Importance of and Satisfaction with Psychosocial Support among Cancer Patients and Survivors in Puerto Rico: Gender, Health Status, and Quality of Life Associations

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Objective: To assess needs perceptions regarding the importance of and satisfaction with psychosocial support among cancer patients and survivors in Puerto Rico.

Methods: A cross-sectional study was conducted in 181 participants (70 men and 111 women) who were either undergoing cancer treatment (patients) or had completed cancer treatment (survivors). Participants completed a sociodemographic and clinical characteristics questionnaire, and the Psychosocial Needs Inventory (PNI).

Results: The participants reported having or having had prostate (36%) or breast (32%) cancer or some other cancer type (32%). Of the 149 participants reporting cancer type, 130 were classified as having a high perceived level of health and quality of life, and 19 were classified as having a low perceived level of health and quality of life. In terms of perceived needs, the highest level of importance were assigned to the Support Network (e.g. family, friends, neighbors, care professionals; M = 2.88, SD = 0.43) and Health Professional (e.g., patient–health professional relationship, etc.; M = 2.80, SD = 0.50) categories, and the Emotional and Spiritual category was given the lowest importance (e.g., help managing negative emotions and spiritual counseling, etc.; M = 2.62, SD = 0.66). These perceptions varied by gender, perceived health status, and date of diagnosis. Women assigned more importance to the Health Professional and Information categories.

Conclusions: The results reflect the importance of considering psychosocial needs when providing psychosocial support to cancer patients and survivors. These findings are anticipated to inform services provided by psychosocial oncology support programs in Puerto Rico. [PR Health Sci J 2017;36:205-211]

Key words: Psychosocial Needs, Cancer, Puerto Rico

According to a report published by the American Cancer Society, 1 in 3 Hispanics (both men and women) will be diagnosed with cancer in their lifetime (1). In Puerto Rico, the cancer incidence has been increasing at a rate of 0.3% per year (2). The most common cancer types are prostate (men), breast (women), and colorectal (men and women) cancers (3). A cancer diagnosis and the associated treatments may result in numerous symptoms and complications that have a significantly negative effect on an individual patient’s health-related quality of life (HRQoL) (4–8). Given the increasing cancer incidence rates in Puerto Rico and the burden of disease as it relates to the HRQoLs of individual patients, there is growing scientific interest in studying the perceived psychosocial needs of Hispanic cancer patients. This trend has also generated government-based initiatives to promote cancer-specific psychosocial support programs to improve patients’ HRQoLs (9–11).

Gender and cultural differences can play important roles in the psychosocial needs of cancer patients (12–14). For example, Tsuchiya and Horn (15) reported that Japanese women with breast cancer value the capacity to remain autonomous throughout the decision-making process, and they desire physical and emotional support from their physicians.
Other studies have identified gender differences in emotional expression and whether or not psychosocial needs are being addressed. For example, women tend to report 2-fold higher cancer-related burden and stress levels than are reported by men (16–17).

Studies have identified several common needs of cancer patients, such as cancer-related health information and emotional and social support (18). However, it is important to consider population-specific differences and priorities when characterizing the psychosocial needs of cancer patients (15). While there is extensive research on patient needs for cancer-specific psychosocial support in general (19–21), less is known about cancer patients in Puerto Rico. When psychosocial needs are identified and addressed, HRQoL can be significantly improved (22).

A qualitative study conducted by members of our team (23) revealed that healthcare providers in southern Puerto Rico were concerned about potential unmet psychosocial needs in cancer patients. They identified needs such as transportation, financial support, social support, and education regarding both cancer care and cancer prevention, as well as the need for access to professional psychosocial support services. A study conducted by Castro et al. (24) revealed a potential gap in the communication about and integration of clinical cancer care services and supportive services for cancer patients and survivors in Puerto Rico. This is inconsistent with the Institute of Medicine (IOM) recommendations (25) that detail the advisability of addressing the psychosocial needs of cancer patients and survivors through the use of integrated healthcare systems. Thus, one way to improve the delivery of psychosocial support services to cancer patients and survivors in Puerto Rico is to identify the psychosocial needs of those patients and survivors, along with their levels of satisfaction with the fulfilling of such needs.

