HHS Public Access

Author manuscript

Int J Nurs Pract. Author manuscript; available in PMC 2019 December 01.

Published in final edited form as:

Int J Nurs Pract. 2018 December ; 24(6): e12700. doi:10.1111/ijn.12700.

"Validation of the Spanish Version of the Cancer Symptom Scale in Hispanic Cancer Patients"

Dr. Velda J. Gonzalez-Mercado, PhD, RN,
Postdoctoral Fellow, University of South Florida College of Nursing

Dr. Leorey N. Saligan, PhD, RN, CRNP, FAAN,
tenure-track investigator and the chief of the Symptom Management Branch of the National Institute of Nursing Research Intramural Research Program., saliganl@mail.nih.gov

Dr. Carmen S. Rodriguez, PhD,
Assistant Professor, University of South Florida College of Nursing, Tampa, FL, United States, crodrig3@health.usf.edu

Desiree Ortiz, BS, MS-II,
Medical Student, St. George's University, Grenada, West Indies, dortiz@sgu.edu

Dr. Elsa Pedro, PharmD., and
School of Pharmacy, University of Puerto Rico, Medical Science Campus, San Juan, Puerto Rico, Elsa.pedro@upr.edu

Dr. Susan C. McMillan, PHD, ARNP, FAAN
Distinguished professor and Thompson Professor of Oncology Nursing and Quality of Life at the University Of South Florida College of Nursing, smcmilla@health.usf.edu

Abstract

Aim: To assess the validity of the translated Spanish-Cancer Symptom Scale.

Background: Instruments to facilitate comprehensive and objective assessments of the cancer symptom experience in underrepresented populations are essential.

Methods: The Cancer Symptom Scale was translated into Spanish and a back translation was conducted. During June 2016, a sample of 121 Hispanic Puerto Rican patients with any cancer diagnosis, all undergoing cancer treatments completed 4 paper surveys. A subgroup of 15 patients

Corresponding author: Gonzalez-Mercado, Velda Janet, PhD, RN, Postdoctoral Fellow, University of South Florida College of Nursing, Tampa, FL, United States, veldag@health.usf.edu, University of South Florida, 12901 Bruce B. Downs Blvd., MDC22, Tampa, FL 33612-4766, Phones: 813-974-2069, cell: 787-457-8508, Fax: 813-974-8025.

Author Contribution

(VJG) contributed to conception, design, acquisition, analyzed the data, and interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; (LS) contributed to design, data interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; (CR) contributed to conception, design, analysis, and interpretation; critically revised the manuscript; gave final approval; (DO) contributed to design, data interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; (EP) contributed to design, data acquisition, interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; and (SM) contributed to design, data interpretation; drafted the manuscript; critically revised the manuscript; gave final approval.

Declaration of Conflicting Interests

The authors have no conflicts of interest to report. All listed authors meet the authorship criteria and are in agreement with the content of the manuscript.

agreed to complete the Spanish-Cancer Symptom Scale a second time after a short delay of 1 to 2 hours. Construct validity and reliability (internal consistency via Cronbach ‘alpha and test-retest reliability) was evaluated.

Results: All the Intensity Items of the Spanish Cancer Symptom Scale correlated significantly with the matched items on the MD Anderson Symptom Inventory. In a subgroup of 77 participants, each Cancer Symptom Scale subscale total of scores correlated significantly with the total scores from the Functional Assessment of Cancer Therapy-General. Discriminant validity was demonstrated between those receiving chemotherapy and those from post treatment. The Spanish-Cancer Symptom Scale internal consistency reliability was 0.98.

Conclusion: The Spanish-Cancer Symptom Scale has excellent evidence of validity and reliability for assessing cancer-therapy-related symptoms.

Keywords

Cancer Symptom Scale; validation; cancer therapy- related symptoms; Hispanic Puerto Ricans

INTRODUCTION

Approximately 62,000 patients were living with cancer in 2010 in Puerto Rico (Centeno et al., 2013). While localized treatments such as radiation and surgery have led to higher cure rates (Abdel-Wahab et al., 2012), they often produce disruptive side effects and symptoms that have negative impacts on health-related quality of life (HRQOL) (Gonzalez-Mercado, Williams, P. D., Williams, A. R., Pedro, & Colon, 2017; Tofthagen, & McMillan, 2010). Further, these symptoms are associated with disability and healthcare overuse, and are therefore a source of considerable economic burden (Carlotto, Hogsett, Maiorini, Razulis, & Sonis, 2013). As a significant number of Hispanics, including Puerto Ricans, immigrate to international territories due to personal and economic reasons (US Department of Commerce, US Census Bureau, Population Division, 2010), taking their cancer risk with them, there is a crucial need for valid and reliable Spanish scales to assess the symptom experience in the Spanish-speaking population.

Despite the variation in symptom reporting that may exist among ethnic groups, it is well documented that Hispanics, including Puerto Ricans, are an understudied population who are underrepresented in clinical trials, especially in symptom research (Canino et al., 2008; Puerto Rico Cancer Control Coalition, 2015). Recent studies suggest that lack of culturally appropriate and language-specific tools may contribute to, or explain Hispanics’ limited participation in research (Galvao, 2011; Jerome-D’Emilia, Suplee, & Akincigil, 2015; Li, McCardel, ClarK, Kinsella, & Berch, 2001). Notably, Spanish validated instruments provide an opportunity to uniformly assess and investigate the symptom burden of Spanish-speaking patients (Sanchez et al., 2016). In addition, incorporating these instruments into practice may help nurses and clinicians to ameliorate some difficulties experienced by patients during the treatment phase, promote self-care and symptom management strategies, dose adjustment or change of therapies, and complement evidence-based practice (Sanchez et al., 2016; Trujillo et al., 2016).

