial clinical measurements.

Participants

Participants for the present study were recruited at their program completion interviews. Patients invited to participate had met these inclusion criteria: consented to being informed of future studies at their initial assessment; completed the 8-week PRP; had no significant cognitive or hearing impairments that would interfere with participation; and could comprehend and speak English. Of 18 patients who were approached to participate, 3 were excluded (1 with hearing impairment, 1 with inability to comprehend English, and 1 with presence of a cognitive deficit). Three participants did not attend an interview because of disease progression, loss of interest, and an unknown reason (contact lost). The final sample included 12 participants.

Measures

Semi-structured Interview

The semi-structured interview was developed by members of the research team. It consisted of 13 open-ended questions addressing topics such as sources of support (“Were there people who offered you support while you were taking part in the program? Who were the people you felt you could turn to?”), types of support (“In what ways were they supportive? What sort of supportive things did they do?”), and perceived availability of support (“How often did you find them to be available? To what extent did you feel like you could turn to them?”). The remainder of the questions addressed the perceived importance of ss and spirituality, and any gaps in support within the program. (The full interview can be found in the supplemental material.) Medical and sociodemographic information was collected before the conclusion of the interview.

Procedure

This study used a purposive sampling method in an effort to capture potential effects of age and sex. To construct a robust understanding of ss in the program, we sought an equal ratio of men and women, a representative age range, and participants with differing marital status. Table 1 presents the characteristics of the sample.

Eligible participants were approached in person by a research assistant at their program completion assessment. All interviews were conducted by the first author between October 2014 and August 2015. Interviews lasted between 10 and 30 minutes (average: 24 minutes). Interviews were audio-recorded and transcribed verbatim for analysis.

Qualitative Analysis

Interviews were analyzed using the qualitative software NVivo (version 11: QSR International, Melbourne, Australia). Data from transcripts were initially coded by type of support (emotional, instrumental, informational); those codes were then further coded into who provided the support (team, family, peers, spirituality). Subthemes were

TABLE 1 Characteristics of the Palliative Rehabilitation Program and the study participants

Characteristic	Value	
	Women	Men
<i>Palliative Rehabilitation Program</i>		
Participants (n)	94	102
Marital status [n (%)]		
Single	37 (40)	25 (24)
Married	57 (60)	77 (76)
Average age (years)	60.09±13.6	65.33±11.8
<i>Study group</i>		
Participants (n)	6	6
Age group (n)		
<40 Years		1
41–60 Years		4
61–80 Years		7
Average age (years)	59.5±11.4	58.6±14.8
Marital status (n)		
Married	1	6
Widowed	3	—
Common-law	1	—
Divorced	1	—
Cancer site (n)		
Head and neck		3
Urogenital		2
Prostate		1
Breast		2
Larynx		1
Lung		1
Lung and larynx ^a		1
Lymphoma		1
Stage		
III		5
IV		5
Unknown		2
Living arrangement		
Alone	2	—
With spouse	—	3
With family or children	4	3
Ethnicity		
European descent	4	6
Hispanic	2	—

^a Double primary.

coded according to the participant's perception of the availability of the support and the specific support received (encouragement, transportation)^{27–29}.

A content query considered the narratives of men and women less than 50 years of age to assess for discrepancies in the narratives of younger participants. The age of 50 was chosen because other authors have found that age to be a turning point in terms of cancer outcomes³⁰.

Patient recruitment ceased because of termination of the program. Of the 12 interviews, 6 were double-coded. Discrepancies in coding included perceived differences between emotional and instrumental support. Those discrepancies were discussed by the coders until consensus was reached.

RESULTS

Participants

Despite attempts to acquire a representative sample, the 12 participants [6 men, 6 women; mean age: 59 years (range: 30–76 years)] with advanced heterogeneous cancers who took part in the interviews included an overrepresentation of widowed women and married men (Table 1 contrasts the overall PRP demographics with the demographics of the study participants). All male participants were in heterosexual marriages; half the female participants were widowed. Most participants were of European descent and living with a partner or children.