The purpose of the current study was to assess perceptions regarding psychosocial needs and the perceived importance of and satisfaction with psychosocial support among cancer patients and survivors living in southern Puerto Rico. Additionally, we explored whether the importance of and satisfaction with psychosocial support differed based on gender, clinical characteristics, perceived health status (PHS), or perceived health-related quality of life (PHRQoL).

Patients and Methods

A cross-sectional exploratory study was conducted with a convenience sample of 181 cancer patients and survivors (70 men and 111 women, belonging to both groups) living in southern Puerto Rico (Table 1). The inclusion criteria were that a participant be 21 years of age or older, a self-reported cancer patient or survivor, and willing and able to provide informed consent. The Ponce School of Medicine’s Institutional Review Board approved the study.

Recruitment

Recruitment sites included outreach activities focusing on cancer education, cancer fundraising events, and private oncology and radiation clinics. At educational and fundraising events, flyers were distributed with information about the study objectives and inclusion criteria. At the oncology and radiation therapy clinics, designated administrative personnel provided patients with the study’s informational flyer. Those interested in study participation were instructed to contact the research personnel, who were located in a private area of each recruitment site. The potential participants were screened in person.

Procedure

After discussing the study’s objectives and procedures with a member of the research team, the potential participants provided informed consent and completed a packet of self-report questionnaires (described in the next section). The duration of this process was approximately 25 minutes. No incentives were provided to participants.

Instruments

Psychosocial Needs Inventory (PNI; Spanish Version)

The PNI was selected based on its psychometric properties and the fact that it measures variables of interest in the current study. Prior to its use in the current study, the PNI was adapted by Eida Castro. The unpublished adaptation process involved the instrument’s translation and revision by Spanish-speaking experts in the field. The PNI is a 48-item self-report instrument that assesses 7 needs categories (26). Within each category, the questionnaire assesses the perceived importance of and satisfaction with various aspects of psychosocial support. The Health Professional needs category (9 items) focuses on access to and interactions with healthcare professionals. The Information category (5 items) relates to access to and provision of cancer-specific health information. The Support Network category includes 5 items related to support provided by family, friends, healthcare providers, and neighbors. The Identity category (5 items) assesses issues with body image, body changes, and an individual’s sense of control. The Emotional and Spiritual category (15 items) relates to feelings of guilt, anger, loneliness, fear, sadness, and hope, as well as exploring sense of purpose and meaning and prayer, among others. The Practical dimension (8 items) evaluates practical needs and chores such as transportation, housework, financial matters, and completing forms. The Practical-child category is a 1-item dimension assessing the importance of and satisfaction with childcare needs.

The participants were asked to rate each item regarding how important it has been to them during the past few weeks (PNI importance scale) and how satisfied they have been with the way that item has been resolved in the past few weeks (PNI satisfaction scale). Importance was assessed using a 5-point Likert scale (1 = not important through 5 = very important) and satisfaction (1 = not satisfied through 5 = very satisfied).
adapted PNI (e.g., the Spanish version) demonstrated adequate consistency. The internal consistency alpha coefficients were 0.96 for the total scale and 0.97 and 0.96, respectively, for the 2 subscales of satisfaction and importance.

