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Health-Related Quality of Life Among Cancer Survivors Attending Support Groups

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Abstract There is limited research on the relationship between Health-related quality of life (HRQoL) and socioeconomic status (SES) among long-term cancer survivors. The goal of this study was to assess Global HRQoL among 102 adult cancer survivors attending support groups in San Diego County and to examine differences by SES and acculturation. Community-based participatory research methods were followed to recruit a purposive sample of English and Spanish-speaking adult cancer survivors attending cancer support groups. Self-report questionnaires assessing age, acculturation (i.e., language), SES (i.e., income and education), cancer history, and Global HRQoL measured by the FACT-G were administered. Multivariate regression examined the relationship between SES and acculturation with HRQoL, adjusting for covariates. Participants were 58.8 years on average (SD=10.06) and varied in terms of SES. Most participants (91.5 %) were women, 51.7 % were non-Hispanic white, and 48.3 % were Hispanic/Latino. Global HRQoL scores in the study sample were lower compared to previously reported studies. After adjusting for covariates, SES and acculturation were not significantly related to HRQoL. Stage at diagnosis was significantly related to HRQoL measures in adjusted analyses. HRQoL did not vary by SES or acculturation. There is a need to increase access to linguistically and culturally appropriate cancer care and supportive care services. Future studies may find existing support group settings useful for targeting psychosocial issues for more advanced stage cancer survivors.

Keywords Health-related quality of life · Survivorship · Cancer · Socioeconomic status · Acculturation · Support groups

Introduction

Cancer is a major public health problem in the United States (US). In 2012, the number of cancer survivors in the US was approximately 13.7 million, with an estimated increase to 18 million by 2022 [1]. When all sites were combined, cancer patients diagnosed between the years 2002–2008 had a 5-year survival rate of 68 % [2], a vast improvement compared to previous time periods. This transition from an active treatment patient to a survivor is a distinct period in the cancer care continuum, where cancer survivors have to cope with the physical, social, and increasingly important psychological issues resulting from cancer and cancer treatments [3], resulting in decrements in survivors' functioning, including a reduction in quality of life [4], as well as psychological concerns (e.g., fear of recurrence, fear of death and dying, and depression) associated with having cancer [5].

Because of these survivorship issues and life expectancy of cancer survivors on the rise, health-related quality of life (HRQoL) has become an important outcome measure for survivors [6]. HRQoL is a subjective, multidimensional construct that encompasses physical, social, functional, and psychological/emotional well-being factors related to the health of an individual [7], with all domains maintaining equal importance when considering survivors' overall well-being [8]. Although for some the acute effects of treatment subside

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as survivorship increases, many survivors experience lingering side effects from treatment that can persist for many years, negatively affecting HRQoL [9].

Researchers have reported many challenges with respect to HRQoL among cancer survivors, mainly with those who are at a social disadvantage [10]. Demographics such as race and ethnicity further influence survivor's HRQoL [4], and the psychosocial distress among survivors may also vary by socioeconomic status (SES) [4]. For example, ethnic minority cancer survivors disproportionately are of lower SES and experience greater socioecologic stress (e.g., employment, financial status), and therefore carry a larger psychological burden [11]. Moreover, data suggest that cultural and contextual factors (e.g., barriers in communication, shame) may contribute to these QoL disparities [4, 12–14]. These variations of SES levels and cultural factors are evident among cancer survivors, resulting in a range of survivorship experiences.

In addition to SES, the degree of one's acculturation to the US society is also related to health outcomes and HRQoL of ethnically diverse cancer survivors [15]. For example, significantly more Latina low acculturated women than white non-Hispanic women reported difficulty understand written material, with a lower acculturation may be linked to poorer HRQoL among Latina women [16]. One of the most commonly used proxies for acculturation is language. Data has shown that with relation to QoL, there are evident differences in QoL and effectiveness in communication among certain ethnic groups [17]. For example, a study comparing Latinas and non-Hispanic white women found that Latinas who had greater use of English reported more effective communication; in turn, those with higher communication effectiveness had greater treatment satisfaction, which predicted more favorable QoL [17]. Further research is needed to examine the role of socioeconomic and acculturation (i.e., language) factors in relation to HRQoL among survivors.

