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African American Patients' Psychosocial Support Needs and Barriers to Treatment: Patients' Needs Assessment

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Abstract

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The authors declare that they have no conflict of interest.

This study assessed adult patient's psychosocial support needs and treatment barriers in an urban diverse cancer center. A needs assessment was conducted with a convenience sample of adult oncology patients (n=113; 71.7% African American). Most patients were parenting school-age children and worried about them (96%); 86.7% would attend a family support program. Among patients who were married or partnered (68%), 63.7% were concerned about communication, coping, and emotional support; 53.9% would attend a couple support program. Patients identified similar treatment barriers: transportation, babysitting for younger children, convenience of time/place, and refreshments. Findings suggest behavioral healthcare providers should be available to screen cancer patients and improve access to appropriate psychosocial oncology support programs.

Keywords

Couple and Family-Based Support Programs; Needs Assessment; Psychosocial Oncology Support

Background

The diagnosis and treatment of cancer is associated with considerable psychosocial distress for both patients and their families [1, 2]. This is especially true during active treatment because cancer patients often report: 1) worry/fears about health outcomes, 2) changes in physical appearance, 3) changes in relationships, 4) financial issues, 5) changes in roles at home and, 6) emotional challenges [3,4,5,6]. Both patients and their family members report experiencing distress, especially partners/spouses of cancer patients [7], and school-age children [8, 9].

Patient assessment of needs is an important first step for identifying psychosocial issues that could impact treatment and recovery, especially among historically underserved populations [10, 11]. Psychosocial oncology support programs should be informed by what matters to patients so support services: 1) respect the patient's and family's values, culture, and needs; 2) provide physical comfort and emotional support; 3) ensure information, education, and communication; 4) involve family and friends; and, 5) remove treatment barriers to improve access to care [3, 12].

Needs assessments are important for program planning because patients do not always communicate psychosocial concerns to their oncology treatment teams [13, 14] and providers are often more focused on treating the cancer and not how patients and family members at home are coping [15]. Cancer patients have physical, psychosocial, and informational needs during all stages of cancer care [15, 16], therefore, psychosocial support programs should be developed to meet these needs. The primary aim of this descriptive needs assessment study was to assess for couple and family-based psychosocial support needs and to understand treatment barriers for future psychosocial support program planning at a northeastern urban racially and socioeconomically diverse cancer center. In this paper we describe findings from an anonymous cross-sectional patient needs assessment with a convenience sample of primarily African American (AA) cancer patients (n=113; 71.7% AA).

Couple and Family Oncology Psychosocial Support Services

In 2014 there were approximately 1.6 million new cases of cancer [1] which affected not only the diagnosed patient, but also their partners/spouses and children. Prior research suggests it is possible to positively impact psychosocial outcomes (e.g., psychological distress, marital satisfaction, and parent-child relationship) for couples in which a partner has cancer [17, 18] and for school-age children coping with parental cancer [19, 20]. Many psychosocial support programs for couples coping with cancer have been developed and evaluated. Badr and Krebs [17] conducted a systematic review (n=23 studies) and a meta-analysis (n=20 studies) and reported that couple-based interventions help to improve both patients' and partners' quality of life, in particular physical, psychological and relationship outcomes [17]. Similarly Regan and colleagues [18] reviewed 23 couple-based psychosocial intervention studies and reported they help to improve couple communication, psychological distress, and relationship functioning. Yet one weakness of these interventions is the lack of inclusion of racially and socioeconomically diverse samples of couples; most participants are white and have higher levels of education. As a result, the generalizability of couple-based psychosocial cancer interventions is uncertain until more programs are developed and evaluated with diverse populations.