Sociodemographic and Clinical questionnaire

The sociodemographic and clinical questionnaire that we used is a 16-item instrument divided into 2 sections. Section I assesses sociodemographic variables such as gender, age, income, employment status, marital status, municipality of residence, religious practices (including presence or absence of), and whether the participant had an active role as a caregiver at the time of the study. Section II assesses clinical and health-related variables such as time of diagnosis, type of cancer, cancer treatment status (e.g. from newly diagnosed to end of life), type of oncology treatment received, perceived health status, and perceived health-related quality of life. PHS and PHRQL were measured through 2 questions: (for PHRQL) 1) How would you describe your quality of life in the past 2 weeks? and (for PHS) 2) How would you describe your health status in the past 2 weeks? For each of these questions, participants answered through a semantic difference scale ranging from 1 (poor PHRQL/PHS) to 7 (excellent PHRQL/PHS). Thus, a composite score was calculated for perceived health status and perceived health-related quality of life. The composite score was computed because PHS and PHRQL scores are strongly correlated ($r=0.70$). Furthermore, the participants’ responses tended to be grouped close to 7 or close to 1. The composite score was dichotomized into 2 levels: high perceived health status/quality of life (HP; ≥5 on both scales) and low perceived health status/quality of life (LP; ≤4 on both scales).

Data analysis

The sociodemographic variables were analyzed using descriptive statistics (for the total sample and by gender). Gender and perceived health quality of life comparisons were made to assess differences with respect to the importance of and satisfaction with psychosocial support, which was one of the objectives of this study. Comparisons by gender were assessed using Chi-square and t tests for independent samples. Comparisons between perceived health status and PNI scores were also assessed using Chi-square tests as well as with one-way analysis of variance (ANOVA) with Dunnett’s method. An alpha level consisting of a p-value lower than 0.05 was considered to be statistically significant.

Results

Sample characteristics

Table 1 displays participant sociodemographic characteristics for the total sample and by gender. Gender differences were found regarding with whom participants were living ($p<0.05$). Most participants reported living with a partner. Conversely, more women (26%) than men (9%) reported living with family or close friends. The majority of the participants reported being retired (52%), and when analyzed by gender, men were more likely to report being retired than women were (70% and 40%, respectively; $p<0.01$). Additionally, women (34%) reported being employed more frequently than men did (12%; $p<0.01$). Overall, 85% of the participants reported having a religious belief, and more women than men reported having a religious belief (92% and 75%, respectively; $p<0.01$).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Female n (%)</th>
<th>Male n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 59</td>
<td>79 (45)</td>
<td>60 (56)</td>
</tr>
<tr>
<td>≥ 60</td>
<td>95 (55)</td>
<td>47 (44)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>109 (61)</td>
<td>59 (54)</td>
</tr>
<tr>
<td>Single</td>
<td>15 (8)</td>
<td>10 (9)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>28 (16)</td>
<td>22 (20)</td>
</tr>
<tr>
<td>With partner, not married</td>
<td>8 (4)</td>
<td>6 (6)</td>
</tr>
<tr>
<td>Widow</td>
<td>19 (11)</td>
<td>13 (12)</td>
</tr>
<tr>
<td>Living</td>
<td>174</td>
<td>109</td>
</tr>
<tr>
<td>With a partner</td>
<td>108 (62)</td>
<td>61 (56)</td>
</tr>
<tr>
<td>With family or close friends</td>
<td>34 (20)</td>
<td>28 (26)</td>
</tr>
<tr>
<td>Alone</td>
<td>32 (18)</td>
<td>20 (18)</td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>45 (25)</td>
<td>37 (34)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>22 (12)</td>
<td>16 (15)</td>
</tr>
<tr>
<td>Retired</td>
<td>92 (52)</td>
<td>44 (40)</td>
</tr>
<tr>
<td>Other (not specified)</td>
<td>19 (11)</td>
<td>12 (11)</td>
</tr>
<tr>
<td><strong>Monthly income (USD)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 300.00</td>
<td>12 (13)</td>
<td>6 (13)</td>
</tr>
<tr>
<td>300.01 – 600.00</td>
<td>14 (15)</td>
<td>6 (13)</td>
</tr>
<tr>
<td>600.01 – 900.00</td>
<td>26 (28)</td>
<td>14 (30)</td>
</tr>
<tr>
<td>900.01 – 1200.00</td>
<td>12 (13)</td>
<td>6 (13)</td>
</tr>
<tr>
<td>≥ 1200.01</td>
<td>29 (31)</td>
<td>15 (32)</td>
</tr>
<tr>
<td><strong>Religious faith</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>152 (85)</td>
<td>100 (92)</td>
</tr>
<tr>
<td>No</td>
<td>26 (15)</td>
<td>9 (8)</td>
</tr>
<tr>
<td><strong>Care of someone else</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>47 (27)</td>
<td>34 (32)</td>
</tr>
<tr>
<td>No</td>
<td>126 (73)</td>
<td>73 (68)</td>
</tr>
</tbody>
</table>