Research on the symptom experience of Hispanics Puerto Rican patients during cancer treatment have most often focused on symptom severity. One study using the Spanish MD Anderson Symptom Inventory (MDASI) showed that fatigue (44.7%), disturbed sleep (42.1%), dry mouth (42.1%), difficulty remembering (36.8%), numbness/tingling (36.8%), and pain (34.2%) are highly prevalent severe symptoms among Hispanic Puerto Rican prostate cancer patients on neoadjuvant hormonal therapy (Gonzalez et al., 2017). In addition, the participants of that study reported that their severity of the symptom experience affected their general activity and mood. Similar findings were also found by Gonzalez, Williams P. D., Tirado, and Williams, A. R. (2011) in their preliminary study of Puerto Rican cancer patients using the Spanish Therapy-Related Symptoms Checklist (TRSC), in which patients reported severe fatigue/feeling sluggish (56%), difficulty sleeping (54%) and depression (46%), and that the TRSC scores correlated negatively with HRQOL ($r=-0.37$; $p<.01$). In another study, one notable finding was that health care providers under-recognized and under-treated cancer-related-symptoms, especially among the Hispanic population (Yoon et al., 2008).

The knowledge base of cancer therapy-related symptoms in Hispanic patients is increasing, yet there have been limited scales that were specifically designed to assess the total symptom experience in patients to date (McMillan, Tofthagen, Choe, & Rheingans, 2015). Therefore, much interest has emerged in developing instruments that measure the presence, intensity, distress, frequency and interference of a list of symptoms such as the Cancer Symptom Scale (CSS). The CSS was developed based on a review of literature and of existing symptom scales (Cleeland, 2014; McMillan et al., 2015; Portenoy et al., 1994). Literature findings supported the development of a scale to assess multiple dimensions of symptoms experienced by persons with cancer. Consequently, the CSS was developed to facilitate the assessment of 35 symptoms beyond the dimension of intensity, allowing for better understanding of the impact of a given symptom, and to prioritize the symptoms causing patients the most distress, or interference at the greatest frequency. However, because the CSS was developed and validated only in English (McMillan et al., 2015), the validation of the tool in Spanish was considered to be critical. Thus, the proposed study provides a unique opportunity to fill this knowledge gap in symptoms science, as well as advance the nursing field, by estimating the psychometric validity of the Spanish-translated CSS in a sample of Puerto Rican patients. A valid Spanish CSS will comprehensively assess symptoms and hastened development of individualized symptom management interventions.

METHODS

Aim

This study aimed to develop a Spanish version of the CSS through the translation of the new CSS from English into Spanish. Additionally, the purpose of this study was to assess the validity of the translated Spanish-CSS.

Methodology

Study design—This study used a descriptive, cross-sectional design to study validity and reliability of the newly translated CSS.

Translation Process—The development of the Spanish version of the CSS was conducted using a double translation and back-translation processes. Specifically, the CSS was translated into Spanish by the principal investigator (P.I.), who is a native Puerto Rican advanced practice nurse. The initial Spanish version was then back-translated into English by a different/second bilingual/native Puerto Rican nurse practitioner. The two nurses then met to modify, discuss, and accept the final version of the instrument. The final version maintained the design and structure of the original instrument. Once the final version was accepted by both authors, the validation process started.

Participants and sample size

A convenience sample was selected for the preliminary assessment of validity of the Spanish-translated CSS in Puerto Rican patients. The convenience sample consisted of 121 Hispanic Puerto Rican men and women with any cancer diagnosis who were undergoing chemotherapy, radiotherapy or concurrent chemo-radiotherapy. The recruitment and data collection of study participants took place at two ambulatory cancer treatment facilities located in San Juan, Puerto Rico.

The statistical power was determined based on earlier study results. The McMillan et al. (2015) study reported a significant correlation of the CSS frequency subscale with the Multidimensional Quality of Life Cancer scale ($r = -0.34$; $P < .001$). Based on this result, we estimate that the statistical power was above 90% using 121 participants, 5% significance level for any value of the Pearson correlation greater than 0.2 (Rosner, 2006).

Instrument

The following self-report instruments were completed by study participants: the CSS Spanish version, the validated Spanish-versions of the MDASI and the Functional Assessment of Cancer Therapy-General (FACT-G). The MDASI and the FACT-G were used to support the validity of the CSS Spanish version. Participants also recorded demographic and health information on the demographic and clinical form.