Emotional Support

Team Members

Participants reported drawing on team members for emotional support. Two subthemes arose: “verbal encouragement” and “listening to concerns.” Participants described team members “spurring” them on and ensuring that they “didn’t do too much or too little.” Listening to concerns was found to be tremendously important to patients, as one participant described: “When I was very depressed and crying, what helped me was for them ... to listen.” Participants further described an environment that fostered acceptance and acknowledged progress. They reported high perceived levels of care and availability from team members, and many expressed feeling comfortable in seeking additional support from team members. Notably, participants perceived the team to be accessible outside the scheduled days of the program.

[The physician] took the time to just talk and listen, and he had some really good, insightful views on things as far as moving forward emotionally about the whole thing. And it was very comforting to have a doctor to take the time to tell you that you’re not alone, and that other people feel the same way, and that you’re going to get through it.
— Mr. D, 49

Spouse, Friends, and Family

Participants described receiving emotional support from spouse, family, or friends while attending the PRP. Support was manifested as “verbal encouragement,” which included

keeping up morale or spirits; taking interest in the program; and acknowledging physical improvements. Others described not “need[ing] to speak too much,” because just the presence of their loved one offered support. Some interviewees found it supportive when a loved one stayed for the duration of the session in the waiting room or met them socially either beforehand or afterward. Some participants described being encouraged by family to partake in additional exercises at home during or after the program.

Oh, yeah, my wife for sure. My daughter, my son, they were all pushing me to go to it and to do it. I wasn't too keen on it at first, but ... it became quite evident that the whole thing was going to help me. I had my wife there for the first one, and she went around with me and said, “Yes, this is going to really help you.” And it did!
— Mr. S, 60

Peers

To some interviewees, attending activities in the gym with peers became a key component of the program and a source of emotional support. Subthemes of “verbal encouragement” and “shared experience” emerged. Verbal encouragement was described as “encouraging one another when one was sick or not feeling well” to complete exercises. Most participants described a “shared experience,” whereby being surrounded by others in a similar situation created a sense of understanding, normalcy, and encouragement. That experience was particularly salient for one participant whose family refused to discuss the existence of terminal cancer. The gym served as a forum to express thoughts and feelings about the cancer with individuals who could relate and provide advice and support. Some participants used peers as a point of comparison to assess their own functioning, stating that “seeing other people and seeing what they were going through made me get out of myself.” Some participants said that they would not have continued the program if the experience in the gym had been solitary, demonstrating the importance of a “shared experience.”

Well, it gave me something to look forward to. I was looking forward to going every week because we were able to talk without them saying, “I don't want to hear about it.” This is how it was at my house or with my friends.... They don't want to hear about it. But for me, it was very helpful to be in a setting where you can speak openly about it and even make jokes about it while we were exercising—then we would help each other on. Like when we were doing the exercise, we would say, “Okay, you only have five minutes. You're doing very well.” We would encourage each other.
— Ms. H, 51

Spirituality

The last form of emotional support described was spiritual. Half the participants sought emotional support from their religious beliefs. It is relevant to note that the program did not offer a spiritual component; however, spirituality was still a salient source of support outside the

program. Participants reported that their faith provided hope, strength, and comfort, and supported them through difficult moments. Subthemes of “adjustment” and “community support” were found. Faith seemed to aid in the acceptance of or adjustment to the life-limiting disease, as participants placed the progression of the disease and death into the hands of a higher power.

I did talk to God, and I was angry and whatever, but I've learned—that's my faith, if it's gonna happen, if I'm meant to be here, I'm going to be here. If it's my time to go, I'm gonna go. It's up to Him to decide, you know, and I'm okay with that.
— Ms. H, 51

For others, “the sense of community from the church is what's really beneficial.” That perceived availability of support was an important component in their ss networks and has previously been documented³¹.

Informational Support

Team Members

Informational support was described only in the context of the team members. The theme of “guidance” arose. Participants reported receiving an array of advice and guidance about aspects such as diet, legal work (that is, last will), returning to work, pain management, driving, energy conservation, medical information, and community programs. In addition, team members were reported to follow up routinely by telephone or e-mail with additional information if necessary.

