The TRSC and Symptom Monitoring, Alleviation, and Self-Care among Mexican-Americans during Outpatient Cancer Treatments

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Abstract. *Background:* Cancer is the second leading cause of death in the USA, exceeded only by heart disease. But studies of diverse or minority groups are limited.

Purposes: To m onitor (a) the oc currence and (b) severity of symptoms among Mexican-American adults undergoing outpatient cancer treatments, and their (c) symptom alleviation and self-care engagement to alleviate symptoms.

Methods: 67 M exican-Americans receiving c are at a n out patient oncology treatment center in a Southwestern USA city. Captured patient symptoms and self-care using tools with g ood psychometric properties: the Therapy-Related Symptom C hecklist (TRSC); the S ymptom Alleviation: S elf C are M ethods (SASCM) tool; and a demographic and health form.

Results: Patients were being treated for various types of can cer, predominantly breast caner; stage range was II-IV. Mean age was 58 (Range: 29-86); female (76%); married (51%); and Catholic (81%) \geq 40% o f patients reported occurrence of \geq 12 symptoms with mean severities over 1 (scale of 0-4). Symptoms self-reported by 40%-73% of patients: Hair loss, feeling sluggish, nausea, taste change, loss of appetite, depression, difficulty sleeping, weight loss, difficulty concentrating, constipation, skin changes, and numb fingers/toes. More than one third also reported pain, vomiting, decreased interest in sexual activity, cough and sore throat. Helpful self-care strategies reported were: Diet/Nutrition (e.g. nutritional s upplements); Lif estyle C hange (e.g., exercise); M ind/Body Control (e.g., relaxation, prayers).

Conclusions/ Implications: Patient-report of symptoms during cancer treatments is facilitated by the use of the TRSC. Mexican-American patients use symptom a lleviation s trategies to help r elieve symptoms during their c ancer treatment. Use of a symptom checklist can identify neglected areas for intervention and p atient ed ucation or ar eas that may require d iscussion of ch anges in care and support with patients. It is not uncommon for patients to report 12 or more symptoms of concern to them.

1 Background

Cancer is the second leading cause of death in the USA, exceeded only by heart disease [1]. Cancer is an illness that affects Americans of all racial and ethnic groups [2]. Epidemiologic d ata s how i ncreasing can cer i ncidence and mortality i n minorities, especially a mong Hispanics, a fast growing ethnic group in the USA. Hispanics of Mexican origin constitute the single, largest group (66.9 % of the Hispanic population) [3]. The US Census Bureau [4] predicts that by the year 2050, Hispanics in the USA may reach 102 million. Cancer is the second leading cause of death, accounting for 20 % of a ll d eaths among Hispanics [3]. Patients u ndergoing cancer treatments experience many side effects that raise the need for symptom monitoring and management.

Conceptual Framework. Information about common symptoms and monitoring the success of self-reported strategies can guide health care providers (HCPs) in optimizing help for platients during treatments for cancer and counseling them on self-care. That is, when HCPs assist individual platients, they must be able to guide patients in the use of medically prescribed treatments and other strategies to be incorporated into "self-care."

Purposes. The purposes of this study were to examine: (a) the occurrence and (b) severity of symptoms as reported on the TRSC, and (c) symptom alleviation and use of s elf-care strategies u sed a mong M exican-American a dults u ndergoing can cer treatments.

2 Literature Review

2.1 Monitoring Symptom Occurrence and Severity

Cancer treatment involving the use of chemotherapy or radiotherapy at high or sustained dosages has intensified over the years. Concern about treatment symptoms and patient reactions has likewise increased. Chemotherapy often has side effects affecting b oth p hysical and mental well-being; these can i mpede the p atient's treatment progress. Patients' decisions to stop treatment are often traced to experiencing its side effects. Studies have documented the importance of systematic assessment of symptoms experienced during c ycles of treatment. Patient self-reports enable health care professionals to more effectively manage the early o nset of conditions threatening successful therapy [5-9].

Williams and colleagues developed the Therapy-Related Symptom Checklist (TRSC) to assess oncology patient-reported symptom occurrence and severity among cancer patients in the USA and in other cultures such as Thailand, the Philippines, China, and Puerto Rico [5-14]. The TRSC was developed specifically for use in busy clinics, and is readily answered by patients in 3 minutes prior to clinic consultations. Recent studies also have used checklists in oncology care delivery [15,16]. For example, one study [15] used the TRSC to monitor symptom occurrence and severity, which then guided e ducation/counseling pr ovided t o pa tients. I mproved f unctional

status and patient satisfaction with symptom management were found among patients who used the TRSC.