*p<0.05  **p<0.01  ***p<0.001

Clinical and health-related characteristics

Several health-related variables were associated with the psychosocial needs of participants. This study included patients with all cancer types; however, 73 of 181 participants (40%) did not report cancer type. Of those who reported a tumor type (N = 108), 36% reported having had prostate cancer, 32% reported having had breast cancer, and 32% were categorized as having had some other type of cancer. The “other” category included the following cancer types: colorectal (3%), lung (5%), uterine (4%), lymphoma/leukemia (5%), oral cavity/oropharyngeal (2%), stomach (2%), ovarian (2%), and non-specified (9%). For the current analysis, participants were divided into 3 cancer-diagnosis categories: breast cancer, prostate cancer, and other.
Among the 149 participants who reported perceived health status and quality of life, 130 (87%) were classified as having HP, and 19 (13%) were classified as having LP. A comparison of gender and the classification of perceived health status/quality of life showed no significant association (in men, 88% were classified as HP [n = 51]; in women, 87% were classified as HP [n = 79]). Perceived health status/quality of life classification (HP or LP) was significantly associated with cancer type, (χ² [2, N = 149] = 6.13; p < 0.05). Overall, the cancer diagnosis distribution of those classified as HP was prostate cancer (39%), breast cancer (35%), and other cancer types (26%). The cancer diagnosis distribution of those classified as LP was other cancer types (67%), prostate cancer (22%), and breast cancer (11%).

Psychosocial needs

More than 84% of the participants who provided information about their psychosocial needs reported Support Network, Health Professional, Information, Identity, and Practical-child as their most important categories of need. Mean importance and satisfaction scores are presented in Table 3. The highest mean level of importance were assigned to the Support Network (2.88) and Health Professional (2.80) categories. The lowest mean level of importance was given to the Emotional and Spiritual category (2.62). The highest mean satisfaction level was given to the Support Network category (2.85), and the lowest mean level of satisfaction was given to the Identity category (2.57).

Psychosocial needs by gender

Mean importance and satisfaction were also analyzed by gender (Table 3). The mean levels of importance given to the Health Professional (t [171] = 2.15; p < 0.05) and Information (t [169] = 2.81; p < 0.01) categories differed significantly by gender. Female participants (M = 2.87, SD = 0.42) gave more importance to the Health Professional category than did male participants (M = 2.70, SD = 0.60), and men gave less importance to Information than women did (M = 2.59 and 2.83, respectively).

Psychosocial needs by clinical/health characteristics

Several clinical and health characteristics were assessed to identify whether they had an effect on the importance and satisfaction levels reported by participants. Satisfaction with the Emotional and Spiritual category varied significantly according to a given participant’s perceived health status (t [152] = 2.36; p < 0.05). Participants classified as having high levels of HP (M = 2.65, SD = 0.61) were more satisfied with the Emotional and Spiritual category than were those classified as having low levels of HP (M = 2.35, SD = 0.66). One-way ANOVA also revealed significant differences in satisfaction scores according to the diagnosis date (prior to 2000, 2000–2004, and 2005–2009). For example, satisfaction with the Health Professional category differed significantly when analyzed by date of diagnosis, (F [2,153] = 4.56; p < 0.05). The mean for Health Professional satisfaction was higher in those diagnosed from 2005 to 2009 (M = 2.77, SD = 0.52) than it was in those diagnosed from 2000 to 2004 (M = 2.42, SD = 0.72).