Cancer Symptom Scale—The CSS measures the presence, intensity, distress, frequency and interference of a list of 35 symptoms (McMillan et al., 2015). The presence of symptoms was defined as a yes or no on each item. For each symptom, patients are asked four questions that describe their experience (intensity, distress, frequency and interference) during the past week. A typical question for the CSS is: “You had “Fatigue; no energy” this week? and How severe or intense Fatigue; no energy has been;” Intensity/severity was rated on numeric 1 to 10 scales from “least” to “most,” (0 was not used because failing to endorse the symptom was considered to be equivalent to a zero score) and distress, frequency and interference on numeric 0 to 10 scales from “least” to “most.” The presence/prevalence of the each symptom was obtained by calculating the number and percentage of patients who endorsed the item. In addition, the scoring for each subscale (intensity, distress, frequency and interference) is computed by adding the individual item scores, and dividing by the number of items answered. Higher scores represent worse symptoms. The reliability and validity of the English version of the CSS was evaluated in a sample of 234 cancer patients. More specifically, construct validity was examined by correlating the English version of the

CSS subscales with the Multidimensional Quality of Life-Cancer scale. Correlations ranged from $r = -0.34$ to -0.56; $p < .001$ (at the hypothesized levels), thus, supporting construct validity. In addition, test-retest reliability coefficients for the English version of the CSS subscales ranged from $r = 0.74$ to 0.81 in a subset of 15 patients, and Cronbach's alphas above .70 were reported (N=234) (McMillan et al., 2015).

MD Anderson Symptom Inventory—The Spanish version of the MDASI was used to validate the construct validity of the CSS. The MDASI contains 13 items measuring cancer patient's severity of multiple common symptoms across all cancer types. For each item, patients are asked to indicate how severe the symptoms have been in the past 24 hours. A typical item for the MDASI is: "Your pain at its worst." It was rated on numeric rating (0 to 10) scales from "not present" to "as bad as you can imagine." Scores of the MDASI can range between 0 and 130. High scores mean higher severity of symptoms.

The MDASI has been tested for reliability and validity with cancer survivors (Cleeland, 2014). The initial MDASI psychometric properties were evaluated in three samples of patients with various cancer types at the M.D. Anderson Cancer Center in Texas (Cleeland et al., 2000). The first sample consisted of 527 outpatients from the Blood and Marrow Transplantation, Hematology, Breast Medical, Radiation, and Thoracic/Head and Neck Medical oncology clinics. The second sample consisted of 30 in-patients undergoing treatment. The third and last group consisted of a cross-validation sample of an additional 113 outpatients from the above mentioned clinics. Researchers found that the 13 items MDASI explained approximately 64% of the variability in symptom interference. With respect to construct validity, findings from the principal axis factor analysis showed that the factor loadings of these 13 core items were distributed across two factors or constructs. The gastrointestinal symptoms of nausea, vomiting, and lack of appetite appeared to load on to the same construct, and the remaining items loaded into a more general symptoms construct. Further, the known-group validity of the MDASI was evaluated by assessing the instrument's ability to distinguish between two groups from the validation sample that are known to be different according to the ECOG performance status (good n = 143 or poor n = 184). Indeed, researchers found significant differences in mean symptom severity scores (2.36 vs. 3.62; $p<0.001$) and mean symptom interference scores (2.95 vs. 5.31; $p < 0.001$) between participants with good performance status compared to those with a poor performance status. Cronbach alphas above 0.80 for the 13 symptoms core items and for the interference items were obtained in both, the validation and the cross-validation sample. In the present study the MDASI (Spanish) internal consistency reliability was 0.69.

The Functional Assessment of Cancer Therapy- General questionnaire—The FACT-G questionnaire was developed by Cella and colleagues specifically to assess QOL in cancer survivors (Cella et al, 1993) The FACT-G version 4 includes 27 statements about five domains of QOL (e.g. "I have lack of energy," "I have accepted my illness") 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 is computed by adding the individual item scores, and dividing by the number of items answered. Higher scores represent better HRQOL (Yost, Elton, Garcia, & Cella, 2011).

The FACT-G has been rigorously tested for reliability and validity. Reliability and validity testing of the scale was conducted on 344 mixed-diagnosis rural cancer patients (Winstead-Fry & Schultz, 1997). The FACT-G showed strong internal consistency (Cronbach's alpha = .93). Further, validity testing revealed: a significantly positive relationship with other known measures of QOL (Functional Living Index-Cancer; $r = 0.84$) and a significant negative relationship with Mood state (Brief Profile of Mood States; $r = -0.82$). Further, 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 (Cella et al., 1998).

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 was granted. The P.I, who is a native Puerto Rican advanced practice nurse, visited the oncology ambulatory clinics to screen potential participants. 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.

Eligible participants were formally asked if they wanted to participate in the study. They were given an information sheet and signed informed consent after they indicated their understanding of the study procedures and willingness to participate. All patients interviewed by the P.I. were assured that their decision to participate would not affect their care in any way. Responses were then recorded on the study instruments. Finally, a subgroup of 15 patients agreed to complete the CSS a second time after a short delay of 1 to 2 hours.

Data Analysis

Descriptive statistics were calculated on demographics and disease characteristics of the sample. In addition, descriptive statistics were conducted on the prevalence of severity, distress, frequency, and interference with the participants' life of the occurrence of each symptom. The construct validity of the CSS was evaluated through comparison with items of a tool that measures the same symptom severity construct. Thus, to investigate the construct validity of the Spanish CSS, we computed the Spearman correlation coefficients between the matched Intensity Items of the CSS and the MDASI. Further, validity was evaluated in a subgroup of participants by computing the Spearman Correlations coefficients between CSS

Subscale total scores and a measure of QOL, a related concept. We expected moderate to strong negative correlations between Subscale total Scores and the FACT-G total scores. In order to evaluate discriminant validity; whether participants receiving treatments would be more likely to report more severe symptoms than a subgroup of patients of the post/treatment/survivorship clinics, an independent samples t-test for the Intensity items of the CSS was computed. The test-retest reliability of the Spanish CSS was evaluated by administering the questionnaire with a brief delay, and computing the Spearman Correlations between test and re-test CSS Subscale total Scores. Spearman's rho is a more conservative estimate when small samples are used. Internal consistency for the subscales scores was measured using Cronbach's alpha.