While many survivors rely on health care providers to receive cancer-related information, [18] others may use other avenues; as a result, cancer survivors often seek support from other cancer survivors through peer support groups [19]. Support groups are increasingly recognized as an effective service for providing psychosocial support for cancer survivors [5]. However, studies have shown that support groups tend to be most utilized by non-Hispanic white, educated, middle to upper class women, and are inadequately studied [20]. There is limited research assessing the HRQoL of cancer survivors who attend these support groups even though utilization of these groups may be an effective tool for health professionals to meet the emotional, information, and coping needs of cancer survivors [3].

To address these gaps concerning sociodemographic differences, we assessed HRQoL in a sample of cancer survivors attending support groups to determine whether HRQoL varies by SES and acculturation (indicated by language use). Results are intended to extend specific suggestions for physicians and those working closely with the survivor community to help reduce disparities in survivorship outcomes for the disadvantaged.

Methods

Hypothesis 1: Cancer survivors with lower SES will have a lower Global HRQoL score.

Hypothesis 2: Less acculturated cancer survivors (indicated by language use) will have a lower Global HRQoL score.

Study Design

Community-based participatory research (CBPR) methods were used to plan and implement this cross-sectional study [21]. Between March 2012 and December 2012, a purposive sample of ethnically diverse English- and Spanish-speaking adult cancer survivors attending cancer support groups across San Diego County were recruited. Eligible participants were as follows: (a) 18 years or older, (b) a resident of San Diego County, (c) able to read and write in English or Spanish, and (d) have a cancer diagnosis. The present study considered a cancer survivor to be an individual who has been diagnosed with cancer, regardless if they have completed treatment or not [22].

Of the 88 cancer support groups in San Diego County, 78 of them targeted adults only. Research assistants recruited participants by contacting the support group facilitators through phone calls, emails, in-person requests at community-based meetings, and snowball sampling, where they requested to visit the support group for in-person data collection. Of the 71 (91 %) English-speaking support groups, 22 were approached and seven agreed to participate due to time constraints and interference with normal support groups meeting agendas. Of the seven (9 %) Spanish-speaking support groups, six were approached and six agreed to participate. Among the support groups, 103 individuals were approached, with 102 cancer survivors agreeing to participate [23].

Procedures

Using San Diego State University IRB-approved methods, a survey was self-administered or interview-administered by trained bilingual research assistants using questionnaires to measure sociodemographics, socioeconomic status, cancer history, and quality of life. Surveys were administered among cancer support groups that had previously agreed to participate. Research assistants explained the general nature of the needs assessment, obtained informed consent in the participant's language of preference and instructed participants how to complete the survey.

Measures

HRQoL HRQoL was measured with the standardized English- and Spanish-validated versions of the Functional Assessment of Cancer Therapy-General (FACT-G) [24]. Items were rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much), according to the frequency with which each statement had occurred within the past 7 days. An overall HRQoL score (Global FACT-G score) is obtained by averaging the items (scores ranging from 0 to 108), with higher scores indicating better HRQoL. Both the total score and the well-being subscale scores were calculated according to the Functional Assessment of Chronic Illness Therapy website scoring algorithm (www.facit.org, 2010). The reliability and validity of the FACT-G is well established [24, 25]. High reliability of the FACT-G has been reported for the Spanish version [26]. The reliability for the current sample was 0.93.

Sociocultural Factors Socioeconomic status was defined by two measures: annual income and education level. Annual income was collected categorically as one of ten self-reported income ranges (from 1 [less than $10,000] to 10 [more than $100,000]). Education was self-reported highest education achieved with five categories ranging from 1 (elementary/primary school) to 5 (university/college). In addition, participants were asked to indicate if they have received a diploma, certificate, or degree (1 [high school diploma or equivalent] to 7 [doctoral degree]). Acculturation was assessed as participants' survey language preference (English or Spanish), a proxy-measure commonly used in health research [27]. Other sociodemographic and medical information assessing participant's age, ethnicity, age, marital status, cancer treatment received, stage at diagnosis, and years since diagnosis were included.