Additionally, approximately 20% of adults within two years of an initial cancer diagnosis are parenting children 18 years of age and younger [21]. Parents who are coping with cancer tend to be less psychologically available, struggle with supervising and being consistent with discipline, and could display irritability, and coerciveness which are all associated with behavioral, social, and self-esteem problems in children [8]. Children and adolescents report experiencing sadness, worry, and fears about their parents' mortality [9]. Older school-age children (ages 12-18) report parents are more irritable throughout treatment and feel an obligation to care for their parents, younger siblings at home, and help out with family routines. Consequently, children may experience increased physical symptoms (e.g., headaches, gastrointestinal distress), family conflict, and less family cohesion. Both structured peer support groups and family-based prevention programs have been developed [19]. Yet most family-based oncology support programs have included white middle-class samples. Thus, to date most couple and family-based oncology support programs have not been evaluated with racially and socioeconomically diverse populations coping with cancer [10, 12].

Cancer Health Disparities and Culturally Sensitive Support Services

Racial and socioeconomic factors influence cancer health disparities [11]. Black men and women in the U.S. have a higher incidence and increased mortality for most types of cancer [1]. White women more often develop breast cancer, but black women have a greater chance of being diagnosed with more aggressive, advanced-stage breast cancer and are more likely to be diagnosed at a younger age and consequently tend to have a worse prognosis [1, 11]. Both black women and men have a higher incidence of colon cancer; black men have a higher incidence of prostate cancer at all ages. Hispanics have lower prevalence rates for all cancers combined when compared to Whites, but generally have higher rates of infection-related types of cancer including uterine, cervix, liver, gallbladder, and stomach cancer.

Minority populations living in the U.S. (e.g., African Americans, Hispanic Americans, Asian Americans, and Native Americans/Alaskan Natives) have a higher total incidence of cancer and higher total death rates compared to Whites [1].

There are also socioeconomic cancer health disparities in the U.S. Individuals living in areas where 20% percent or more are below the poverty line have cancer mortality rates that are 13% higher than individuals who live in more affluent counties [22]. Patients who live in less affluent areas have lower five-year survival rates [22]. Lack of medical coverage, barriers to early detection and screening, and unequal access to improvements in cancer treatment help to explain some of these differences in survival [11]. Additionally, approximately half of cancer survivors (46%) are 70 years old or older because cancer is more commonly diagnosed in older individuals, but is also steadily increasing among minorities [1]. Consequently, distress levels are likely to be higher in these groups.

Psychosocial and supportive care interventions should attend to needs related to race/ethnicity, gender, literacy, and socio-economic variables. Unfortunately, many minority cancer patients underutilize oncology support programs. Researchers suggest a perceived lack of cultural sensitivity and institutional and structural barriers to participation help to explain underutilization of psychosocial oncology support services [10, 12]. Although differences in attitudes, daily functioning, and levels of distress among different ethnic and racial groups are well-documented, most psychosocial support services have not been evaluated or tailored for culturally diverse cancer populations [11,12]. A better understanding of the psychosocial support needs and barriers to treatment can help to inform the development of culturally sensitive couple and family-based oncology support services. This can help to improve treatment engagement, retention, and satisfaction among racially and socioeconomically diverse cancer patients and their families.

In order to improve service utilization by this vulnerable population, we need to first understand their needs, preferences, and barriers to treatment. Conducting need assessments with diverse samples of patients are an important first step for developing appropriate services [3, 15, 16, 23]. The primary aim of this needs assessment study was to survey a racially diverse sample of cancer patients to better understand patients' psychosocial support needs and treatment barriers in a northeastern urban cancer center. We conducted an anonymous patient needs assessment (N=113) to understand the support needs and treatment barriers of a primarily AA sample of cancer patients who are resource poor at an urban minority cancer center.

Methods

Study Design

In summer 2014, after receiving Institutional Review Board approval at the authors' institutions to gather needs assessment data, we anonymously surveyed a primarily AA sample of 113 oncology patients. In the next section we describe the inclusion criteria and measure used for the patient needs assessment.