ETHICAL CONSIDERATIONS

The study was approved by the Human Subjects Committee of the University of Puerto Rico Medical Science Campus. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

RESULTS

Sample Characteristics

The demographic and disease characteristics of the 121 patients are illustrated in Table 1. The participants' average age was 61.6 years (*SD = 12.0*; range 30 to 91). More than half of the participants were female (58.7%) and White-Hispanics (92%). The participants were, for the most part, well-educated with an average of 12.4 years of education (SD = 4.5). Table 2 shows the percentages of occurrence and with Means and SD of Symptom Scores for Intensity, Distress, Frequency, and Interference.

Validity via Correlations

All the intensity Items of the Spanish MDASI correlated significantly with the matched items on the Spanish CSS (rho .55-.82, p<.002) (Table 3). In a subgroup of 77 participants that responded to both scales (CSS and FACT-G), CSS subscale total scores correlated significantly with the total scores from the QOL scale, the FACT-G (Table 4). All correlations were moderate (rho −.61 to −.65, p<.001) as expected. With respect to discriminant validity (Table 5), participants receiving chemotherapy treatment (n= 51) tended to experience significantly worse hair loss, taste change, poor appetite, and worry than those participants from the post/treatment/survivorship clinic (n = 32) (z =−1.9—2.2, p<.05). However, participants receiving chemotherapy treatment did not differed significantly on the remaining intensity items than those participants from the post/treatment/survivorship clinic.

Reliability of the CSS

Results of the test-retest reliability of the Spanish CSS showed adequate stability over time of all four of the scales, with the frequency subscale having the highest estimate of reliability (rho .74, p<.001) (Table 6). In the Puerto Rican sample, the Spanish CSS internal consistency reliability was 0.98.

DISCUSSION

As new cancer therapies are being developed, and with them new side effects and behavioral symptoms being reported, it is particularly important to have available useful, reliable, and valid Spanish translated instruments that can be widely used in clinical practice and research (Sanchez et al., 2016; Trujillo et al., 2016). Overall, the items of the CSS contain four key aspects/domains (i.e. severity, distress, frequency, and interference with daily life) of the symptom experience that cancer patients need to cope with during their disease trajectory. In the current study, we reported on the psychometric validity of a Spanish-translated CSS in a sample of Puerto Rican patients. Our findings suggest that the Spanish CSS has good validity and reliability for determining the symptom profile of Puerto Rican cancer patients during treatments, who participated in this study.

Findings of the current study have potential international relevance. Although not studied in other Spanish speaking populations, it is possible that this scale might be usable in them. While there are some differences in how the language is spoken among Spanish speaking countries, the words in this scale are generally those that would have a direct translation from English into Spanish, and thus, it is likely that the Spanish version may be widely useful around the world. However, further research is needed to confirm this.

Symptom research contributes to the exploration of the complexities associated with cancer therapy and symptom management. In the original study using the English version of the CSS, fatigue, pain, dry mouth, change in taste, and numbness/tingling feet were reported as the symptoms with higher prevalence (McMillan et al., 2015). Interestingly, although Hispanic Puerto Ricans in the current study also reported experiencing those same symptoms as the top ones, the percentages of occurrence were higher than expected based on the results from the McMillan et al. (2015) study. These reported symptoms are consistent with adverse effects of radiotherapy, and various types of chemotherapy drugs (e.g. 5-fluorouracil, capecitabine and irinotecan) used in oncology (Stein, Voigt, & Jordan, 2010). However, when combined with the fact that participants in the current study **all** had mean intensity and frequency scores greater than the midpoint of the scale, and that twenty-two symptoms had mean distress and intensity scores equal or greater than the midpoint of the scale, it does highlight the importance of conducting a routine assessment of symptoms during the cancer trajectory. Nevertheless, it is an important concern for nurses that not only severe and distressing symptoms may be exacerbated during treatments and interference with daily life but, may also lead to a need for dose adjustment or interruption of treatments, non-compliance, and/or abandonment of treatment, and thus decreased survival if left untreated (Aguado Loi et al., 2013; Cleeland, 2007; Gunn et al., 2013; Hanna et al., 2015).

Validity

As expected, we observed that the Intensity Items of the Spanish CSS correlated significantly with the matched items on the Spanish MDASI. This finding provides one piece of evidence of the validity of the Spanish CSS. Further evidence of construct validity was provided by the moderate and significant negative correlations with QOL as measured by the FACT-G; as expected, when symptoms got worse, QOL was lower.

Additional evidence of validity was provided by the differences found in patients who were currently undergoing treatment compared to cancer survivors who had completed treatment. Participants receiving chemotherapy treatment perceived significantly greater severity of some symptoms (e.g. hair loss) than those participants from the post/treatment/survivorship clinic, which demonstrates the good discrimination ability of these items on the instrument. Unexpectedly, the differences with the other 27 intensity symptoms (e.g. fatigue) were not significant. The lack of significant difference may suggest that the subgroup of participants from the post/treatment/survivorship clinic may continue to have persistent severe symptoms after completion of treatment; further study of this issue is needed. Nonetheless, this suggests that there may be a greater need to extend symptom surveillance, treatment and control beyond treatment, in order to enhance the health and functioning of our patients (Cleeland et al., 2013). Further, longitudinal studies with a larger sample should examine the trajectory of cancer and cancer-therapy related symptoms and evaluate the need to include an ongoing individualized plan to manage symptoms in clinical practice.

