

The Health related Quality of Life of Puerto Ricans during Cancer Treatments; A Pilot Study

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Objective: To examine the health related quality of life (HRQOL) experienced by 79 Puerto Rican adults during cancer treatments.

Methods: This study used a descriptive, cross-sectional design. Participants completed a demographics form and the Functional Assessment of Cancer Therapy-General QOL questionnaire (FACT-G). Descriptive statistics were generated.

Results: Participants were ages 28-78; most of the participants had breast (38.0%), prostate (14.0%) and cervical and ovarian cancers (10.1%) treated with chemotherapy (45.6%). The participants had a mean total score on the FACT-G of 75.2 (SD = 18.9). As a group, the functional well-being was the most affected (mean 17.2, SD 6.8), and the Social/Familial was the least affected (mean 20.7, SD 6.0).

Conclusion: Cancer is the leading cause of death in the island of Puerto Rico. Female Puerto Rican cancer patients in this study sample had increased risk for experiencing worse: overall HRQOL, physical well-being and emotional well-being compared to males. Given that the Hispanic oncology population does not always report symptoms, risking under-assessment and under-management, this suggests there may be a greater need for HRQOL surveillance for this population. [*PR Health Sci J* 2018;37:46-51]

Key words: Health Related Quality of Life, Puerto Ricans, Cancer Treatments

Cancer in Hispanic Puerto Ricans touches almost every family and is the leading cause of death (1). Often, Hispanics are diagnosed at a later stage needing intense treatments and experiencing worse symptoms and health related quality of life (HRQOL) (2,3,4). A review of the literature reports that this vulnerability of experiencing worse cancer-related outcomes among Hispanics may be attributable to multiple factors including cultural (e.g. illness perceptions), psychosocial (e.g. coping), behavioral (e.g. engagement in cancer screening), cancer disease-specific (e.g. stage of diagnosis and tumor characteristics), and medical factors (infectious agents) as well as economic status (e.g. economic adversity) and health care (e.g. patient-physician communication) (4). According to the Puerto Rico Central Cancer Registry estimate, approximately 62,000 patients were living with cancer in 2010 (5). While localized treatments have led to higher cure rates (6), it often produces disruptive side effects such as cancer-therapy related symptoms with negative impacts on HRQOL (7). Although HRQOL is a clinical priority of comprehensive oncology, the assessment of HRQOL of Hispanic Puerto Ricans during treatment has received limited attention.

In oncology, the assessment of HRQOL during treatment is an emerging research priority (8). HRQOL is defined by Victorson, Barocas, Song, and Cella (2008) as “the extent

to which one’s usual or expected physical, emotional and social well-being is affected by a medical condition and/or its treatment.” Numerous studies have described the HRQOL during treatment of predominantly non-Hispanics (9,10).

Despite this body of evidence, few studies have examined the HRQOL of Hispanics Puerto Rican during cancer treatments. As a significant number of Puerto Ricans emigrate to international territories for economic reasons or other (11), taking their cancer risk with them (1), it is crucial that clinicians and researchers also become skilled in assessing the HRQOL of Puerto Ricans undergoing cancer treatments to optimize clinical care and improve the HRQOL of patients and families. Therefore, the purpose of this pilot study was to describe the HRQOL of a sample of Puerto Ricans undergoing cancer treatments.

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Methods

Design and Sampling

This study used a descriptive, cross-sectional design. A convenience sample (N = 79) was drawn from Hispanic Puerto Rican men and women with any cancer diagnosis all undergoing cancer treatments as outpatients. The participants were included if they: had a diagnosis of cancer; had received at least two or more rounds of therapy; and, were at least 21 years of age or older. Data collection was conducted in June 2016. The recruitment and data collection of study participants took place at two ambulatory cancer treatment facilities located in San Juan, Puerto Rico.

Quality of life - FACT-G

The Functional Assessment of Cancer Therapy- General (FACT-G) QOL questionnaire instrument was developed by Cella and colleagues specifically for cancer survivors (12). The FACT-G version 4 includes 27 statements containing 4 subscales: physical (e.g. "I have lack of energy; 7 items), functional (e.g., "I sleep well"; 7 items"), social/family (e.g., "My family have accepted my illness"; 7 items) and emotional well-being (e.g., "I feel sad"; 6 items) were rated by the patients who were asked to indicate the degree to which they felt that each statement was true during the preceding week. Each item is anchored by a five-point Likert-type scale response (0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, or 4 = very much). Scores on the FACT-G can range between zero and 108. After appropriately reverse coding items, scoring for this scale was computed by adding the individual item scores, and dividing by the number of items answered. Higher scores represent better HRQOL (13).