2.2 Symptom Alleviation and Self-Care Strategies

Research on cancer symptom monitoring a nd a lleviation a mong H ispanics in the USA were not found, although studies on cancer screening practices and the use of self-help have been reported [17,18]. Researchers have studied self-care methods used by non-Hispanic patients during cancer treatments to manage various symptoms. Williams and co-investigators [10-14] have developed and reported classification categories for the u se of "complementary car e." T hese i nclude diet/nutrition; li festyle change; mind/body control; herbal/biologic treatment; other; and the use of prescribed medicines.

3 Methods

3.1 Study Design and Sample

A cross-sectional study was conducted u sing a convenience sample of 67 pa tients receiving chemotherapy at a private cancer treatment center in the southwestern USA. The inclusion criteria were: a) at least 18 years of age; b) have had at least two weeks of chemotherapy; c) be able to read, write and speak Spanish/English; d) sign an informed consent witnessed by a study advocate. Institutional R eview B oard (IRB) approvals both at university and study settings were obtained.

3.2 Data Collection Instruments and Procedures

Instruments. The study used two instruments: the Therapy-Related Symptom Checklist (TRSC), described in the first paper in SS 14 and the Symptom Alleviation: Self-Care M ethods (SASCM) to ol. The S ymptom Alleviation: S elf-Care Met hods (SASCM) tool is used to report self-care strategies used to alleviate the symptoms reported on the TRSC-C. For each symptom reported, the patient was asked on the SASCM what methods were used to alleviate the symptom, and whether or not the method helped (yes/no answer). Studies reported good internal consistency reliability of the SASCM – see paper in SS 14. Higher SASCM scores indicate more frequent engagement in p arental care. Data c ollection was d one b y a trained bilingual researcher who is female. All study tools were administered by interview face to face with the patient in a private room.

Data Analyses. The first two study purposes were addressed using descriptive statistics. The third purpose was addressed using content analysis; the symptom alleviation self-care categories developed by Williams and colleagues were used in this analysis [10-14].

4 Findings

4.1 Sample Characteristics

The convenience sample of 67 Mexican-American patients, at a clinic in the Southwestern USA were receiving chemotherapy for various types of cancer, mostly breast cancer; stage range was II-IV. The patient mean age was 58.1 years; mostly women (76%), married (51%), and Catholic (81%). More than half (70%) had some high school or some college education, while 16% had a bachelor's education or higher; 40% were employed full time in a variety of professions/occupations; 27% and 31% of the patients were retired or unemployed, respectively.

4.2 Symptom Occurrence and Severity

The data showed that 45% or more of patients reported 12 symptoms on the TRSC: Feeling sluggish, hair loss, nausea, taste change, appetite loss, depression, difficulty sleeping, weight loss, difficulty concentrating, constipation, skin changes, and numb fingers and toes. More than one third also reported pain, vomiting, decreased interest in sexual activity, cough and sore throat. Overall, on 14 s ymptoms of the 25 on the TRSC, participants reported mean severity ratings greater than 1.0. Note that "mean severity" conservatively included the "0" scores; that is, symptom not present or of no concern to patient. If the severity calculation is based on scores 1-4 alone (i.e., those who ex perienced the s ymptom), the mean severity score would be about one p oint higher, mildly severe or severe. Also noteworthy is that all 25 TRSC symptoms were reported by patients with varying frequencies. The implication is that many patients are concerned about multiple symptoms and use if the TRSC as an assessment tool can more easily elicit complete or comprehensive symptom lists including symptom clusters than the standard (and usually quick) clinic interview.

4.3 Symptom alleviation and use of self-care

The self-care strategies reported were in the following categories: Diet/nutrition (e.g., protein d rinks); Lifestyle c hange (exercise); M ind/Body c ontrol (pray, r elaxation); Ethnomedicine/Biological T reatment (herbs, v itamins); M edication (e.g., P axil, T y-lenol), and Other (e.g. leave it alone or do nothing). The least used was the category Ethnomedicine/Biological T reatment. The 67 participants reported a t otal number of 265 self-care strategies to manage the symptoms reported on the TRSC. Over 90% of respondents affirmed the helpfulness of the self-care methods reported on the SASCM.

5 Conclusions

A large number of patients reported 12 or more symptoms on the TRSC, and symptom alleviation with self care methods were widely used. The more helpful self-care strategies were in the categories: Diet/Nutrition, Lifestyle Change, and Mind/Body Control. Findings are consistent with studies of other patients in diverse racial/ethnic groups.

Implications for Clinical Practice and Research. A systematic tracking and assessment of p atient-reported s ymptoms d uring th erapy i s e ssential. S uch tracking enables o neology car e p roviders to b etter c ollaborate with p atients to id entify and prioritize symptoms needing intervention as well as focus on patient self-care strategies used at home. Health Care Providers (HCPs) can e nhance the p erformance of symptom alleviation among patients. Recent studies have used checklists in oncology care delivery [15,16]. The use of the TRSC in health care delivery and its effects on outcomes such as functional status, quality of life, and should be studied, as illustrated in a recently published study on the use of the adult TRSC [16].

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