Reliability

Excellent evidence of reliability was provided using two approaches. First, the internal consistency of the CSS as reported by Cronbach’s alpha was very encouraging. Second, test retest with a brief delay in even this small sample of 15 patients provided helpful evidence that the CSS is stable over time. Is it obvious that many symptoms, for example, pain and fatigue may vary from moment to moment and may depend on what is happening to the patient at that moment. Thus, although test-retest may not seem to be the ideal approach to reliability assessment for symptom scales, it never-the-less gave very acceptable results.

LIMITATIONS

Limitations of this study include the use of basic statistics. A more detailed examination of the CSS using regression modeling could be considered in the future. Other acknowledged limitations is the relatively modest sample size with heterogeneity in cancer diagnoses, type of treatments, and time points of treatment. A longitudinal study with a larger sample would have permitted a subset analysis of the ability of the instrument to discriminate among clinical characteristics, and to evaluate changes in symptoms over time. Another limitation was the involuntary error that the Spanish version did not include items on “feel drowsy,” “difficulty sleeping,” and “difficulty swallowing.” The symptoms of “feel drowsy” and “difficulty sleeping” ranked as second and third most common in the original study among non-Hispanics. Future research should examine the latter three symptoms in the Hispanic Puerto Rican population. Finally, our sample was limited to two sites; therefore, the findings may not be representative of the entire cancer population in Puerto Rico, nor of Puerto Rican

cancer patients living outside of Puerto Rico. Although the translated scale was not pre-tested among the target population, none of the participants reported that they had difficulty understanding the instructions nor the individual items. Nonetheless, we were able to evaluate the preliminary validity of the instrument; however, future studies including a larger sample and more representative of Puerto Rican cancer patients, are needed.

CONCLUSION

Our study demonstrated that the Spanish-CSS has good validity and excellent internal consistency for assessing cancer-therapy related symptoms. It discriminates between participants receiving chemotherapy treatment and those in post/treatment/survivorship clinics. Although symptom management is a clinical priority of comprehensive oncology care, the assessment of symptoms in Hispanic adult men and women during cancer treatments has received limited attention. With the worldwide increase in migration of Spanish-speaking families, and that cancer is highly prevalent among the Hispanics population (Centeno-Girona et al., 2013), nurses need to become familiar with and use valid and reliable symptom assessment instruments to provide culturally competent nursing practice (Sanchez et al., 2016; Trujillo et al., 2016).

Acknowledgments

Special appreciation to all the staff at Tome and Ubiñas Radiotherapy Center and at the Oncology Hospital Dr. Isaac Gonzalez Martinez. Thanks are extended to Miss. Sara Marrero for her insightful proofreading and editing role.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This article was made possible by the National Institute of Nursing Research (NINR) of the National Institutes of Health (NIH) under award number F32NR016618. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH

REFERENCES

Abdel-Wahab M, Mahmoud O, Merrick G, Hsu IC, Arterbery VE, Ciezki JP,Yamada Y (2012). ACR Appropriateness Criteria(R) external-beam radiation therapy treatment planning for clinically localized prostate cancer. J Am Coll Radiol, 9(4), 233–238. doi: 10.1016/j.jacr.2011.12.030 [PubMed: 22469373]

Aguado Loi CX, Baldwin JA, McDermott RJ, McMillan S, Martinez Tyson D, Yampolskaya S, & Vandeweerd C (2013). Risk factors associated with increased depressive symptoms among Latinas diagnosed with breast cancer within 5 years of survivorship. Psychooncology, 22(12), 2779–2788. doi: 10.1002/pon.3357 [PubMed: 24000126]

Carlotto A, Hogsett VL, Maiorini EM, Razulis JG, & Sonis ST (2013). The economic burden of toxicities associated with cancer treatment: review of the literature and analysis of nausea and vomiting, diarrhoea, oral mucositis and fatigue. Pharmacoeconomics, 31(9), 753–766. doi: 10.1007/s40273-013-0081-2 [PubMed: 23963867]

Canino G, Vila D, Normand SL, Acosta-Perez E, Ramirez R, Garcia P, & Rand C (2008). Reducing asthma health disparities in poor Puerto Rican children: the effectiveness of a culturally tailored family intervention. J Allergy Clin Immunol, 121(3), 665–670. doi: 10.1016/j.jaci.2007.10.022 [PubMed: 18061648]

Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, . . . et al. (1993). The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. J Clin Oncol, 11(3), 570–579. [PubMed: 8445433]

Cella D, Hernandez L, Bonomi AE, Corona M, Vaquero M, Shiomoto G, & Baez L (1998). Spanish language translation and initial validation of the functional assessment of cancer therapy quality-of-life instrument. Med Care, 36(9), 1407–1418. [PubMed: 9749663]

Centeno-Girona H, Cotto-Negrón C, Flores-Febo M, González-Lorenzo K, Pérez-Caraballo A, Serrano-Collazo C, Ortíz-Ortíz K, Pérez N, Torres C, Ortiz AP. (2013). Sobrevivientes de cáncer en Puerto Rico: Una guía informativa sobre aspectos relacionados a la sobrevivencia de cáncer. Registro Central de Cáncer de Puerto Rico, Centro Comprensivo de Cáncer de la Universidad de Puerto Rico Retrieved from: http://www.rcpr.org/Portals/0/Bolet%C3%ADn%20Registro%20de%20C%C3%A1ncer%20Sobrevivientes.pdf

Cleeland, 2014 The M. D. Anderson Symptom Inventory user guide. Retrieved from: http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tols/MDASI_userguide.pdf.

