

Group-based psychosocial services: assessing outpatient oncology needs

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Background Group-based services can improve quality-of-life outcomes for oncology patients.

Objective To assess patient preferences for supportive and wellness programming to better meet patient needs and allocate resources.

Methods Patients from 3 cancer centers in New York City completed a 15-item questionnaire about their interest in educational topics (wellness, nutrition, legal issues, etc) and services (support groups, lectures, and exercise programs).

Results 311 patients participated in the survey. Mean age was 59 years, and 74% were women. The most common cancer was breast (40%), followed by genitourinary (15%). Women preferred wellness workshops most, followed by informative sessions; men most preferred informative sessions, followed equally by posttreatment support and wellness workshops. Older age was related to an increased likelihood of group attendance. Overall, 68% of participants reported that they would be likely to attend groups. For lectures, nutrition was of greatest interest for men (43%) and women (34%), followed by anxiety management (17% and 18%, respectively). Overall, 64% of participants reported that they would be likely to attend a lecture. A majority of respondents (54%) expressed a desire for exercise programs.

Limitations Generalizability to all cancer centers is limited, because data was not tracked on those who refused to complete the questionnaire.

Conclusions Obtaining patient feedback on psychosocial programs is imperative for understanding patient preferences and developing effective support programming.

An estimated 1,685,210 people will receive new cancer diagnoses in 2016.¹ Patients with cancer, as well as survivors, frequently encounter emotional or mental health issues secondary to their cancer diagnosis.^{2,3} The diagnosis and treatment of cancer is often accompanied by uncertainty and psychological distress that can be managed with appropriate psychosocial interventions. Therefore, many cancer centers, as well as local and national organizations, provide psychosocial support aimed at improving adjustment to disease, quality of life, and management of side effects.⁴ Moreover, the Institute of Medicine (IOM) recommends that “all components of the health care system involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards in addressing clinical care.”^{5(p.9)}

Although support groups, psychoeducational workshops (eg, lectures), and wellness programs (eg, yoga) are well-established interventions in cancer care, their use rates are low and there is little evidence that the existing services are based on patients' requests for these types of services.⁶⁻¹² Offering pro-

grams to treat psychological distress is a key factor in providing optimal care to patients with cancer, especially because patient wellbeing is enhanced when psychological morbidity is reduced.¹³ Attention to psychosocial needs has been linked to higher patient satisfaction with medical care and is fundamental in developing an effective care response.^{14,15} Psychosocial interventions can improve the psychological and physical health outcomes in patients with cancer, so offering support and wellness group-based services is a cost-effective way for institutions to provide psychosocial care.¹⁶

While efforts have been directed toward establishing the efficacy of group interventions for patients with cancer, there remains little systematic evidence about which types of services patients would like.¹⁰ McGarry and colleagues have reported that women with breast cancer wanted supportive programs available to them onsite at the hospital.¹⁷ A recent study by Marbach and Griffie⁸ found that patients wanted additional support groups for each cancer type. The authors noted that patients should have a myriad of support programs from which to choose.⁴

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Support groups are an established and effective way to provide psychosocial care to those who have been affected by cancer, and, as a result, are commonly offered in outpatient cancer centers.¹⁸⁻²¹ Support groups facilitated by professionals provide patients with an opportunity to talk with peers, which allows for therapeutic experiences that can improve quality of life.¹⁹ Group-based psychosocial programming can assist patients and families with adjusting, coping, and managing the emotional, social, and physical aspects of a cancer diagnosis.⁷ Peer support is considered to be an important factor for those seeking support at the time of diagnosis.^{22,23} General support-group participation has been associated with improved attitudes toward health care providers; decreased prevalence of mood disturbances, including anxiety and depression; and increased knowledge about one's disease.²⁴ Furthermore, study findings have indicated that group interventions are effective for patients at all points of the cancer continuum, from early stages to advanced disease.²⁵

Lectures and support groups are common modalities in which patients receive psychoeducation. Providing education to cancer patients aims to reduce the sense of helplessness many patients experience as a result of uncertainty and lack of knowledge. Psychoeducation may include disease-specific resources and can also include information about coping, side effects, and wellness.¹⁶ Psychoeducation can offer patients a sense of mastery over their disease and subsequently, a sense of control over their lives in the context of cancer care. Needs are complex and shift from diagnosis, through treatment, to after treatment.²³

Exercise and wellness programs, such as yoga, are known to increase strength and physical fitness and decrease fatigue. Yoga has also been found to have a positive impact on psychological functioning, quality of life, and self-esteem.²⁷⁻²⁹ McGarry and colleagues found that women with breast cancer were interested in exercise programs tailored for cancer patients.¹⁷ Moreover, Marbach and Griffie found that services such as yoga and exercise classes were identified as desirable by participants.⁸ Even if patients did not use the services, they found it important to know that the programs were being offered.

