

Commentary

The state of psychosocial services in cancer care in the United States

Teresa Deshields^{1*}, Brad Zebrack² and Vicki Kennedy³

¹Siteman Cancer Center at Barnes-Jewish Hospital and Washington University, St. Louis, MO, USA

²University of Michigan School of Social Work, Ann Arbor, MI USA

³The Cancer Support Community, WA, USA

*Correspondence to: Siteman Cancer Center, 4921 Parkview Place, MS: 90-35-703, St. Louis, MO 63110, USA. E-mail: tld2593@bjc.org

Abstract

Objective: In 2009, the APOS commissioned a survey of its members and attendees of the annual meetings in 2008 and 2009. The goal of the survey was to assess the scope of psychosocial support services for cancer patients in the USA.

Methods: Two hundred thirty-three individuals (27% response rate) completed the survey, which included questions assessing the extent to which respondents' institutions provided informational and psychosocial support services and conducted screening for psychosocial distress.

Results: Respondents were primarily psychologists, although oncologists, nurses, social workers, and others were represented, as well. A broad array of informational and support services were endorsed as being provided to cancer patients, both at no charge or for a fee. Respondents identified social workers as the professionals most often providing psychosocial services to cancer patients. Respondents also indicated that most psychosocial services have not been tailored to fit a culturally diverse population. Furthermore, most of the organizations represented in the survey do not routinely screen cancer patients for psychosocial distress.

Conclusions: A broad range of psychosocial services are provided in cancer treatment settings; however, despite National Comprehensive Cancer Network and Institute of Medicine recommendations, routine screening for distress is not offered in a majority of cancer care organizations. Despite the racial, ethnic, cultural, and linguistic diversity of the US population, most organizations have not adapted their educational materials nor their psychosocial services to meet the needs of a diverse patient population.

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Introduction

Psychosocial problems associated with cancer (e.g., depression, inadequate coping skills) can be effectively addressed by supportive care services and psychosocial interventions [1]. Nonetheless, the psychosocial needs of cancer survivors are not being met, according to a 2006 report by the Institute of Medicine (IOM) and National Research Council [2].

In 1995, Coluzzi and colleagues published results of a survey of supportive care services offered at National Cancer Institute (NCI)-designated cancer centers [3]. At that time, 68% of responding institutions offered counseling services and 90% offered support groups. Ninety percent had a spiritual care department. The source for most of the funding for these services was institutional funds.

The American Psychosocial Oncology Society (APOS) endeavored to update the previous survey and examine the current state of psychosocial services for cancer survivors. The primary goal of the new survey was to establish baseline evidence against which the field can measure progress on meeting the strategic

imperatives promulgated in the IOM report, *Cancer Care for the Whole Patient* [1].

Methods

Participants

Data were collected from participants through an online survey (Survey Monkey) between November 2009 and February 2010. The link to the survey was e-mailed to APOS members and attendees at APOS annual conferences in the previous 2 years ($n = 850$).

The survey

The survey included questions assessing the extent to which respondents' institutions provided psychosocial services, including individual/family consultation, educational materials, support groups, and survivorship programs. The survey also solicited information about psychosocial screening procedures and barriers. The questions were drawn from the Coluzzi study [3], with additional questions added by the authors and APOS Board members.

Data analysis

Given the primary focus of the survey to provide information about institutional practices (not individual behaviors), survey data from respondents from the same institution were condensed into a single institutional response. In cases where there were discrepancies, a set of decision rules was devised to determine the composite score. If one respondent from an institution reported their institution offered a program or service, or experienced a particular barrier to care, the composite case was coded as having that particular program, service, or barrier. In instances where respondents from the same institution reported differing numbers or proportions (e.g., of staff, services, barriers to care), the composite score reflected the greater number. With regard to costs, if one respondent reported services as being offered 'at no cost,' whereas another respondent from the same institution reported services as offered 'for a fee,' the composite response was coded as 'both at no cost and for a fee.'