The FACT-G has been validated with Spanish-speaking cancer patients, with good psychometric properties including: significant negative relationships with a related concept of Mood state (Brief Profile of Mood States; $r = -0.54$) and Performance Status (Eastern Cooperative Oncology Group Performance Status Rating; $r = -0.47$); and an anticipated lack of relationship with social desirability (short form of the Marlowe-Crowne Social Desirability Scale; $r = 0.18$). The overall Cronbach's alpha was 0.89 (14).

Demographic data and Health form

Demographics included the respondent's age, gender, ethnicity, and years of education. Information on diagnosis and treatment modality was also obtained. The research assistant obtained that information from the participants' self-report on the demographic form.

Data collection

Prior to beginning data collection, approval by the Human Subjects Committee of the Medical Science Campus and the Oncology Hospital Dr. Isaac Gonzalez Martinez was granted. Eligible participants were formally asked if they wanted

to participate in the study, which involved self-report of questionnaire, demographics and disease characteristics. They were given an information sheet and signed informed consent after they indicated their understanding of the study procedures and willingness to participate. Participants recorded responses on the study instruments.

Data analysis

Descriptive statistics including the frequency, percentages, means, and standard deviations (SDs) were performed on demographics and disease characteristics of the sample. In addition, descriptive statistics including the means, standard deviations (SDs), and medians were computed for the FACT-G subscales and the FACT-G total. Since histograms showed that the FACT-G data was not normally distributed, a non-parametric (*Mann-Whitney test*) statistical test was used to evaluate pairwise differences between sexes (Female, N=50; Male, N=29). Specifically, *Mann-Whitney test* was conducted to determine whether the population medians of the HRQOL (FACT-G subscales and the FACT-G total) between sexes differ (Female vs. Male). The data was analyzed using Statistics Package for Social Sciences SPSS, version 22.0 for windows. All statistical testing used a significance level of 0.05.

Results

The demographic and disease characteristics of the 79 patients are illustrated in Table 1. The participants' average age was 59.5 years (SD = 11.2; range 28 to 78). Most of the participants were female (63.3%) and White-Hispanics (92.0%). The participants were well-educated with an average of 11.8 years of education (SD = 4.5). Cancer diagnoses included: breast (38.0%), prostate (14.0%) and cervical and ovarian (10.1%) treated with chemotherapy (45.6%).

HRQOL

The mean, standard deviations of the FACT-G subscales and the FACT-G total score are shown in Table 2. The mean physical well-being (PWB) scores of the 79 participants of the current study was 18.8 (SD = 7.3); the mean emotional well-being (EWB) score was 18.7 (SD = 5.0); the mean social/family well-being (SWB) score was 20.7 (SD = 6.0), and the mean functional well-being (FWB) score was 17.2 (SD = 6.8). It is noted that in this study the participants had a mean total score on the FACT-G of 75.2 (SD = 18.9). The Spanish FACT-G internal consistency reliability Cronbach alpha was 0.87.

HRQOL differences between Sexes

Follow-up tests using *Mann-Whitney test* showed significant pairwise differences between sexes (See table 3). FACT-G total score was lower (worse HRQOL) for female patients (median = 73.0) than for males (median = 84.0, $p < 0.05$). In addition, PWB score was lower (worse PWB) for female patients (median = 18.0) than for males (median = 24.0, $p < 0.05$); as well as

Table 1. Characteristics of the study population

Variable	Frequency	Percent
Gender		
Female	50	63.3
Male	29	36.7
Ethnicity		
White hispanic	72	92.0
Black hispanic	7	8.0
Marital status		
Married	44	56.0
Single	13	17.0
Widow	12	16.0
Divorced	10	11.0
Cancer diagnosis		
Breast	30	38.0
Prostate	11	14.0
Cervical & Ovarian	8	10.1
Colorectal (anal)	6	7.6
Lung	5	6.3
Head and neck (laryngeal, lip & oral cavity)	5	6.3
Gastrointestinal (esophageal, gastric)	2	2.5
Genitourinary (Bladder, testicular)	2	2.5
Other solid tumors (neuroblastoma, pituitary, melanoma)	10	12.7
Type of treatment		
Chemotherapy	36	45.6
Radiotherapy	30	37.9
Chemo-radiation	13	16.5
	Mean	SD
Age	59.5	11.2
Years of education	11.8	4.5