Statistical Analyses

Frequencies and descriptive statistics for all variables are reported. Analysis for the FACT-G included calculation of means and SDs for scores. Analyses using Pearson correlations and one-way analysis of variance (ANOVA) tested the relationship between HRQoL and language, education, and income, as well as demographics variables. We fit a linear regression model with sociodemographics, cancer history, and SES to determine whether SES would remain a contributing factor of HRQoL, controlling for covariates (Table 3). Interaction effects between ethnicity and SES were examined. All statistical analyses were performed using the SPSS version 20 for Windows (IBM SPSS, Armonk, NY).

Results

Table 1 displays the descriptive statistics for all sociodemographic and cancer history variables by language. A total of 102 cancer survivors met the eligibility criteria and participated in this study. To be able to compare non-Hispanic/Whites to Hispanic/Latinos, eight participants of African American, Asian American and Native American descent were excluded; therefore, 94 participants were analyzed. Overall, participants mean age was 58.8 years old (SD=10.06). The sample was mostly non-Hispanic/White (51.7 %) and the remaining participants were Hispanic/Latino (48.3 %). The majority was women (91.5 %) and the

Table 1 Sample demographics by language (*n*=94)

	English (*n*=58) M (SD) or *n* (%)	Spanish (*n*=36) M (SD) or *n* (%)	Total (*n*=94) M (SD) or *n* (%)
Characteristics			
Age (years)	62.0 (9.76)	54.6 (9.03)	58.8 (10.06)
Gender			
Female	54 (93.1 %)	32 (88.9 %)	86 (91.5 %)
Male	4 (6.9 %)	4 (11.1 %)	8 (8.5 %)
Ethnicity			
Non-Hispanic White/Caucasian	45 (84.9 %)	1 (2.8 %)	46 (51.7 %)
Hispanic/Latino	8 (15.1 %)	35 (97.2 %)	43 (48.3 %)
Education			
Elementary/primary	–	6 (16.7 %)	6 (6.4 %)
Middle School/ junior high	–	11 (30.6 %)	11 (11.7 %)
High school	9 (15.5 %)	10 (27.8 %)	19 (20.2 %)
Trade/vocational school	4 (6.9 %)	3 (8.3 %)	7 (7.4 %)
University/college	45 (77.6 %)	6 (16.7 %)	51 (54.3 %)
Annual household income			
<$25,000	13 (25.0 %)	22 (73.3 %)	35 (42.7 %)
$25,000–$50,000	11 (21.2 %)	7 (23.3 %)	18 (22.0 %)
>$50,000	28 (53.8 %)	1 (3.3 %)	29 (35.4 %)
Cancer history			
Years since diagnosis			
<5	34 (63.0 %)	24 (68.6 %)	58 (65.2 %)
5–10	11 (20.4 %)	10 (28.6 %)	21 (23.6 %)
>10	9 (16.7 %)	1 (2.9 %)	10 (11.2 %)
Stage of diagnosis			
0	5 (9.3 %)	1 (3.0 %)	6 (6.9 %)
I	18 (33.3 %)	7 (21.2 %)	25 (28.7 %)
II	15 (27.8 %)	13 (39.4 %)	28 (32.2 %)
III	9 (16.7 %)	9 (27.3 %)	18 (20.7 %)
IV	7 (13.0 %)	3 (9.1 %)	10 (11.5 %)

M mean, *SD* standard deviation

Table 2 HRQoL by sociodemographic and clinical variables ($n=85$)