Several open-ended questions were included in the survey. Open-ended responses were coded and then organized into categories determined by study authors.

Results

Respondents

The online survey was completed by 233 people (27% response rate), representing 146 institutions across the USA. Thirty-six percent of respondents were psychologists, followed by social workers (19%), and nurses

(13%). Most respondents (79%) provided clinical care and were APOS members (61%).

Among the 146 institutions represented, 58 (40%) were NCI-designated comprehensive cancer centers or large cancer treatment/research institutions. Forty (27%) of the institutions were patient service or advocacy organizations. Thirty-three (23%) of the institutions were community-based treatment centers (community hospitals, ambulatory care centers, small medical practices). Fifteen (10%) of the institutions were nonmedical institutions not providing clinical care, such as university departments.

Informational and psychosocial support services

Psychosocial clinical care coverage: Across 131 institutions providing clinical services, the size of clinical staffs varied. Almost half of the institutions (41%) reported 3–10 employees who provide psychosocial services. Approximately 19% of comprehensive centers, 39% of community-based treatment centers, and 28% of patient advocacy organizations reported staffs of fewer than three psychosocial professionals.

With regard to funding psychosocial care, most settings relied on multiple financial sources. Sixty-seven percent of comprehensive centers and 88% of community-based treatment sites are supported by general operating funds. Approximately, one-third of comprehensive centers (29%), community-based centers (30%), and patient service organizations (38%) depend

Table 1. Types of services ($n = 131$)

Services	Comprehensive cancer center $n = 58$ freq (%)		Community-based treatment centers $n = 33$ freq (%)		Patient service or advocacy organizations $n = 40$ freq (%)	
	Offered	Charge ^a	Offered	Charge ^a	Offered	Charge ^a
Professionally-led support groups	44 (76%)	3 (7%)	26 (79%)	4 (15%)	20 (50%)	2 (5%)
Peer support network	29 (50%)	0	21 (64%)	0	18 (45%)	0
Culturally-tailored support groups	18 (31%)	1 (6%)	8 (24%)	0	13 (33%)	1 (8%)
Survivorship care program	37 (64%)	5 (14%)	23 (70%)	1 (4%)	19 (48%)	1 (5%)
Individual counseling	46 (79%)	11 (24%)	25 (76%)	9 (36%)	22 (55%)	5 (23%)
Family counseling	44 (76%)	11 (25%)	24 (73%)	7 (29%)	21 (53%)	4 (19%)
Psychiatric consultation	44 (76%)	36 (82%)	20 (61%)	17 (85%)	4 (10%)	2 (50%)
Pastoral/ spiritual care	43 (74%)	0	24 (73%)	0	7 (18%)	0
Genetic counseling	43 (74%)	36 (84%)	23 (70%)	15 (65%)	1 (3%)	0
Fertility counseling	38 (66%)	31 (82%)	12 (36%)	8 (67%)	1 (3%)	0
Employment counseling	21 (36%)	4 (19%)	11 (33%)	2 (18%)	6 (15%)	0
Financial counseling	43 (74%)	2 (5%)	26 (79%)	0	12 (30%)	1 (8%)
Exercise/ fitness program	28 (48%)	7 (25%)	17 (52%)	5 (29%)	15 (38%)	0
Rehabilitation/ physical therapy	41 (71%)	37 (90%)	23 (40%)	21 (91%)	3 (8%)	0
Diet/ nutrition program	45 (78%)	21 (47%)	26 (79%)	8 (31%)	14 (35%)	0
Child care	8 (14%)	2 (25%)	2 (6%)	0	2 (5%)	0
Transportation assistance	35 (60%)	2 (6%)	21 (64%)	1 (5%)	7 (18%)	0
Educational materials	46 (79%)	4 (9%)	28 (85%)	2 (7%)	25 (63%)	1 (4%)
Internet access	38 (66%)	0	26 (79%)	0	19 (48%)	0
Patient education specialist	31 (53%)	2 (6%)	22 (67%)	0	16 (40%)	0
Patient education resource center	36 (62%)	0	28 (85%)	0	20 (50%)	0
Educational classes, workshops	42 (72%)	5 (12%)	29 (88%)	5 (17%)	20 (50%)	2 (10%)
Informational website	42 (72%)	0	28 (85%)	0	23 (58%)	0
Individual/family education consultation	45 (78%)	26 (58%)	30 (91%)	15 (50%)	27 (68%)	7 (26%)