Patient Needs Assessment

We conducted an anonymous patient needs assessment with a convenience sample of inpatient (n=41), outpatient (n=65), and palliative care cancer patients (n=7) to assess for psychosocial couples and family support and to understand barriers to attending psychosocial support programs (e.g., location of group, transportation). The sampling frame for the patient needs assessment included any adult oncology patient (ages 18 and older) currently receiving care at a northeastern urban cancer center. Specific inclusion criteria included: 1) ability to read and answer a self-report survey in English, 2) over 18 years of age, and 3) currently receiving care at the network of oncology clinics. All information collected from participants preserved patients' anonymity and had no identifying information. Regarding our approach to sampling, inpatients were screened by a chart review of age and social history, and by talking to nursing staff who are often more aware of parenting or marital status and household members of patients under their care. Outpatients were screened at the time of a clinic visit by the social worker, nurse, or mid-level provider gathering standard information about the patient's home resources and support. Potential participants were assured that participation in this study would not have direct implications for their oncology care. All participants were informed this needs assessment study was being conducted to improve oncology support programs; there was no compensation offered for participation.

Some sample questions included in the patient needs assessment are: 1) What is your age, gender, race, ethnicity, job status, current marital/relationship status?; 2) If you answered yes, you currently live with your partner or spouse, please choose one response that describes your level of concern about the following areas: a) How much do you think your partner/spouse has been affected by the cancer? b) How well my partner and I currently talk about the illness and how we are both coping with the treatment; c) Emotional support that my partner and I are providing to each other. If you have children between the ages of 12 to 18 living at home: 1) How much do you think your children have been affected by the cancer: 2) Because of the cancer I am concerned about talking about the illness with 1 or more children at home: 3) Because of the cancer I am concerned about helping/participation in household activities from one or more children at home; 4) Because of the cancer I am concerned about coping or emotional well-being of 1 or more children at home; 5) How interested are you and your children in receiving support services; 6) How interested are you in coming to a family support program where parents and children come in together?; and, 7) What are the things you would need to help attend a support program?

Data Analysis

This study was primarily exploratory in nature, so only descriptive statistics are presented here, however, we also compared responses by gender, race (black/not black), and Hispanic ethnicity using Kruskal-Wallis tests. Due to the substantial number of tests performed (33 tests) we applied a Bonferroni adjustment to test p-values ($\alpha = .05 / 33 = .00152$). None of the comparisons pointed to statistically significant differences across these stratifying variables and so results are reported only for the overall sample. Patient need assessment data was first entered and verified against the completed questionnaires, using SPSS 21.0. Frequencies, range checks, and descriptive statistics (e.g., M, SD) as appropriate to the level of

measurement were evaluated for patient needs assessments to ensure accuracy and logical consistency.

Results

Patient Needs Assessment Findings (N=113)

Regarding the demographic profile of the convenience sample of 113 patients who completed the anonymous needs assessment (see Table 1), more than half (57.5%) were from outpatient, 36.3% were from inpatient, and 6.2% were from palliative care clinics. Most were African American (71.7%), 27.4% were White, and 4.4% were Asian; 15% were Latino. More than half were female (66.4%) and ages ranged from 28 to 67 years old, with an average age of 45. Approximately half (54%) reported no more than a high school degree, with the remaining reporting some college to graduate or professional degrees. Approximately one-third (37.2%) reported being employed full-time, 12.4% not working, 8% employed part-time, 5.3% raising children at home, 31.9% disabled, and 3.5% retired, suggesting that this is a low to middle income sample of patients.

Among patients (n=108 out of 113) who reported currently parenting school-age children at home (see Table 2): 1) 14.2% reported their school age children are somewhat, 33.4% are a lot affected, 28.3% are very much, and, 4.4% are the most possible affected by their cancer; 2) 19.5% reported because of the cancer they are somewhat, 34% reported they are a lot, 23% reported they are very much, and 15% reported they are the most possible concerned about talking about the illness with one or more children at home; 3) 38.9% reported that because of the cancer they are somewhat, 15.9% are a lot, 6.2% are very much, and 2.7% are the most concerned about how much household/childcare help children are providing at home; 4) 11.5% are somewhat, 35.4% are a lot, 28.3% are very much and 17.7% are the most possible concerned about coping or the emotional well-being of one or more children at home; 5) 25.7% are somewhat, 26.5% are a lot, 22.1% are very much, and 14.2% are the the most possible interested in receiving support services; and, 6) 45.1% are somewhat, 23% are a lot, 10.6% are very much, and 8% are the most possible interested in coming to a family support program with their children.