Characteristics	Global FACT-G		
	Mean (SD)	*n*	*P* value
Language			0.000
English	77.18 (20.96)	49	
Spanish	59.54 (8.16)	31	
Ethnicity			0.000
Hispanic/Latino	60.37 (13.04)	36	
White/Caucasian	78.50 (19.61)	44	
Income level			0.001
<\$25,000	62.83 (16.71)	30	
\$25,000–\$50,000	64.86 (16.09)	14	
>\$50,000	80.01 (19.96)	27	
Education level			0.012
Elementary/primary	62.16 (11.03)	5	
Middle school/junior high	62.23 (8.84)	9	
High school	64.81 (15.98)	15	
Trade/vocational school	55.66 (6.68)	6	
University/college	76.67 (21.10)	45	
Stage at diagnosis			0.002
0	84.81 (14.56)	6	
I	81.41 (16.69)	21	
II	62.93 (15.47)	23	
III	68.50 (17.12)	17	
IV	61.20 (24.92)	9	
Years since diagnosis			0.409
<5	68.53 (18.33)	48	
5–10	74.47 (19.21)	19	
>10	74.90 (20.24)	8	
	Global FACT-G Pearson correlation		*P* value
Age	0.206	93	0.047

HRQoL is measured by the FACT-G, Functional Assessment of Cancer Therapy-General

SD standard deviation

majority completed surveys in English (61.7 %). Breast cancer accounted for the most common form of cancer (76.5 %), with the majority diagnosed less than 5 years ago (65.2 %) and a range of stages of diagnosis. Over half of the participants earned at least a college or university education (54.3 %) and had an annual income of less than \$25,000 (42.7 %). No interaction with ethnicity or with language was observed in the relationship of socioeconomic indicators with the HRQoL measure; therefore, Tables 2 and 3 present data for the entire sample.

Bivariate Relationships with Global HRQoL

Table 2 presents the bivariate relationship between sociodemographic, clinical variables, and main study outcome (HRQoL). HRQoL scores differed by demographic, socioeconomic, and acculturation. For income, those who earned more than \$50,000 scored higher compared to those who earned less than \$25,000 (p values<0.001). Those with a university-level education had significantly higher HRQoL scores ($p<0.01$) compared to those who earned a lower-level education.

For acculturation, Spanish-speaking survivors (59.54) had significantly lower HRQoL scores compared to English-speaking survivors (77.18) ($p<0.01$). In addition, Hispanic/Latinos (60.37) had significantly lower HRQoL scores compared to non-Hispanic white (78.5), ($p<0.001$). However, the mean FACT-G score for all participants (69.0) was lower than the mean score (88.8) from a multicenter validation study by the authors of the FACT-G scale [25]. HRQoL (i.e., Global FACT-G score) was positively correlated ($p<0.01$) with age. There were no statistically significant differences by cancer type, participant sex, and time since diagnosis.

Multivariate Relationships with Global HRQoL

Table 3 contains the results of the multivariate linear regression model that examined the adjusted relationship between age, language, income, ethnicity, stage at diagnosis, education, and income and the dependent variable HRQoL (i.e., Global FACT-G scores). The model accounted for 34.9 % of the variance (SE=16.33) of HRQoL. In comparison to the bivariate results (Table 2), stage at diagnosis was the only variable that remained significant ($\beta=-0.33$, $p<0.001$) in multivariate analyses after adjusting for covariates. All other variables were not significantly related to HRQoL in these adjusted analyses (Table 3).

Table 3 Multivariate linear regression model of sociodemographic factors and stage at diagnosis in relation to HRQoL among cancer survivors ($n=69$)

DV=HRQoL	β (S.E.)	R^2
Model	–	34.9
Age	0.18 (0.26)	–
Language	0.31 (9.38)	–
Ethnicity	0.03 (9.83)	–
Stage at diagnosis	−0.33 (1.78)**	–
Education	−0.14 (2.19)	–
Income	0.20 (3.19)	–

Higher scores denote higher HRQoL, age, education, income, and stage at diagnosis. Dichotomous variables are coded as follows: language of survey (1=English, 0=Spanish; ethnicity: 1=Non-Hispanic White and 0=Hispanic/ Latino). *HRQoL measured by the FACT-G* Functional Assessment of Cancer Therapy-General

DV dependent variable, *S.E.* standard error

**$P\leq0.01$

Discussion

This study was designed to examine the relationship between SES (i.e., education and income) and HRQoL among a sample of cancer survivors. The FACT-G is a standardized instrument that has been used for assessing quality in several chronic diseases, most specifically cancer. We have described the HRQoL of cancer survivors in San Diego County attending support groups in terms of the overall FACT-G scores. To the best of the authors' knowledge, no other study has analyzed HRQoL among cancer survivors by acculturation (i.e., language), specifically among those attending cancer support groups. This brings light to an area of research with limited knowledge on this specific population.