^aNumber/percentage that charge for the service of those institutions that offer the service.

upon philanthropic funds. Forty-one percent of comprehensive centers reported charging fees for some services, compared with 30% of community treatment centers and 13% of patient service organizations. Between 17% and 26% of all institutions reported grants as a source of financial support.

Types of psychosocial services provided: Table 1 summarizes the psychosocial services offered. Services are provided both free of charge and fee-for-service across different settings. A majority of community-based treatment centers and comprehensive cancer centers and about half of patient service organizations offer professionally-led support groups, with a subset charging a fee for this service. Also, psychiatric consultation, genetic counseling, fertility counseling, and rehabilitation therapy are most often offered by comprehensive centers and community treatment settings, with over 50% of those charging a fee.

Informational services (the provision of educational materials and community resources) were offered in most settings (see Table 1). Most institutions (63–85%) provide educational materials, with very few charging for these materials. Most comprehensive centers and community sites and about half of patient service organizations provide free internet access for patients. Patient education resource centers were available at many comprehensive centers and community treatment sites and half of patient service organizations. Patient education specialists were more available at community sites than at comprehensive centers or patient service organizations. Most comprehensive centers and community sites and half of patient service organizations offered free educational classes or workshops.

A minority of responding organizations (31% of comprehensive cancer centers, 24% of community treatment centers, and 33% of patient service organizations) offer culturally tailored support groups. Despite the widespread availability of informational and educational resources, over half of comprehensive centers (52%), community centers (64%), and patient service organizations (58%) reported minimal adaptation of these materials (<25%) to culturally or linguistically diverse patient groups. Only five comprehensive centers (9%), four community centers (12%), and two patient service organizations (5%) indicated substantial adaptation of educational materials (>50%).

Providers of psychosocial services: Although a variety of clinicians deliver psychosocial services (see Table 2), oncology social workers are most often responsible for delivery of services. In comprehensive cancer centers and community-based sites, social workers were most often identified as the providers of resource referral, case management, community outreach/education, and patient navigation. With regard to counseling services, social workers were most often identified across all sites as the providers of employment and vocational assistance, individual/family

counseling, and telephone counseling. Psychologists were also identified as providers of individual/family counseling and telephone counseling.

Social workers were also most often identified as providing assistance with insurance, finances, housing, transportation, and legal resources, as well as providing psycho-educational programs. Psychologists provide complementary medicine services and also psycho-educational programs. In patient service organizations, social workers were most likely to provide all such services, as well as online information and referral.

Greater variety was observed in the delivery of lifestyle and health behavior interventions. In comprehensive cancer centers, nurses most often provided sexual health counseling, smoking cessation services, and nutrition information/counseling. Physicians and psychologists were also likely to provide sexual health counseling and smoking cessation services. Social workers were more likely to organize activities, such as survivorship events, or deliver appearance/body image programs. In community care sites, nurses were more likely to perform counseling related to sexual health, nutrition, and exercise/fitness, whereas social workers were again more likely to provide appearance/body image programs and organize patient activities. In patient service organizations, social workers and psychologists were most likely to be identified as providing sexual health counseling and appearance/body image programs and organizing patient activities, whereas nurses were endorsed as also providing sexual health counseling and appearance/body image programs but more likely to provide nutrition information/counseling.