Needs assessments allow patients to identify areas of interest and make it possible to identify and prioritize the aspects of service delivery that must be improved.³⁰ It is helpful to assess the self-defined need for support to anticipate demand and participation.³¹ The objective of this needs assessment was to examine patient preferences for psychosocial cancer group-based services across a sample of outpatients. Conducting a psychosocial needs assessment is a direct method to identify the services most desired by patients.⁹ This information may be helpful to other cancer centers in determining and responding to the psychosocial needs of outpatient cancer patients.

Methods

This needs assessment survey was conducted at a large academic medical center in New York City. The center treated 5,322 patients in 2013 across 3 outpatient cancer clinics. A robust portfolio of support groups, exercise and wellness programs, and psychoeducational programs are offered on a weekly and monthly basis. Our support groups are led by licensed clinical social workers, and our wellness programs (yoga, aerobics, reiki, and so on) are led by certified personnel. In general, the support groups are open-ended format. The 3 outpatient cancer centers where the survey questionnaires were distributed provide care to individuals with a range of cancer diagnoses. Since a broad range of patients are served by the institution, patients were approached 5 days a week by trained volunteers in the waiting rooms of the chemotherapy and radiation treatment areas, rather than surveying only those who had previously attended a support program. We obtained verbal consent from all participants. The volunteers then collected the completed paper-based questionnaires, or they were left with the receptionist. The questionnaires were completed in the radiation and medical oncology waiting rooms and the infusion suites. Patients were not offered a questionnaire if they did not have a cancer diagnosis or if they lacked capacity to complete the questionnaire.

Ethical considerations

The questionnaires were anonymous, and we did not collect any identifying information from participants. We inquired about the need for Institutional Review Board approval and were told that the IRB approval process was not needed because the survey was designed as a program evaluation and met criteria as an exempt protocol.

Questionnaire

The questionnaire used in the study consisted of 15 items and was translated into Spanish and Chinese. The translation was conducted to ensure that patient populations served at the center had an equal opportunity to express programmatic interests. The questionnaire was developed by social work staff on the cancer supportive services team, and input was obtained from cancer survivors familiar with the programs. Questions were selected based on available support and wellness programming, which is why a previously developed questionnaire was not selected. Demographic questions included gender, age, educational level, and type of cancer. Programmatic questions included whether patients would be likely to attend support groups, lectures, or exercise programs for cancer patients. Patients could select as many topics that interested them.

Specific to support groups, patients were asked to identify the type of group in which they were interested. For example, the questionnaire listed: informative sessions, emotional support, workshops (eg, chemobrain, lymphedema,

TABLE 1 Patient characteristics (N = 311)

Characteristic	No. of respondents (%)
Median age, y (SD):59.1 (12.4)	—
Female sex	231 (74.3)
Level of education (n = 191)	
High school	62 (32.5)
College	72 (37.7)
Master's	33 (17.3)
Doctorate	6 (3.1)
Other	18 (9.4)
Questionnaire language (n = 302)	
English	265 (87.8)
Spanish	20 (6.6)
Chinese	17 (5.6)
Cancer type (n = 307)	
Breast	123 (40.1)
Genitourinary	46 (15.0)
Lymphoma/leukemia/myeloma	36 (11.7)
Lung	27 (8.8)
Head and neck	21 (6.8)
Colorectal	19 (6.2)
Other	35 (11.4)

and so on), posttreatment support, practical support/guidance (eg, legal, insurance, financial), wellness workshops (meditation, hypnosis, reiki), and other. The patients were also asked which type of support group the patient would be most likely to attend: disease-specific, gender-specific, language-specific, sexual orientation-specific, age-specific, or other. The questionnaire explored patients' interest in varying lecture topics, as well as in creative arts programs, such as knitting, writing, fashion, cooking, drawing/painting, and any other mediums. It also addressed barriers that may prevent patients from attending programs and asked about which days and times of the week were most convenient. Patients were asked about the importance of having programs offered at their own treatment locations and about other programs that they attended in the community, such as Cancer Care. They were also asked which format they preferred for their participation in supportive programs, for example, face-to-face, by telephone, or online.