Table 2. Distributions, means and SDs for sub-scales and total scores for the functional assessment of Cancer therapy-General QOL questionnaire (FACT-G)

Variable	Mean	SD	Range	Reference range
Functional well being	17.2	6.8	3-28	0-28
Emotional well being	18.7	5.0	1-24	0-24
Physical well being	18.8	7.3	1-31	0-28
Social/Familial well being	20.7	6.0	0-28	0-28
HRQOL total score	75.2	18.9	42-107	0-108

Table 3. Summary of *Mann-Whitney test* for the for sub-scales and total scores for the functional assessment of Cancer therapy- General QOL questionnaire (FACT-G) between sexes

	Pairs Female vs. Male	Mann-Whitney U	p-value*
Functional well being		667.0	0.55
Emotional well being		522.0	0.04*
Physical well being		475.5	0.01*
Social/Familial well being		579.0	0.14
Total score		527.5	0.05*

*Significance values p<0.05.

lower (worse EWB) for female patients (median = 19.0) than for males (median = 21.0, p < 0.05). However, there were no significant differences between sex for the SWB neither for the FWB subscales p > 0.05.

Discussion

While the finding that Puerto Rican participants reported that their functional well-being was the most affected HRQOL domain during cancer treatment is not surprising, it does highlight the importance of conducting a routine assessment of HRQOL and functional status during the cancer trajectory. Similar findings were reported by Cella et al. (14) in the Spanish validation study. Also, it is an important concern for clinicians to also routinely assess symptoms during cancer treatments because symptoms may have a direct impact on individuals functioning well-being. For example, one study found that approximately one-third of cancer patients reported experiencing severe pain, fatigue, emotional distress and disturbed sleep, and that those symptoms affected their physical and emotional well-being, and overall quality of life (15). In another study, Gonzalez, Saligan, Rodriguez, Pedro, & McMillan, (16) found that approximately 30% of the Puerto Rican cancer patients experienced diarrhea during therapy. With this concept/symptom of diarrhea in mind, it is plausible that patients with diarrhea also experience watery stools and fecal incontinence, feeling an urgent need to defecate, and need for the use of protective clothing or diapers that produces interference with functional well-being and daily activities.

Both physical and emotional well-being of participants were also affected. An earlier study with Hispanics showed similar findings (14). Likewise, the physical and emotional burden imposed by cancer therapy-related symptoms (e.g. diarrhea), can result in multiple restrictions including reduction of physical, hobbies and leisure activities and can lead to a higher perception of disturbance of physical and emotional well-being. Nevertheless, HRQOL should be continuously assessed because it is often a first sign to providers that patients are not coping well with treatments.

An interesting clinical finding in the current study is that our participants reported that the Social/Familial well-being was the least affected. Similar findings was obtained in the Spanish validity study (14). This finding is consistent with the idea that family members of Hispanics and other ethnic groups have become aware that social support during cancer treatments might impact the course and success of treatment (17,18).

The finding that the mean total score on the FACT-G in this study sample was similar (75.2, SD = 18.9) to the mean total score on the validation study among a rural sample in the US (78.92, SD 13.60; n=344; ethnicity not reported) (19) and the mean total score on the validation study with Hispanics (78.11, SD 17.32; n=92) (14) was unexpected. In comparison, a growing number of studies have demonstrated that Hispanic cancer patients may be at increased risk for experiencing worse

overall HRQOL compared to non-Hispanic Whites (4). Although direct comparisons between these studies and our study are limited, future research comparing clinical and patient-reported cancer outcomes among ethnic minority patients would be a logical investigation to pursue. Nonetheless, this suggests that regardless of the advances in new cancer therapy and the need to conduct future investigations in disparities in cancer outcomes between Hispanics and other ethnic groups, there may be a need for HRQOL surveillance across the disease trajectory.

Studying HRQOL is an important endeavor in enhancing health care professionals' understanding of patient-reported outcomes that reflects subjective health status (4). Additionally, given the evidence that non-pharmacological interventions (e.g. exercise, music, cognitive behavioral, psychoeducational, supportive and counselling, online support groups) may have a beneficial effect on the HRQOL of cancer survivors (20,21,22,23), future studies should consider the development of culturally tailored interventions and/or exploring the efficacy of these interventions in improving the HRQOL among Puerto Ricans with cancer.