Approximately half reported being married (49.6%), 16.8% were in a relationship but not married, 11.5% were single and never married, 17.7% were divorced or separated, and 2.7% were widowed at the time of completing the survey. Finally, most patients (96.6%) reported raising children between the ages of 12 to 18 at home. Among the 77 patients who reported being in a committed relationship: 1) 6.2% reported somewhat, 25.7% reported a lot, 21.2% reported very much, and 13.3% reported partners are the most possible affected by cancer; 2) 15% reported somewhat, 15.9% reported a lot, 20.4% reported very much, and 12.4% reported the most possible concerned about communication and coping with their partners; 3) 6.2% reported somewhat, 20.4% reported a lot, 21.2% reported very much, and 15.9% reported the most possible concerned about the level of emotional support provided to each other; and, 4) 29.2% reported somewhat, 15% reported a lot, 5.3% reported very much, and 4.4% reported the most possible interested in attending a couple support group with their partners.

Additionally, approximately half (51.3%) reported it does not matter if psychosocial support programs occur at the hospital or in another clinic, 9.7% preferred attending a program at the hospital where they currently receive care, and 30.1% felt having support programs at a location other than the cancer center would provide a more comfortable environment for their children. Finally, 87 out of the 113 patients provided a number of recommendations to remove treatment barriers, for example: 1) childcare (13.3%); 2) train/bus fare (25.7%); 3) convenient time and place (23.9%); 4) refreshments at the groups (8.9%); and, 5) convenient parking (2.7%).

Discussion

A cancer diagnosis followed by diagnostic planning, discussion, and treatment are stressful experiences that affect patients' physical and psychological health and are linked to negative outcomes such as poor treatment compliance, quality of life, and satisfaction with care [3, 5, 6]. In busy oncology clinics, patients and families at significant risk for distress will not be identified, if they are not routinely screened [13, 23]. Psychosocial screening and needs assessments during acute cancer care has been gaining attention in clinical practices, especially in clinical oncology settings [5]. There is a shift in medical reimbursement toward revenue schedules linked to value-based care [24]. Patient and family satisfaction scores factor into reimbursement which has led more oncology clinics to routinely assess for underlying psychosocial factors and barriers that can impact patients' levels of psychosocial support in acute cancer care [24].

The primary aim of this descriptive study was to assess for couple and family-based psychosocial support needs and treatment barriers for future program planning at an urban racially and socioeconomically diverse cancer center. Patient assessments are especially important among historically underserved populations to facilitate the identification, referral, and retention of patients and families who may respond better to culturally sensitive support services [10, 11, 12]. An anonymous cross-sectional patient needs assessment with a convenience sample of primarily AA adult oncology patients (n=113) was conducted.

Most patients in this sample (n=108 out of 113) were parents or guardians of school-aged children. Our results suggest AA parents/guardians with current concerns about their school-age children were more interested in attending a family support group. Parenting adolescents can be challenging under the best of circumstances; AA families may have additional stressors based on economic and social factors [11, 19, 20]. Navigating and adapting to the additional burdens of parental cancer will impact the ability of families to cope; providing culturally sensitive support programs can lead to better quality of life and outcomes. Parents with potential interest needing help with transportation, parking, babysitting for younger children, convenient times/places, refreshments, and for some parents there was a preference for meeting outside of the cancer center so their children would be more comfortable. Assessing needs before developing psychosocial support programs demonstrates a commitment to the patient/family experience [12, 16]. Additionally, most patients who were married or partnered (n=77) reported their partners were affected by the cancer and were concerned about how they were coping. Noteworthy, most (70%) were interested in attending a couple support group program. This is important because couple

distress is associated with impaired parenting practices [25]. Notably, patients identified similar needs and treatment barriers to overcome (e.g. transportation, child-care) that would support participation in couple and family-based oncology support services.