Satisfaction with the Information category was also significantly different among participants according to the diagnosis date (F [2,150] = 4.99; p < 0.05). The mean for the Information category was significantly higher among those diagnosed from 2005 to 2009 (M = 2.72, SD = 0.58) than it was in those diagnosed from 2000 to 2004 (M = 2.33, SD = 0.11). Moreover, satisfaction with
the *Practical* category differed significantly when analyzed by date of diagnosis ($F \ (2,142) = 4.05; \ p<0.05$). Follow-up tests confirmed significant differences in the *Practical* satisfaction mean scores between participants diagnosed from 2005 to 2009 ($M = 2.63, \ SD = 0.06$) and those diagnosed from 2000 to 2004 ($M = 2.30, \ SD = 0.11$).

Finally, satisfaction with the *Identity* category was significantly different among participants according to cancer type ($F \ (2,81) = 3.28; \ p<0.05$). Higher levels of satisfaction with the *Identity* category were reported by participants with other cancer types ($M = 2.71, \ SD = 0.62$) than were reported by those with prostate cancer ($M = 2.22, \ SD = 0.83$).

In sum, the findings of this study describe a sample, the members of which more frequently reported being married, being women, having religious beliefs, and being diagnosed between 2005 and 2009, as well as having completed their oncology treatments. The highest importance of needs was given to *Support Network*. Moreover, importance given to the *Health Professional and Information* categories was significantly higher in women than men. Furthermore, there are significant differences between groups classified by date of diagnosis regarding satisfaction with psychosocial needs.

**Discussion**

The results of this study reflect the importance of considering psychosocial needs when providing psychosocial support for cancer patients and survivors. These findings are anticipated to inform services provided by psychosocial oncology support programs in Puerto Rico.

Compared with men, women gave more importance to their interactions with healthcare professionals and to cancer-specific health information. Previous studies have shown that gender differences are important variables that may impact health perceptions and health outcomes (27–28). A population-based study ($N = 19,030$) that evaluated cancer patients’ information needs revealed gender differences in terms of the preferred type of cancer information sought (29). These differences reflect the importance of considering gender-specific needs when providing psychosocial support for cancer patients/survivors in Puerto Rico. Future studies in Puerto Rico are warranted to explore the interactions of these variables with the HRQoLs of patients and/or survivors.

For both men and women, the least important psychosocial need was related to emotional and spiritual issues. A qualitative study conducted by Baker and colleagues (30) showed that those who had not yet started cancer therapy accorded less importance to addressing emotional needs than did their counterparts who had started it, whereas patients undergoing cancer therapy acknowledged the importance of confronting emotional needs. In contrast, another qualitative study reported fear of cancer recurrence (FCR) or metastasis of cancer as the most dominant psychosocial issue (31). Furthermore, the Florida Initiative for Quality Cancer Care has shown changes in the psychosocial quality of care indicators where there has been increased identification of patients with emotional well-being-related problems (32). Some level of distress is normal at the time of diagnosis and during treatment; yet, untreated distress may eventually evolve into other psychiatric disorders (33–35). When patients do not recognize the importance of maintaining emotional health, it may be difficult to determine who will benefit from emotional support. Therefore, it is important to promote awareness about this issue.

Most participants were less satisfied with identity issues. Identity issues include changes in body image and sexuality and physical changes that are perceived to affect an individual’s sense of control. Ours is not the only study to report such findings: Others have demonstrated the need to address the issue of identity as it relates to both quality of life (36) and quality of care (37) in cancer patients. In order to address this challenge, we recommend the integration of healthcare and support services (24).

An interesting finding was that the levels of satisfaction with the PNI needs categories *Health Professional, Information,* and *Practical* were significantly related to date of diagnosis (2000–2004 vs. 2005–2009). There may be other unknown factors mediating and/or moderating these findings. Therefore, it is important to elucidate how such differences (in terms of satisfaction with the provision of these needs) may influence both healthcare service satisfaction (38) and the making of informed clinical decisions (38–43).