HRQOL differences between Sexes

The *Mann-Whitney test* result showed that Puerto Rican female participants differ significantly in the overall HRQOL, PWB and EWB from male patients. Indeed, there is increasing evidence focusing on patient characteristics that most influence the impairment of quality of life (QOL), which shows that females often report lower HRQOL than men (24,25). Our findings are consistent with those results. While this finding is not surprising, it does highlight the importance of considering that sex may have an influence on the perception of HRQOL.

Specific reasons why Puerto Rican female participants differ significantly in the overall HRQOL, PWB, and EWB from males are not fully understood. Some factors that have been proposed include sex-related differences in role functioning, family communication difficulties, emotional distress, socio-cultural, nutrient metabolism and dietary practices, and biological factors (e.g. genetic and epigenetic differences between sexes) (26,27,28,29). For example, previous research has found that among Latina Breast cancer survivors, a favorable doctor-patient relationship was positively related to exercise, and in turn, influenced physical and emotional well-being (30). It is also plausible that a female patient's need for role adjustment (e.g. female patients may have additional responsibilities such as being a care provider, greater household responsibilities) after cancer diagnosis plays an important role in cancer-related outcomes (31). This finding also suggests the need for sex-based approaches to improve the HRQOL in survivorship care within the family unit. Indeed, Lim and Shon's (27) study found that cancer patient's spouses' perceived family communication was a mediated factor between the survivors' family cohesion and physical HRQOL.

Limitations

This study had a relatively small sample size. A sample with a larger representation of the most common cancers in each group, with longer follow up, would have permitted a subset analysis to evaluate differences in HRQOL according to type of diagnosis, type and time of treatment, and/or to evaluate changes in HRQOL over time. For example, mounting evidence suggests that patients receiving concurrent chemotherapy and radiation therapy experience worse overall QOL and cancer-related symptoms compared to patients undergoing RT alone (32,33). In addition, cancer patients in a preoperative state have a better QOL compared to patients in a later postoperative chemotherapy state (34). It is also important to collect additional information on factors that can influence the cancer-treatment outcomes such as delays in diagnosis and treatment, social support, language barriers, and patient-physician communication (34,35). A qualitative study is also needed to investigate the impact of those factors on the HRQOL, then this information would lead to more knowledge on how to help these populations. Finally, our sample was limited to two sites; therefore, the findings may not be representative of the cancer population in Puerto Rico.

Conclusion

Assessment of HRQOL during cancer treatments will help identify at-risk patients for difficulty coping with cancer-related therapy, so appropriate interventions and clinical management of symptoms can be offered early in the treatment. Findings from the current study suggest that gender is a key component of the HRQOL among the Puerto Rican oncology population. Specifically, female patients were at increased risk of experiencing worse overall HRQOL, PWB and EWB than males. Future studies should explore the role of sex-related biological and socio-cultural differences in the HRQOL of Puerto Ricans with cancer. With the worldwide increase in migration of Puerto Rican families, clinicians need to become familiar with their HRQOL status to provide culturally competent oncology care. This practice will also improve our understanding of the trajectory of HRQOL in order to identify therapeutic targets and improve QOL of patients and families.

Resumen

Objetivos: Examinar la calidad de vida relacionada a salud que experimentaron 79 Puertorriqueños adultos durante el tratamiento para el cáncer. Métodos: Este estudio utilizó un diseño descriptivo, transversal. Los participantes completaron un formulario demográfico y el cuestionario de Evaluación Funcional de la Terapia del Cáncer-General (FACT-QOL). Se generaron estadísticas descriptivas. Resultados: Los participantes tenían entre 28 y 78 años; la mayoría de los participantes tenían cáncer de mama (38.0%), próstata (14.0%)

y cáncer cervical y ovárico (10.1%) tratados con quimioterapia (45.6%). Como grupo, los participantes tuvieron una puntuación media total en el FACT-G de 75.2 (DE = 18.9). El bienestar funcional fue el más afectado (media 17.2, DE 6.8) y el bienestar social/familiar fue el menos afectado (media 20.7, DE 6.0). Conclusión: El cáncer es la principal causa de muerte en la isla de Puerto Rico. Las pacientes femeninas con cáncer en Puerto Rico en la población de estudio tuvieron un mayor riesgo de experimentar un peor bienestar general, físico y emocional en comparación con los pacientes masculinos. Debido a que la población de oncología Hispana no siempre reporta los síntomas/efectos secundarios que siente durante el tratamiento, arriesgando una sub-evaluación y un manejo inadecuado, puede haber una mayor necesidad de vigilancia de la calidad de vida relacionada a salud en esta población.

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