Analyses

Descriptive statistics were calculated for responses to each item. Logistic regression was used to examine the effect of gender, age, and education (more than high school education vs high school education or less) on the likelihood

(defined as Likely or Very Likely) of attending support groups, lectures, and creative arts programs. Descriptives and chi-square analysis was used to assess interest in each subtype of support service by sex to assess if specific programming would be of interest to both men and women. All analyses were conducted the the Statistical Analysis System (version 9.3).

Results

Participants

Participants were predominantly women (74.3%) and had a mean age of 59.11 years (SD, 12.4; Table 1). Breast cancer was the most common cancer type among them (40.1%), followed by genitourinary cancer (15.0%).

Correlates of likelihood to attend support services

Age was a statistically significant correlate ($P < .001$) of reported likelihood of attendance at support groups for cancer patients (Table 2). After adjusting for gender and education, each 1-year increase in age was associated with a 7% increase in the odds of likelihood of attendance (95% confidence interval [CI], 1.03-1.10). Overall, 68.2% of participants reported that they would likely or very likely attend support groups (Table 3). None of the 3 variables were found to be statistically significant in the logistic regression model for likelihood of lecture attendance. Overall, 63.9% of participants reported that they would likely or very likely attend a lecture on a topic of interest. Women and persons with a high-school education or less were more likely to attend creative arts programs.

Association between sex and types of programming

For women, wellness workshops were the most desired

TABLE 2 Demographic correlates of likelihood to attend support services

Service/variable	Odds ratio	95% CI	P value
Support group			
Sex (female)	0.54	0.26, 1.15	.11
Age	1.07	1.03, 1.10	<.001
Education (>HS)	0.98	0.47, 2.07	.97
Lecture			
Sex (female)	0.56	0.27, 1.15	.11
Age	1.01	0.98, 1.04	.46
Education (>HS)	0.60	0.30, 1.20	.15
Creative arts program			
Sex (female)	3.32	1.56, 7.05	<.01
Age	0.98	0.98, 0.95	.11
Education (>HS)	0.43	0.43, 0.21	.02

CI, confidence interval; HS, high school

TABLE 3 Interest in and likelihood of attending support services

Item	No. of respondents (%)	Item	No. of respondents (%)
Likelihood of support group attendance (n = 280)		Interest in support group type (selected all that apply)	
Very likely	65 (23.2)	Wellness workshop	138 (44.4)
Likely	126 (45.0)	Informative sessions	120 (38.6)
Not likely	89 (31.8)	Emotional support	104 (33.4)
Likelihood of lecture attendance (n = 269)		Post-Treatment support	91 (29.3)
Very likely	53 (19.7)	Workshops	85 (27.3)
Likely	119 (44.2)	Practical support/guidance	67 (21.5)
Not likely	97 (36.1)	Interest in lecture topics (selected all that apply)	
Likelihood of creative arts program attendance (n = 267)		Nutrition	163 (52.4)
Very likely	51 (19.1)	Exercise	83 (26.7)
Likely	107 (40.1)	Anxiety and depression	81 (26.0)
Not likely	109 (40.8)	Legal/financial	58 (18.6)
Support group most likely to attend (n = 292)		Body image	40 (12.9)
Disease-specific	174 (59.6)	Sexual health	25 (8.0)
Age-specific	49 (16.8)	Creative arts programs of interest (selected all that apply)	
Language-specific	34 (11.6)	Cooking	111 (35.7)
Gender-specific	30 (10.3)	Drawing/painting	81 (26.0)
Sexual orientation-specific	5 (1.7)	Knitting	62 (19.9)
Support group format preference (n = 281)		Fashion	49 (15.8)
Face-to-face	211 (75.1)	Writing	45 (14.5)
Online	41 (14.6)	Barriers (selected all that apply)	
Telephone	29 (10.3)	Physical/fatigue	100 (32.2)
Desire for more exercise programs (n = 232)		Time of day	95 (30.5)
Yes	126 (54.3)	Transportation	85 (27.3)
Importance of on-site treatment location (n = 277)		Location	85 (27.3)
Very important	144 (52.0)	Work schedule	72 (23.2)
Somewhat important	67 (24.2)	Weather	45 (14.5)
Not important	66 (23.8)		

group type (23.9%), followed by informative sessions (18.2%; Figure 1). Men had the greatest interest in informative sessions (25.9%), followed by posttreatment support groups and wellness workshops (18.9%; Figure 1). There was no statistically significant association between sex and interest in group type ($X^2(5) = 8.39, P = .14$).