The results indicate that most psychosocial services are not tailored for culturally diverse populations. Three fourths of institutions reported having adapted little (<25%) of their psychosocial and lifestyle/behavioral health services in this manner. Only 11% of institutions had tailored many (>50%) programs for multilingual and multicultural populations.

Barriers for psychosocial care for minority patients: Survey respondents listed three significant barriers to psychosocial care for patients from racial, ethnic, or linguistic minority groups: finances (22%), language (21%), and culture (20%). Comprehensive cancer centers and community-based treatment centers endorsed finances (17% and 36%, respectively) and cultural issues (14% and 30%, respectively) as the most significant barriers to psychosocial care. Patient service organizations were more likely to endorse language (35%) and geography/transportation (30%) as significant barriers.

Psychosocial screening

Only 67 (51%) of the organizations offering clinical care conduct routine psychosocial screening for new cancer patients. Twenty-five comprehensive centers (43%), 22 community-based practices (67%), and 19

Table 2. Providers of psychosocial services (n = 131)

	Large cancer centers freq (%)						Community care sites freq (%)						Patient service organizations freq (%)												
	Physician		Social Worker		Patient Navigator		Physician		Social Worker		Patient Navigator		Physician		Social Worker		Patient Navigator		Physician		Social Worker		Patient Navigator		
	Nurse	Out	Worker	Out	Navigator	Out	Nurse	Out	Worker	Out	Navigator	Out	Nurse	Out	Worker	Out	Navigator	Out	Nurse	Out	Worker	Out	Navigator	Out	
Case management	6 (13.6)	27 (61.4)	37 (84.1)	4 (9.1)	14 (31.8)	15 (34.1)	7 (25.9)	17 (63.0)	24 (88.9)	2 (7.4)	13 (48.1)	5 (18.5)	NA	2 (6.7)	2 (6.7)	NA	NA	1 (3.3)	19 (63.3)						
Community outreach	21 (47.7)	25 (56.8)	32 (72.7)	21 (47.7)	16 (36.4)	6 (13.6)	3 (13.0)	16 (69.6)	17 (73.9)	9 (39.1)	6 (26.1)	1 (4.3)	9 (30.0)	4 (13.3)	17 (56.7)	9 (30.0)	5 (16.7)	3 (10.0)							
Resource referral	14 (31.1)	25 (55.6)	43 (95.6)	22 (51.1)	18 (40.0)	3 (6.7)	9 (36.0)	14 (56.0)	22 (88.0)	8 (32.0)	13 (52.0)	3 (12.0)	10 (34.5)	3 (10.3)	16 (55.2)	10 (34.5)	5 (17.2)	3 (10.3)							
Patient navigation	2 (4.7)	15 (34.9)	16 (37.2)	5 (11.6)	28 (65.1)	1 (2.3)	3 (12.0)	11 (44.0)	13 (52.0)	4 (16.0)	15 (60.0)	NA	NA	1 (3.3)	13 (43.3)	4 (13.3)	5 (16.7)	8 (26.7)							
Pain & palliative care	43 (100.0)	35 (81.4)	17 (39.5)	22 (51.2)	2 (4.7)	6 (14.0)	24 (88.9)	22 (81.5)	13 (48.1)	9 (33.3)	4 (14.8)	4 (14.8)	2 (6.9)	2 (6.9)	3 (10.3)	2 (6.9)	NA	15 (51.7)							