Cleeland CS (2007). Symptom burden: multiple symptoms and their impact as patient reported outcomes. J Natl Cancer Inst Monogr(37), 16–21. doi: 10.1093/jncimonographs/lgm005 [PubMed: 17951226]

Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, & Engstrom MC (2000). Assessing symptom distress in cancer patients: the M.D. Anderson Symptom Inventory. Cancer, 89(7), 1634–1646. [PubMed: 11013380]

Cleeland CS, Zhao F, Chang VT, Sloan JA, O'Mara AM, Gilman PB, . . . Fisch MJ (2013). The symptom burden of cancer: Evidence for a core set of cancer-related and treatment-related symptoms from the Eastern Cooperative Oncology Group Symptom Outcomes and Practice Patterns study. Cancer, 119(24), 4333–4340. doi: 10.1002/cncr.28376 [PubMed: 24114037]

Galvao M (2011). Underrepresentation of minorities in clinical trials: a current problem with escalating future implications. Heart Lung, 40(5), 391–392. doi: 10.1016/j.hrtlng.2011.05.006 [PubMed: 21784528]

Gonzalez VJ, McMillan SC, Groer M, Imbert S, Pedro E, & Tome J (2017). Symptom Burden: Experiences of Puerto Rican Men With Prostate Cancer Prior to External Beam Radiation Therapy. Clin J Oncol Nurs, 21(1), 104–112. doi: 10.1188/17.cjon.104-112 [PubMed: 28107324]

Gonzalez V, Williams PD, Tirado M, & Williams DD (2011). Patient-reported symptoms, alleviation and self-care methods, daily activities, and health-related quality of life during outpatient cancer treatments in Puerto Rico. Presented at Poster Session at the 2011 MNRS Annual Research Conference's, Columbus, Ohio March.

Gonzalez-Mercado VJ, Williams PD, Williams AR, Pedro E, & Colon G (2017). The symptom experiences of Puerto Rican children undergoing cancer treatments and alleviation practices as reported by their mothers. Int J Nurs Pract, 23(1). doi: 10.1111/ijn.12500

Gunn GB, Mendoza TR, Fuller CD, Gning I, Frank SJ, Beadle BM, Rosenthal DI (2013). High symptom burden prior to radiation therapy for head and neck cancer: a patient-reported outcomes study. Head Neck, 35(10), 1490–1498. doi: 10.1002/hed.23181 [PubMed: 23169304]

Hanna EY, Mendoza TR, Rosenthal DI, Gunn GB, Sehra P, Yucel E, & Cleeland CS (2015). The symptom burden of treatment-naive patients with head and neck cancer. Cancer, 121(5), 766–773. doi: 10.1002/cncr.29097 [PubMed: 25369213]

Jerome-D'Emilia B, Suplee P, & Akincigil A (2015). Validation of the Spanish Version of the Mammography-Specific Self-Efficacy Scale. Oncol Nurs Forum, 42(3), E279–286. doi: 10.1188/15.onf.e279-e286 [PubMed: 25901390]

Li RM, McCardel P, ClarK RL, Kinsella K, & Berch D (Eds.). (2001). Diverse voices-The inclusion of language-minority populations in national studies: Challenges and Opportunities. Retrieved from: https://www.nichd.nih.gov/publications/pubs/documents/Diverse_Voices.pdf

McMillan SC, Tofthagen C, Choe R, & Rheingans J (2015). Assessing Symptoms Experienced by Patients with Cancer Occurrence, Intensity, Interference, and Fatigue. J Hosp Palliat Nurs, 17(1), 56–65. doi: 10.1097/njh.0000000000000123

Portenoy RK, Thaler HT, Kornblith AB, Lepore JM, Friedlander-Klar H, Kiyasu E, et al. (1994). The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer, 30A(9), 1326–1336. [PubMed: 7999421]

Puerto Rico Cancer Control Coalition, P. R. Cancer Control Plan (PRCCC) 2015–203, (2015). Unpublished Manuscript.

Rosner B (2006). Fundamentals of Biostatistics, 6th ed. California: Duxbury Press.

Sanchez D, Chala A, Alvarez A, Payan C, Mendoza T, Cleeland C, & Sanabria A (2016). Psychometric Validation of the M. D. Anderson Symptom Inventory-Head and Neck Module in the Spanish Language. J Pain Symptom Manage, 51(6), 1055–1061. doi: 10.1016/j.jpainsymman.2015.12.320 [PubMed: 26899822]

Stein A, Voigt W, & Jordan K (2010). Chemotherapy-induced diarrhea: pathophysiology, frequency and guideline-based management. Ther Adv Med Oncol, 2(1), 51–63. doi: 10.1177/1758834009355164 [PubMed: 21789126]

Tofthagen CS, & McMillan SC (2010). Pain, Neuropathic Symptoms, and Physical and Mental Well-Being in Persons with Cancer. Cancer Nurs, 33(6), 436–444. doi: 10.1097/NCC.0b013e3181e212b4 [PubMed: 21479139]