[The occupational therapist] was very supportive. She outlined a few things I should do to improve energy and ... what I should watch for if I'm driving. She was very helpful.
— Ms. K, 66

Instrumental Support

Spouse, Family, and Friends

Instrumental support manifested only from spouses, family, and friends. The theme of “transportation” was the chief tangible aid provided by spouses, family, and friends. Without that support, many participants explained that they would be unable to attend the program. Other tangible supports provided by family were house chores, groceries, and meal preparation.

And we've had friends drive us as well.... So I have my sister-in-law lives close by, and I have a cousin that lives close by, too, and they've often drove us down to the hospital and picked us up when we were finished.
— Mr. W, 69

Effect of Sex

Men and women expressed differences in how ss was perceived. When asked directly about the importance of ss during the program, men indicated less dependence on

ss, relating their success instead to “self-motivation” and “self-reliance.” Most women described ss as an important component of the program, stating that it fostered acceptance and encouragement. Women also cited their children as either their primary or sole source of support outside the PRP; men cited their wives.

I'd say medium [importance of social support]....
Yeah, because I'm fairly self-motivated. I would have kept participating regardless of what anyone thought.
— Mr. F, 65

Effect of Age

The transcripts of participants less than 50 years of age ($n = 4$) were assessed for any notable differences that might have been attributable to their younger age. The youngest man (30 years) noted increased stress in balancing his work schedule and the weekly program. Another man (49 years) expressed fear of “abandoning” his family after death. Neither woman (45 and 50 years) expressed any notable age-related differences.

From day one, my wife and daughter were my biggest concern. There was kind of a sense that you were abandoning them and that was gravely eased by knowing that there were people that came forward to take care of things.
— Mr. D, 49

DISCUSSION

In the present study, we aimed to understand the areas of ss that were most beneficial for patients who had completed the 8-week PRP. Emotional support was the type of ss most referenced by participants. Sources of emotional support were team members, spouses, family, friends, peers within the program, and lastly, spiritual beliefs and communities. Team members were found to be the primary source of informational support. Spouses, family, and friends played a critical role in the provision of instrumental support to participants—specifically, transportation. Compared with women, men reported that ss was less important to them. The support needs and sources of stress for younger and older men differed based on family or vocational roles.

Patients reported benefiting from an encouraging and supportive team to complement their existing ss. They endorsed the team's support as often as familial support. That finding potentially speaks to the role of an interdisciplinary team that can provide multifaceted support. Such a team possesses professional knowledge in several areas that families might have been ill-equipped to address, particularly with respect to informational support (such as dietary or legal information, community programming, or returning to work and driving). The team also has the knowledge, ability, and comfort to discuss and listen to difficult topics such as cancer and death. That aspect seemed to be particularly salient for participants, because many described the importance of being listened to and heard, which is contrary to the experiences of many cancer patients with health care providers¹³. Many families might

not be emotionally able to broach such subjects together, potentially leaving one another with disenfranchised grief³²—that is, grief that is not socially acceptable and therefore cannot be expressed.

An inability to grieve can leave a person unable to process their experience, which could hinder the ability to adapt and move forward³². Therefore, in the context of palliative rehabilitation programs, it is important for health care providers to offer emotional support to patients. Peers within such a program could also serve the same function: the experience of “shared fate” could be instrumental in reducing stress and anxiety³³. Participants described being able to openly discuss cancer and to use humour, fostering a sense of normalcy and acceptance. That openness could be particularly beneficial for patients with late-stage cancers, because studies have shown high levels of avoidance in discussing the existence of the cancer on the part of families of patients with advanced cancers³⁴.

Patients report relying on family for emotional and instrumental support. Such reliance is beneficial for the patient, but can simultaneously take a toll on the caregiver's QOL, resulting in psychological distress and caregiver burden^{35–37}. Others have found that integrating caregivers into interventions can substantially improve caregiver QOL^{38,39}. The PRP offered caregivers the opportunity to attend consultations; however, caregivers were not formally integrated. When participants use the team and their peers as a strong source of emotional support, some caregiver burden might be alleviated¹⁴. Still, because participants rely heavily on familial support, formal integration and provision of services to the family in rehabilitation programs might be a worthwhile pursuit³⁷. Future studies could assess the effectiveness of a supportive–expressive caregiver support group that runs in parallel to gym sessions⁴⁰.