Screening and needs assessment tools should facilitate more open communication by giving patients and families a chance to express concerns about their partners/spouses and children at home, and to identify logistical or material needs [3, 13]. Results of needs assessments and psychosocial assessments should then be shared with the patient and his/her health care team. An appropriately trained healthcare provider (or team) should then confirm patients' needs, develop a patient and family-centered treatment plan, and monitor both medical and psychosocial outcomes. The assessment and recommendations should be readily accessible (e.g. in the Electronic Medical Record) to facilitate communication between providers and patients [13]. Although baseline needs assessments are most often self-reported, mechanisms for review at several levels (depending on the level of distress or need) should be provided within the system, as well as the capacity for response or intervention. This requires support from trained personnel, as well as a formal referral system that is responsive to patient and family needs.

Limitations to effective screening and response can also be hampered by patient health literacy, clinical access and reimbursement for mental health services, adding more appointments to an already stressed patient and their support system, and the potential for fractured care involving several different providers [3, 23]. Office visits may be very busy with patient registration activities, blood sampling, education or consent sessions in anticipation of cancer therapy, time with physicians or mid-level providers, scheduling visits, and dependent on time, travel or transportation flexibility. Finally, although very important, the identification and planning for psychosocial needs assessments during pivotal medical appointments (achieving remission, progression or recurrence of disease) may be overshadowed by discussions of data or events concerning the medical treatment of the cancer. Despite access to a variety of tools that can screen for patient and family psychosocial distress; more research is needed to identify feasible approaches that can be easily interpreted and directly inform care among diverse populations of patients, couples, and families coping with cancer [6, 16]. Attending to patients' needs will lead to better patient satisfaction, which is a key determinant of quality of care and an important component of pay-for-performance metrics [24].

Study Limitations

A limitation of our needs assessment study is that we used a non-probability approach to sampling with cancer patients. Second, we did not have access to data capturing the type and stage of cancer, however, these variables can be expected to influence patients' views about couple and family oncology support programs.

Conclusions

Oncology support programs that help couples and children cope with the impact of cancer are urgently needed, particularly those designed to reach low-income AA populations. Based on our findings, we recommend making behavioral healthcare providers available to screen

cancer patients upon intake so both medical and psychosocial “vital signs” are assessed and integrated into oncology care. Using the anonymous patient needs assessment (N=113), we are now setting up feasible recruitment procedures for a culturally sensitive couple and family-based psychosocial oncology support program at our cancer center. Providing culturally sensitive psychosocial couple and family support has the potential to change the nature of treatment support options available to a group that is overrepresented and underserved by existing interventions and reduce potentially harmful distress.

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Table 1

Demographic Profile of Cancer Patients (N=113 Adult Cancer Patients).

Category	Frequency
Cancer Setting	
Inpatient	36.3% (n=41)
Outpatient	57.5% (n=65)
Palliative Care Clinic	6.2% (n=7)
Race	
White	27.4% (n=31)
Black/African American	71.7% (n=81)
Asian	4.4% (n=5)
Ethnicity	
Latino	15% (n=17)
Not Latino	81.4% (n=92)
Gender	
Female	66.4% (n=75)
Male	32.7% (n=37)
Age	
39 or below	34.2% (n=38)
40 to 49	37% (n=41)
50 to 59	21.6% (n=24)
60 or above	5.4% (n=8)
Highest level of education completed	
Less than high school	18.6% (n=21)
High school	35.4% (n=40)
Some college or associates degree	17.7% (n=20)
Bachelors degree	20.4% (n=23)
Graduate or professional degree	7.1% (n=8)
Current job status	
Not working or unemployed	12.4% (n=14)
Employed part-time	8.8% (n=10)
Employed full-time	37.2% (n=42)
Homemaker, raising children or others	5.3% (n=6)
Disabled	31.9% (n=36)
Retired	3.5% (n=4)
Current marital status	
Single, never married	11.5% (n=13)
Currently Married	49.6% (n=56)
Divorced or separated	17.7% (n=20)
Not married but in a relationship	16.8% (n=19)

Category	Frequency
Widow	2.7% (n=3)
Do you have children between 12 and 18 at home?	
Yes	95.6% (n=108)
No	3.5% (n=4)

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Table 2

Cancer Patients: Psychosocial Family and Couple Needs Assessment (N=113).