Trujillo A, Feixas G, Bados A, Garcia-Grau E, Salla M, Medina JC, Evans C (2016). Psychometric properties of the Spanish version of the Clinical Outcomes in Routine Evaluation - Outcome Measure. *Neuropsychiatr Dis Treat*, 12, 1457–1466. doi: 10.2147/ndt.s103079 [PubMed: 27382288]

US. Department of Commerce, US census Bureau, Population Division. (2010). Puerto Rico and the Island Areas. Retrieved from: http://www.census.gov/prod/2011pubs/12statab/outlying.pdf

Yoon J, Malin JL, Tisnado DM, Tao ML, Adams JL, Timmer MJ,. Kahn KL (2008). Symptom management after breast cancer treatment: is it influenced by patient characteristics? Breast Cancer Res Treat, 108(1), 69–77. doi: 10.1007/s10549-007-9580-1 [PubMed: 17638071]

Yost KJ, Eton DT, Garcia SF, & Cella D (2011). Minimally important differences were estimated for six Patient-Reported Outcomes Measurement Information System-Cancer scales in advanced-stage cancer patients. J ClinEpidemiol, 64(5), 507–516. doi: S0895–4356(10)00431–2 [pii]10.1016/j.jclinepi.2010.11.018[doi]yost

Winstead-Fry P, & Schultz A (1997). Psychometric analysis of the Functional Assessment of Cancer Therapy-General (FACT-G) scale in a rural sample. Cancer, 79(12), 2446–2452. [PubMed: 9191537]

Summary Statement:

What is already known about this topic?

The Cancer Symptom Scale English version has proven to be useful for symptom management research and is currently it being used as a method to evaluate the effectiveness of interventions or palliative treatments in ameliorating cancer-therapy related symptoms.

What this paper adds:

The Spanish Cancer Symptom Scale is a valid and reliable instrument for determining the symptom profile of Hispanic Puerto Rican patients undergoing cancer treatments.

The implications of this paper:

The Spanish-Cancer Symptom Scale is an easy to answer numeric rating instrument that has the potential to be included in clinical practice settings to achieve a more comprehensive and objective assessment of the symptom experience.

Table 1

Characteristics of participants

Variable	Frequency	Percent
Gender		
Female	71	58.7
Male	50	41.3
Ethnicity		
White Hispanic	111	92
Black Hispanic	10	8
Marital Status		
Married	70	58.3
Single	20	16.7
Widow	18	15
Divorced	12	10
Cancer diagnosis		
Breast	39	32.2
Prostate	25	20.7
Colorectal (anal)	10	8.8
Cervical	9	7.4
Lung	6	5
Head and neck (laryngeal, lip & oral cavity)	6	5
Gastrointestinal (esophageal, gastric)	5	4
Sarcoma	4	3
Lymphoma	4	3
Multiple Myeloma	3	2.5
Genitourinary (Bladder, testicular)	3	2.5
Other solid tumors (neuroblastoma, pituitary, melanoma)	3	2.5
Ovarian	2	1.7
Skin	2	1.7
Type of Treatment		
Chemotherapy	51	42
Radiotherapy	53	44
Chemo-radiation	17	14

Table 2

Symptom Occurrence with Means and standard deviations (SD) of Symptom Scores

Symptom/Problem	Percent Reporting Symptom	Intensity		Distress		Interference		Frequency	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
Fatigued/tired	72.7	6.27	2.5	5.9	3.3	5.7	3.6	5.9	3.1
Dry mouth	59.5	6.2	2.8	5.7	3.6	4.8	3.8	6.4	3.4
Pain	57	6.3	2.9	6.0	3.3	5.8	3.7	7.2	3.1
Change in taste	44.6	7.6	2.8	7.4	3.5	6.0	4.2	7.7	3.0
Poor appetite	41.3	6.7	2.5	6.2	3.4	5.4	3.8	7.1	2.9
Constipation	38.8	6.4	3.4	6.3	3.8	5.7	4.0	6.3	3.5
Numbness/tingling feet	33.9	6.4	3.1	6.3	3.7	5.8	3.9	6.7	3.4
Nausea	33.1	5.4	2.9	5.3	3.4	4.4	3.7	5.3	3.3
Numbness/tingling hands	30.6	5.7	3.1	5.4	3.7	5.1	3.7	6.3	3.4
Hair loss	30.6	7.4	3.3	4.6	4.3	4.1	4.3	8.1	2.9
Dizziness	29.8	5.5	2.9	5.4	3.7	5.5	3.7	6.3	3.4
Feeling anxious	28.9	6.8	2.8	7.2	2.9	6.6	3.3	7.1	3.1
Feeling sad	28.9	7.2	2.6	7.2	2.9	6.9	3.2	7	3
Diarrhea	28.9	5.2	3.1	5.8	3.3	5.1	3.6	5	3.4
Worrying	28.9	7.6	2.6	7.1	3	6.4	3.6	7.2	3
Feeling bloated	26.4	6.9	3.3	6.7	3.8	6.1	4.1	7.4	3.4
Weight loss	25.6	5.8	3.2	4.0	3.9	3.9	3.4	5.6	3.5
Sweats	24.8	6.7	2.8	5.9	3.6	5.2	4.0	6.7	3.0
Changes in skin	24.8	6.2	3.5	5.2	3.9	4.2	4.1	7.4	3.2
Itch	24	6.5	2.9	5.5	3.8	4.2	3.9	6	3.2
Feeling depressed	24	7.0	2.8	7.0	3	6.7	3.3	6.8	2.7
Problems with urination	21.5	6.2	3.3	6.3	3.4	6	3.6	6.5	3.5
Cough	21.5	4.7	2.9	4.8	3.5	4.3	3.7	6.1	3.7
Sore Mouth	20.7	6.7	3.3	5.9	3.8	5.1	4.0	6.1	3.7
Difficulty concentrating	19.8	6.4	2.9	6.6	3.4	6.5	3.4	6.8	3
Swelling	19	6.7	3.1	5.4	4.2	5.5	4.2	6.7	3.5
Vomiting	19	5.5	3.5	5.3	4.5	4.9	4.4	5.3	3.7
Shortness of breath	17.4	5.6	2.8	4.9	3.1	5.1	3.2	5.0	3.0
Problems with sex	16.5	7.2	2.8	6.5	3.1	5.3	3.8		
Feeling nervous	16.5	7.5	3.2	7.7	3.2	7.4	5.3	7.8	3.1
Rash	14.9	5.2	3.4	3.6	3.5	2.5	3.3	4.9	3.7
Feeling Irritable	13.2	6.2	2.8	6.2	3.1	5.3	3.4	6.2	3.2