Employment/ vocational assistance	3 (6.8)	1 (2.3)	21 (47.7)	4 (9.1)	5 (11.4)	18 (40.9)	NA	NA	11 (40.7)	NA	NA	16 (59.3)	NA	1 (3.7)	2 (7.4)	NA	1 (3.7)	17 (63.0)							
Individual or family counseling	17 (37.8)	11 (24.4)	23 (51.1)	39 (86.7)	4 (8.9)	6 (13.3)	3 (11.5)	3 (11.5)	18 (69.2)	14 (53.8)	NA	6 (23.1)	3 (10.3)	3 (10.3)	14 (48.3)	11 (37.9)	NA	6 (20.7)							
Telephone counseling	6 (13.6)	16 (36.4)	21 (47.7)	19 (43.2)	7 (15.9)	9 (20.5)	3 (11.1)	12 (44.4)	16 (59.3)	7 (25.9)	6 (22.2)	6 (22.2)	6 (20.7)	3 (10.3)	16 (55.2)	6 (20.7)	3 (10.3)	7 (24.1)							
Online support groups	NA	3 (6.7)	6 (13.3)	3 (6.7)	2 (4.4)	7 (15.6)	NA	NA	NA	1 (4.0)	NA	8 (32.0)	1 (3.6)	NA	6 (21.4)	1 (3.6)	1 (3.6)	10 (35.7)							
Insurance assistance	1 (2.3)	7 (15.9)	42 (95.5)	NA	13 (29.5)	4 (9.1)	2 (7.4)	2 (7.4)	23 (85.2)	1 (3.7)	6 (22.2)	4 (14.8)	NA	NA	6 (20.7)	NA	2 (6.9)	17 (58.6)							
Financial assistance	NA	8 (18.2)	42 (95.5)	4 (9.1)	9 (20.5)	9 (20.5)	1 (3.7)	6 (22.2)	22 (81.5)	NA	7 (25.9)	8 (29.6)	NA	NA	5 (16.7)	NA	3 (10.0)	20 (66.7)							
Housing assistance	NA	2 (4.7)	38 (88.4)	NA	9 (20.9)	11 (25.6)	NA	2 (7.7)	18 (69.2)	NA	3 (11.5)	9 (34.6)	NA	NA	2 (6.7)	NA	2 (6.7)	19 (63.3)							
Complementary therapies	14 (30.4)	21 (45.7)	16 (34.8)	29 (63.0)	2 (4.3)	15 (32.6)	9 (33.3)	11 (40.7)	12 (44.4)	12 (44.4)	1 (3.7)	9 (33.3)	2 (7.1)	4 (14.3)	14 (50.0)	12 (42.9)	NA	4 (14.3)							
Psycho-educational programs	7 (15.6)	23 (51.1)	27 (60.0)	25 (55.6)	7 (15.6)	10 (22.2)	5 (18.5)	10 (37.0)	21 (77.8)	13 (48.1)	5 (18.5)	5 (18.5)	5 (18.5)	3 (10.7)	15 (53.6)	12 (42.9)	1 (3.6)	6 (21.4)							
Transportation assistance	1 (2.2)	4 (8.7)	38 (82.6)	3 (6.5)	9 (19.6)	8 (17.4)	1 (3.8)	2 (7.7)	19 (73.1)	NA	4 (15.4)	8 (30.8)	NA	1 (3.4)	5 (17.2)	NA	NA	17 (58.6)							
Sexual health counseling	27 (60.0)	25 (55.6)	12 (26.7)	23 (51.1)	4 (8.9)	8 (17.8)	15 (55.6)	16 (59.3)	12 (44.4)	12 (44.4)	4 (14.8)	4 (14.8)	4 (14.8)	2 (6.9)	4 (13.8)	10 (34.5)	NA	5 (17.2)							
Appearance/ body image programs	4 (9.1)	14 (31.8)	23 (52.3)	13 (29.5)	8 (18.2)	16 (36.4)	2 (7.4)	9 (33.3)	14 (51.9)	5 (18.5)	5 (18.5)	7 (25.9)	1 (3.4)	3 (10.3)	7 (24.1)	3 (10.3)	NA	7 (24.1)							
Nutrition information/ counseling	10 (23.3)	17 (39.5)	5 (11.6)	4 (9.3)	2 (4.7)	2 (4.7)	8 (29.6)	14 (51.9)	7 (25.9)	NA	2 (7.4)	4 (14.8)	1 (3.3)	3 (10.0)	4 (13.3)	2 (6.7)	1 (3.3)	8 (26.7)							
Exercise/fitness info/counseling	8 (19.0)	15 (35.7)	6 (14.3)	8 (19.0)	4 (9.5)	7 (16.7)	6 (23.1)	12 (46.2)	7 (26.9)	1 (3.8)	1 (3.8)	16 (61.5)	1 (3.3)	2 (6.7)	5 (16.7)	1 (3.3)	1 (3.3)	9 (30.0)							
Smoking cessation	15 (35.7)	22 (52.4)	11 (26.2)	17 (40.5)	6 (14.3)	8 (19.0)	8 (32.0)	9 (36.0)	7 (28.0)	8 (32.0)	1 (4.0)	10 (40.0)	2 (6.9)	1 (3.4)	NA	1 (3.4)	NA	14 (48.3)							