No statistically significant associations were found between gender and interest in lecture topic ($X^2(5) = 3.14, P = .64$), as shown in Figure 2. Nutrition was the lecture topic that received the greatest interest among both women (34.5%) and men (43.2%). Given multivariate findings showing significantly higher interest in creative arts programming among women, we did not break out interest in topics of programming by sex.

A statistically significant association between gender and a desire for more exercise programs was found, ($X^2(1) = 5.21, P = .02$). A majority of women (58.8%) reported

a desire to see more exercise programs offered, compared with 41.7% of men, (odds ratio, 1.41; 95% CI, 1.07, 1.87).

Discussion

This needs assessment investigated psychosocial program needs among outpatient cancer patients from different demographic backgrounds, but within the same hospital system. Older age was associated with increased likelihood of attending support groups. Fukui and colleagues found that participants who were 50–65 years old were more likely to participate in groups than were those aged 49 years or younger.³² Older patients may be more agreeable to disclosing needs and have more time and fewer demands on them, which enables them to attend sessions.

The differences between men and women in relation to their interest in types of support groups and lectures were not statistically significant. Krizek and colleagues found

that men reported no less interest than women in sharing their concerns and comparing their emotional and physical progress with other patients.¹² Similarly, Sherman and colleagues did not find gender differences in level of interest in group participation.¹¹ Women preferred wellness workshops and exercise programs and were more likely to attend creative arts programs, whereas men were interested in informative sessions. A literature review by Stuckey and Nobel focusing on the link between art and healing, noted that medical professionals were beginning to realize the role creative arts play in the healing process, specifically artistic engagement, which they summarized has significant positive effects on health.³³ The finding that men prefer informative sessions is consistent with the literature that men focus on gaining information about their disease.^{34,35}

It is of note that the majority of patients preferred face-to-face support groups. That was surprising to the authors because of the prevalence of online groups in this internet age. There are hundreds of online groups for cancer patients.^{36,37} The findings may suggest that patients are looking for in-person social support and interpersonal connections, which are harder to find given the anonymity allowed by the internet. The fact that patients prefer face-to-face support programs is also consistent with patients' desire to have supportive programming at their own treatment location. This is also interesting, given the plethora of free support programming offered by national and local cancer nonprofit agencies throughout New York City.

In our survey, patients reported that fatigue, time of day, transportation, and location were barriers to participation in support programs. Sherman and colleagues also found that patients listed fatigue as a barrier to support group participation.¹¹ Since exercise is an evidence-based intervention for fatigue, we have partnered with nursing in order to promote our onsite free classes. This has proven to be especially beneficial in radiation oncology, where fatigue is a common side effect of treatment. In New York City, patients have access to the large subway system; however, travel can be tiring and costly for some. Patients also indicated a preference for joining support groups at their treatment location, perhaps to avoid unnecessary or additional travel. Others listed time of day as a barrier. Therefore, an effort was made to provide programs at various times of the day, 5 days a week. We also partnered with community organizations to promote free programming in the outer boroughs to ensure that a broad range of patients are aware of opportunities to attend supportive programming.

Sherman and colleagues surveyed 425 cancer patients and found that 59.7% did not know where to find support groups.¹¹ Moreover, Krizek and colleagues found that a third of the cancer patients they surveyed were unaware of support groups.³¹ Therefore, another benefit of this survey was promoting the availability of programs offered at our centers. We recently revised our distress screening tool (National

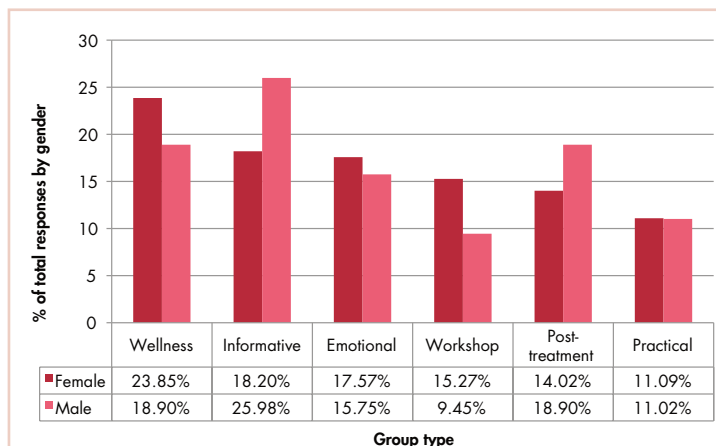


FIGURE 1 Interest in group type by gender.