Sex differences consistent with the literature emerged spontaneously in patient interviews⁴¹. Men attributed their success to “self-reliance” and named their spouse as their primary source of support; women valued several sources of support¹². Women tended to cite their children as a primary source of support. Emotional support from adult children substituting for that of a spouse can be less accessible, less intimate, and less sensitive⁴². Widowed women might therefore be a vulnerable group, which could help to explain their emphasis on the team and peers as salient sources of support.

The difficulty in purposefully recruiting married women or single men without ss might have been another spurious finding rather than a limitation. It might indicate an interaction between ss values (men value self-reliance, women value external ss) and an effect of marriage. Compared with married women and unmarried men, married men (presumably heterosexual, given the sex differences cited in Umberson⁴³) have been found to experience health benefits, hypothesized to be a result of their wives managing their health care. Our sex and marriage difference might reflect that interaction: married men could have been more likely to attend the PRP because of their wife's influence; women might have been more likely to attend if they lacked spousal support. Those observations are preliminary and would need more rigorous, quantifiable, and well-powered follow-up⁴³.

Only men less than 50 years of age expressed age-related concerns (balancing work and a weekly program, and leaving behind a young family), which is consistent with the literature^{44–46}. Those circumstances could be potential barriers to attending daytime programs for individuals who are married or employed. Alternatively, they could be expressions of existential suffering that have to be addressed with loved ones or other sources of support, if amenable.

Despite the program not offering a spiritual care counsellor, no participant who discussed spirituality as a source of emotional support suggested incorporating a spiritual component in the program. The lack of such suggestions is potentially attributable to the individual having their own community resources or being habituated to the lack of spiritual care in Canadian hospitals. Alternatively, fostering a relationship of trust and understanding with the team members might have facilitated conversation about spiritual needs⁴⁷. However, providing the option of spiritual counselling might be an important component of comprehensive care, given that religiosity has been found to result in better patient-reported physical health and adjustment^{47,48}. Such an offer could be particularly important for patients with advanced cancer, because a diagnosis of a terminal illness can result in spiritual disengagement and feelings of anger toward God, which could adversely affect adjustment⁴⁹.

Strengths and Limitations

The main strength of the present study was its purposive sampling method, which permitted the observation of some preliminary effects that sex, age, and marital status might have on ss in patients with advanced cancer. There are several limitations to note. The main limitation is sample size. Unfortunately, because of termination of the program, recruitment was ended, limiting the generalizability of our findings. However, the preliminary findings warrant further investigation with a larger sample, particularly with regard to single men. Only patients who completed the 8-week program were interviewed. Those lacking outside support might have been unable to begin or complete the program, particularly given that most participants reported relying on a family member or a spouse for transportation. Interviews were conducted by a research team member who was not part of the clinical team. That distinction was clearly stated during the consent process, but might have affected patients in various ways. It could have been a strength that allowed freedom of expression; it could have been motivation to portray the team favourably; or it could have elicited complaints about disliked elements. Most participants were of European descent, and thus the results of the study might not be generalizable to patients from other cultures. For example, Asian or Hispanic culture might place different emphases on types, preference, and norms for ss^{50,51}. Ottawa is the capital of Canada and has both an educated workforce (multiple post-secondary education institutions, hospitals, and government) and a relatively stable job market. Reports of ss might vary in other Canadian provinces or countries with a different socioeconomic status, religion (or religious conservatism), general education, and health care system, among other factors.

CONCLUSIONS

To our knowledge, the present study is the first to look at the types and sources of ss found to be the most beneficial by patients with advanced cancer in a rehabilitation program. The theme of emotional support—and particularly verbal encouragement and listening—seems to be the most sought and received by patients, predominantly women. Men cited self-reliance and their wives as their greatest support, although it is important to consider that unexpressed needs might remain, particularly considering traditional masculinity norms and the belief that men should not express negative emotions or distress⁵². Single or widowed men and women could be a vulnerable group. Given the seemingly high degree of reliance on caregivers for instrumental and emotional support, it might be worthwhile to formally integrate caregivers into palliative rehabilitation programs to reduce the risk of caregiver burnout. Providing the option of spiritual counselling within a program could benefit patients who are struggling existentially or who rely on religion for meaning and emotional support.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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