The analysis also explored whether cancer type was related to patient-perceived health/quality of life. Given that the “other” cancer type category contained many different diagnoses, we were unable to identify the specific cancer type associated with the perception of low health status/quality of life, thereby limiting further analyses. Health-status perception may be influenced by the burden of disease as reflected by physical and clinical variables. For example, a cross-sectional study conducted in Brazil ($N = 934$) revealed that the prevalence and intensity of chronic pain correlated with perceived health status in elderly patients (44). Similarly, another study, this one conducted with cancer survivors, showed that those who experienced disease progression reported lower perceived health status than did disease-free cancer survivors (45).

Considering the fact that the *Support Network* category had the highest importance rate, we strongly encourage clinics and community-based organizations in Puerto Rico to screen for social support needs and the type (or types) of support needed. If possible, we recommend having a list of community support resources (e.g. support groups, American Cancer Society, Puerto Rico, Susan G. Komen, Puerto Rico, etc.) available for referral. Moreover, we recommend that healthcare providers make sure health-information needs are met. Perhaps the inclusion of health educators in busy clinics may provide further health-information support. Finally, identity issues can be addressed with the integration and collaboration of other support services, such as palliative care (e.g. pain management), psychosocial care...
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(e.g., identity issues/self-esteem), and physical/occupational therapy, among others. To conclude, in order to address the psychosocial needs of Puerto Rican cancer patients and survivors, we need to make the necessary changes in the Puerto Rico health system to facilitate the integration of medical and psychosocial-support/ancillary services.

The limitations of this study include the generalizability of the results, the fact that it was a convenience sample, and that, as expected, the sample consisted predominantly of patients with and survivors of breast or prostate cancer. Another limitation was the large amount of missing data regarding the tumor types of the participants. Regardless of these limitations, we identified important associations that warrant further exploration. This study contributes to the body of research aimed at understanding the perceived importance of and satisfaction with psychosocial support among Puerto Rican cancer patients and survivors.

Resumen

Objetivo: Evaluar la importancia y satisfacción percibida respecto a las necesidades de apoyo psicosocial de pacientes oncológicos puertorriqueños. Método: Estudio transversal con una muestra de 181 participantes (70 hombres y 111 mujeres) en tratamiento oncológico (pacientes) o fuera del mismo (sobrevivientes). Los participantes completaron un cuestionario socio-demográfico y clínico e inventario de necesidades psicosociales (PNI, por sus siglas en inglés). Resultados: El 36% reportó un diagnóstico de cáncer de próstata, el 32%, un diagnóstico de cáncer de seno y el 32% informó otros tipos de cáncer. Entre los 149 participantes que informaron el tipo de cáncer, 130 fueron clasificados con percepción de alta calidad de vida y de salud y 19 fueron clasificados con percepción de baja calidad de vida y de salud. En cuanto a las necesidades percibidas, el nivel más alto de importancia fue otorgado a la categoría Red de Apoyo (ej; familia, amistades, vecinos, profesionales de salud; M = 2.88, DE = 0.43) y a Profesionales de la Salud (ej; relación paciente-profesional de la salud, etc. M = 2.80, DE = 0.50). Identificaron la categoría de apoyo Emocional/Espirital como menos importante (ej; manejo de emociones, consejería espiritual, M = 2.62, DE = 0.63). Reportaron menor satisfacción con la categoría Red de Apoyo (M = 2.85, DE = 0.43). Las percepciones variaron en función del género, estatus de salud percibido y fecha de diagnóstico. Las mujeres asignaron mayor importancia a las categorías Profesionales de la Salud e Información. Conclusión: Es importante considerar las necesidades psicosociales al momento de ofrecer apoyo a los pacientes oncológicos. Estos hallazgos pueden tomarse en consideración al momento de proveer servicios de apoyo psicosocial.

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