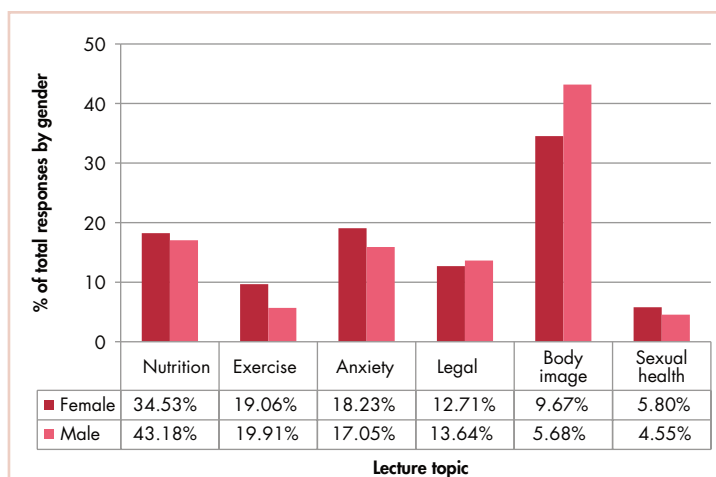


FIGURE 2 Interest in lecture topic by gender.

Comprehensive Cancer Network distress thermometer) and added a question exploring whether or not patients wished to receive our monthly support and wellness calendar. By sharing their e-mail address, they would be added to our e-mail distribution list, allowing more patients to be kept informed about the availability of support programs.

This needs assessment is a starting point to identify the psychosocial preferences as expressed by those living with cancer, and it helps us translate these preferences and interests into meaningful support programs. Addressing the quality-of-life issues experienced by adult cancer patients should benefit patients, families, caregivers, and the health care system. Patients with unmet psychological needs have higher use of medical services and higher medical costs.³⁸⁻⁴⁰ Moreover, Simpson and colleagues⁴⁰ reported that in a sample of breast cancer patients, participation in group psychosocial interventions can reduce billing for general medical expenses, thereby justifying the availability of these programs in cancer treatment facilities.

Limitations

In terms of limitations, the sample was relatively small and conducted in only 1 hospital system (at 3 distinct locations). Thus, generalizability to all cancer centers is limited. In addition, we did not keep track of the number of patients who refused to complete the survey, or their reasons for refusal. Moreover, it would be important to capture whether patients are in active treatment, or have completed treatment, a relevant component when designing support programs. It is also probable that there are factors not assessed in this survey that are influential in determining needs for psychosocial support, such as perceived social support. Another limitation is that patients were not specifically asked if they would commit to attending programs. Because the intention to participate is not a strong indicator that people will attend programs, program planners need to be considerate and account for that.

Conclusion

The main purpose of conducting this survey of patients with cancer was to improve the psychosocial care provided at our outpatient cancer centers. The management of psychological distress is an important aspect of clinical care. The information obtained from the needs assessment is helpful for future program development in that it informs the planning of services that benefit patient care. For example, as a result of the patient feedback, more nutrition lectures and workshops are now offered, as well as more exercise programs. Cancer centers that have limited staffing to

facilitate support programs can consider partnering with community-based nonprofits to increase the availability of onsite programming. The psychosocial programmatic needs assessment identified the services that are most preferable to patients. This approach can be used by other cancer centers seeking to develop programming for outpatient cancer patients. Increasing the knowledge afforded to clinicians can positively impact patients' experiences by identifying aspects of programming that best meet patient needs. It also serves as an impetus for the development and testing of interventions to meet the psychosocial needs of cancer patients. It is important to routinely monitor the needs of cancer patients so that oncology clinicians can implement and streamline services offered. Cancer service providers should understand the expectations of their patients and recognize that psychosocial needs vary among patient groups; interventions must target patients facing a broad range of issues. Increased efforts of the interdisciplinary team to educate patients regarding the availability and benefits of support programs are needed.

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