Category	Frequency
How much do you think your partner/spouse has been affected by the cancer?	
Not at all	.9% (n=1)
A little	.9% (n=1)
Somewhat	6.2% (n=7)
A lot	25.7% (n=29)
Very much	21.2% (n=24)
The most possible	13.3% (n=15)
Because of the cancer I am concerned about how well my partner and I are talking about the illness and how we are coping with cancer treatment	
Not at all	.9% (n=1)
A little	3.5% (n=4)
Somewhat	15% (n=17)
A lot	15.9% (n=18)
Very much	20.4% (n=23)
The most possible	12.4% (n=14)
Because of the cancer I am concerned about emotional support that my partner and I are providing each other	
Not at all	.9% (n=1)
A little	3.5% (n=4)
Somewhat	6.2% (n=7)
A lot	20.4% (n=23)
Very much	21.2% (n=24)
The most possible	15.9% (n=18)
How interested are you in coming to a couple support program where you and your partner come in together?	
Not at all	6.2% (n=7)
A little	8% (n=9)
Somewhat	29.2% (n=33)
A lot	15% (n=17)
Very much	5.3% (n=6)
The most possible	4.4% (n=5)
How much do you think your children (ages 12-18) have been affected by the cancer	
Not at all	.9% (n=1)
Somewhat	14.2% (n=16)
A lot	35.4% (n=40)
Very much	28.3% (n=32)
The most possible	16.8% (n=19)

Category	Frequency
Because of the cancer I am concerned about talking about the illness with one or more children at home	
Not at all	2.7% (n=3)
A little	.9% (n=1)
Somewhat	19.5% (n=22)
A lot	34.% (n=39)
Very much	23% (n=26)
The most possible	15% (n=17)
Because of the cancer I am concerned about helping/participating in household activities from one or more of my children at home	
Not at all	12.4% (n=14)
A little	19.5% (n=22)
Somewhat	38.9% (n=44)
A lot	15.9% (n=18)
Very much	6.2% (n=7)
The most possible	2.7% (n=3)
Because of the cancer I am concerned about coping or emotional well-being of one or more children at home	
Not at all	1.8% (n=2)
A little	.9% (n=1)
Somewhat	11.5% (n=13)
A lot	35.4% (n=40)
Very much	28.3% (n=32)
The most possible	17.7% (n=20)
How interested you and your children (ages 12-18) in receiving support services?	
Not at all	1.8% (n=2)
A little	5.3% (n=6)
Somewhat	25.7% (n=29)
A lot	26.5% (n=30)
Very much	22.1% (n=25)
The most possible	14.2% (n=16)
How interested are you in coming to a family support program with your children?	
Not at all	4.4% (n=5)
A little	4.4% (n=5)
Somewhat	45.1% (n=51)
A lot	23% (n=26)
Very much	10.6% (n=12)
The most possible	8% (n=9)
Would you rather attend a program at the hospital or at another clinic?	
Attend program at hospital	9.7% (n=11)

Category	Frequency
Attend program at another clinic	30.1% (n=34)
It does not matter to me	51.3% (n=58)
What would you need to help attend a family support program?	
Tokens/bus fare	1.8% (n=2)
Childcare	6.2% (n=7)
Convenient time	17.7% (n=20)
Convenient time and place	6.2% (n=7)
Food and vouchers	1.8% (n=2)
Program description	13.3% (n=15)
Child care, tokens, and food	7.1% (n=8)
Program content and parking	2.7% (n=3)
Kids separate from parents in intervention	2.7% (n=3)
Tokens, convenient time, food	16.8% (n=19)
Missing data	23.9% (n=27)

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