Table 3

Spearman Correlations Between the Matched Intensity Items of the Cancer Symptom Scale and the MD Anderson Symptom Inventory

Variables	***rho***	***p-value***
	rho	
Pain	.58	.001**
Fatigue	.73	.001**
Nausea	.69	.001**
Sad Intensity	.60	.001**
Dry mouth	.64	.001**
Poor appetite	.49	.001**
SOB	.66	.001**
Numb/feet	.55	.001**
Numb/hand	.68	.001**
Vomiting	.61	.002*
Difficulty Remembering	.82	.001**
Emotional Suffering (depressed)	.77	.001**

* p≤.05,

** p≤.001

Table 4

Spearman Correlations Between Cancer Symptom Scale Subscale Scores and Quality of Life Scores N=77

Subscale	*rho*	*p-value*
Intensity	-.65	.001**
Distress	-.62	.001**
Frequency	-.61	.001**
Interference	-.62	.001**

** p<.001

Table 5

Summary of Independent Samples t-test for the Intensity items of the Cancer Symptom Scale (Chemotherapy N = 51, Post-treatment/Survivorship clinic N = 32)

	Paired Samples t-test			
	Pairs	***Mean (SD)***	***t***	***p-value***
Fatigue	Chemo vs.	6.95 (2.3)	2.0	.05*
	Post-treatment	5.6 (2.7)		
Pain		6.9 (2.6)	.64	.52
		6.4 (2.7)		
Numb/feet		6.6 (2.8)	1.2	.23
		5.4 (2.9)		
Numb/hand		6.4 (3.0)	1.1	.29
		5.1 (3.2)		
Itching		6.1 (3.0)	.36	.72
		5.6 (3.0)		
Dizziness		6.0 (2.8)	2.0	.05*
		3.0 (2.0)		
Swelling		7.7 (2.8)	.60	.56
		6.2 (4.1)		
Nausea		5.4 (2.6)	.78	.44
		4.4 (2.4)		
Vomiting		5.4 (3.3)	.79	.44
		3.5 (3.5)		
Hair loss		7.6 (3.2)	2.2	.03*
		4.4 (2.4)		
Dry mouth		6.1 (2.4)	.09	.93
		6.0 (3.4)		
Taste change		7.8 (2.5)	2.5	.01*
		4.6 (3.4)		
Poor appetite		7.0 (2.2)	2.6	.01*
		4.5 (2.8)		
Weight loss		6.2 (2.9)	.56	.58
		5.3 (2.9)		
SOB		5.8 (2.8)	2.1	.05*
		3.0 (1.9)		
Cough		5.3 (3.3)	.68	.51
		4.2 (2.9)		
Constipation		6.7 (3.3)	.73	.47
		5.8 (3.9)		
Diarrhea		5.1 (3.1)	.47	.64

	Paired Samples t-test		
Pairs	***Mean (SD)***	***t***	***p-value***
	4.0 (4.2)		
Sweats	6.9 (2.6)	1.4	.17
	5.0 (3.1)		
Bloated	7.2 (2.8)	2.2	.04*
	4.0 (3.1)		
Sore mouth	6.0 (2.6)	.78	.45
	4.3 (4.9)		
Urination problems	5.5 (3.4)	.07	.95
	5.3 (4.0)		
Skin	7.2 (3.4)	1.6	.14
	3.7 (3.8)		
Rash	5.9 (3.4)	1.5	.15
	3.0 (2.1)		
Anxious	7.9 (2.0)	2.1	.05*
	5.7 (3.6)		
Depressed	7.9 (2.0)	2.1	.05*
	5.8 (3.5)		
Sex problems	7.1 (2.5)	.39	.71
	6.5 (4.1)		
Concentrate	6.8 (2.9)	1.5	.16
	4.8 (2.1)		
Sad	7.6 (2.3)	2.0	.05*
	5.6 (3.3)		
Worry	8.1 (2.4)	2.5	.02*
	5.5 (3.2)		
Nervous	8.1 (2.7)	1.5	.16
	6.1 (3.2)		
Irritable	7.3 (2.3)	1.1	.29
	6.0 (3.0)		

* $p \leq .05$

Table 6

Test-retest reliability

Subscale	*rho*	*p-value*
Intensity	.71	.003*
Distress	.73	.002*
Frequency	.74	.001*
Interference	.70	.004*

* p≤.05,

** p≤.001