patient service organizations (48%) conduct such screening. Open-ended interviews were the most common approach to psychosocial assessment (88% of comprehensive centers, 82% of community-based centers, and 100% of patient service organizations), followed by administration of a distress measure (72%, 68%, and 42%, respectively). Of the 64 institutions reported as not conducting psychosocial screening, the most common barrier was inadequate staffing, with 26 institutions (41%) indicating this to be the case. Lack of administrative support (28%) and lack of funding (23%) were the next most common barriers. Twelve respondents (19%) indicated that their institutions did not have a strategy to implement psychosocial screening and six cited staff resistance (9%).

Discussion

Consistent with the findings of the 2008 IOM report [1], a broad range of supportive services are offered for cancer patients. Although a multidisciplinary cohort of oncology health professionals delivers these services, the diverse sample of survey respondents (nurses, social workers, psychologists, chaplains) agreed that social workers were the primary providers of oncology psychosocial services. Most respondents indicated that support services are offered at no charge, with funding from a variety of sources, most notably institutional funds. The ratio of funding sources varied by setting, with comprehensive cancer centers being more diversified but relying most heavily on institutional funds and fee for service. Holland has noted the inadequacy of reimbursement for billed psychosocial services [4], a difficulty for organizations that depend on fee for service income. The dependence on institutional funds is unchanged from the Coluzzi report on services delivered in NCI-designated cancer centers [3]. Community-based treatment centers rely most heavily on institutional funds, and patient advocacy organizations rely most heavily on philanthropic funds.

Unfortunately, most organizations providing care to cancer patients have not adapted their educational materials and psychosocial/behavioral health services for a culturally or linguistically diverse patient population. Furthermore, respondents indicated that language and cultural barriers are noteworthy obstacles to providing psychosocial care for minority patients. With racial and ethnic minority populations nearing 50% of the US population, these findings are troubling and represent a major shortcoming in oncology care in the USA. They are also consistent with the IOM report suggesting that psychosocial care for minorities is inadequate [1].

Despite the recommendation that all cancer patients be screened for distress [5] and anticipation of the

American College of Surgeons' Commission on Cancer mandate for routine distress screening [6], only about half of the settings represented in this survey do so. Comprehensive cancer centers were relatively less likely to perform routine screening than community-based centers. Furthermore, the method most endorsed for conducting screening—face-to-face interviews—while being methodologically valid, is inefficient and labor-intensive. Indeed, the most commonly identified barrier to screening was insufficient qualified personnel. It could be that some survey respondents confused psychological assessment (more likely to be conducted by interview) with distress screening, and thus the prevalence of distress screening may be even lower than reported here. Lacking screening, many cancer patients' distress may go unrecognized, and thus, unaddressed.

Although it is encouraging that a wide variety of psychosocial services are provided in cancer settings and communities, the provision of these services is variable. Given that a majority of cancer patients remain unscreened for psychosocial distress, it is likely that patients are not being linked with appropriate resources to meet their needs. An area for growth is the implementation of routine screening for distress. This will likely be facilitated by the adoption of the Commission on Cancer accreditation standard in 2015 [6]. Another critical area for growth and improvement is the tailoring of psychosocial services and educational materials for a culturally diverse population.

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