Results indicate cancer survivors' mean FACT-G score (69.0) was lower than the mean score (88.8) from a multicenter validation study by the authors of the FACT-G scale [21]. According to the literature, cancer survivors tend to have lower overall FACT-G scores in comparison to the US general population norms; however, this sample of cancer survivors has scored lower than cancer survivor norms. Findings suggest that HRQoL was not influenced by SES factors, in contrast to many studies that have found the opposite; most research demonstrates that cancer survivors of lower SES tend to have poorer HRQoL [11, 28–30]. Several studies support that SES is an important determinant of quality of life in survivors [4, 24, 25]. Perhaps these results illustrate that cancer survivors, regardless of their income and educational level, are equally affected by this disease, and therefore, their quality of life is equally affected.

Our second hypothesis was partially supported. Acculturation initially appeared to be associated with HRQoL, but after accounting for other factors (e.g., SES and cancer-related issues), the effect of acculturation disappeared. This suggests that the relationship between acculturation and HRQoL is much more complex than anticipated, and should be explored further. While research shows that those with greater command of English are likely to experience fewer barriers [31], there may be other factors involved beyond acculturation that have an even greater impact on HRQoL that were not examined in the current study, further emphasizing the need to understand its complex nature. Finally, it is crucial that cancer care providers have the tools to inform all survivors, regardless of their level of acculturation, about available psychological services, so that they are able to access and participate.

Support groups provide survivors the opportunity to share concerns with peers, obtain emotional support, gain information about treatment, and receive assistance with navigating the health care system [20]. This could be especially beneficial for survivors with more advanced stages of cancer, since that was the only factor that remained significant in both unadjusted and adjusted analyses. It is possible that those with more advanced stages are not seeking these resources, and therefore experiencing lower HRQoL. Although SES was not statistically significant in the adjusted analysis, it is critical to note that in San Diego, Spanish-speaking support groups are greatly outnumbered by English-speaking support groups, and therefore, access to these inexpensive and valuable psychosocial resources are highly limited. A possible solution for addressing this disparity is to increase the availability of support groups for all survivors, particularly for those with more advanced stages, especially since, "The contribution and value of the groups expand the paradigm of supportive care and extend the net of psychosocial care to underserved and under-represented cancer survivors" [32].

Limitations

There were some limitations in this study. The cross-sectional design does not allow for documentation of HRQoL changes over time or causality between other study variables. Also, given that participants were recruited from cancer support groups, the motivation of this population may have presented the potential for volunteer bias. Also, since our sample is predominately comprised of women (91 %) and breast cancer survivors (77 %), these results cannot be generalized to the overall cancer survivor population. Moreover, due to the small sample size, results are difficult to apply to the cancer survivor population. Also worth noting is the use of language as a proxy for acculturation as a possible limitation. Other potentially influential aspects of acculturation were not captured in the current study. Despite these limitations, our study builds upon and adds to existing literature about cancer survivors attending support groups.

Conclusions

This study offers insight into the survivor experience of cancer survivors attending support groups. Emphasis needs to be placed on raising awareness among cancer survivors and their physicians about the potential benefits of cancer support groups as a resource to cope with psychosocial issues that may affect HRQoL, predominately those with more advanced stages. Also, there is worth in further exploring the complex nature of acculturation with relation to HRQoL. These results, as well as a small but growing body of research, indicate that there are unmet needs with regards to HRQoL among this unique population. Further research should direct attention to psychosocial interventions targeting the needs of survivors with advanced stage cancers, regardless of SES.

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