Translation and Customization of the Persian Version of Cancer Survivors Assessment Questionnaire (NCCN2.2020)

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ABSTRACT

Background & Objective: Gynecological cancer survivors have been growing, as a result of advancements in national cancer screening strategies, resulting in early-stage diagnosis, and cancer treatments developments. Lack of a valid documented assessment tool to measure their requirements for supportive care is detected. The aim was to develop a comprehensive scale that comprises all features of gynecologic cancer survivors` requirements in Iranian population.

Materials & Methods: The Cancer Survivors Assessment Questionnaire NCCN2.2020 (National comprehensive cancer network) was translated including the instructions, and the answer choices by two native translators, including one fluent translator and one linguist. For qualitative face validity of the questionnaire at the disposal of 10 specialists were delegated to make the necessary changes. Content validity and content validity index were evaluated in terms of qualitative face validity and quantitative face validity. Necessary changes were applied.

Results: The original Cancer Survivors Assessment Questionnaire NCCN2.2020 (National comprehensive cancer network) was condensed from 27 to 24 questions during the customization process. Questions related to lymphedema, and immunization were eliminated from the survey, as a result of low content validity index and scores. According to the panel of experts, ten questions including number 3, 5, 6, 9, 10, 13, 17, 18, 19, and 25 of the questionnaires were changed to a more suitable and comprehensible ones in Persian language.

Conclusion: We suggest that the Persian version of cancer survivors' assessment questionnaire be applied in populations with Persian language and that its sensitivity to variation be measured.

Keywords: Survivorship, Translation, Cross-Culture care, Questionnaire, Cancer

Introduction

In 2019, nearby 17 million cancer patients, containing 1.7 million new cases, were discovered in the United States **(1)**. Cancer patients encounter various degrees of distress affecting the body, mind, and sufferings related to the disease itself, or the treatment. Documentation and management of these complications in cancer patients is one of the most crucial apprehensions of cancer care **(2)**. Cancer survivorship care tries to discover improved healthy lifestyles for cancer patients, rather than just managing the complications; thus, it seems necessary to identify the aspects associated with general well-being in order to design proper care, and confront difficulties that cancer survivors encounter such as anxiety, depression, cognitive dysfunction, weakness, fatigue, pain, sexual dysfunction, and sleep disorders **(3-6)**. Cancer survivorship assessment from the National Comprehensive Cancer Network clinical practice guidelines in oncology (NCCN guidelines. survivorship, version 2.2020) is one of the most valid tools for measuring the quality of life in cancer survivors **(5-8)**.

It seems indispensable to provide a translated adapted version of NCCN survivorship questionnaire, to offer the Iranian cancer care providers have the prospect in comparison and approaches in a transcultural framework. The present study proposed to represent a renovated double back translation to revise

and culturally adapt the original English version of cancer survivors' assessment questionnaire into the Persian version in order to achieve a reliable tool that meets the clinical research needs of Iranian researchers at the desired level. The aim was to develop a comprehensive scale that comprises all features of gynecologic cancer survivors` requirements in Iranian population, equivalent to NCCN guideline hypothetical concept.

Methods

The study was confirmed by the Shahid Beheshti University of Medical Sciences. The aim of the study was to provide a Persian version of the questionnaire, practically equivalent to the English one to offer information collecting and assessment among different nations. The Cancer Survivors Assessment Questionnaire NCCN2.2020 (National comprehensive cancer network) was translated including the instructions, and the answer choices by two homegrown translators, including one fluent translator and one linguist. Two translations were compared to prevent any discrepancy between the versions. In case of any discrepancy between the two translations, it was translated by a third translator. There was no difference between two versions.

Evaluation, including perceptive questioning to examine the simplicity, unambiguousness, interpreting, relevance, and cultural significance of the questionnaire was considered. For qualitative face validity of the questionnaire at the disposal of 10 specialists including radio-oncologists; gyneco-oncologist; psychiatrist and hemato-oncologist. They were delegated to make the necessary changes. Questions were previously confirmed by qualitative face validity scale. Based upon expert panel judgement, five points Likert scale was used to determine the quantitative face validity scale of each question. The Likert scale was measured with these psychometric responses to specify subjects` level of agreement to each question: Strongly agree (5 points); Agree (4 points), Neither agree nor disagree (3 points); Disagree (2 points), and strongly disagree (1 point). The questionnaire with above mentioned scales was delivered to 15 individuals including 7 patients and 8 experts. Influence coefficient was calculated based on their responses for each question. The question that had an influence coefficient for more than 1.5 remained in the set of questions.

Content validity and content validity index were evaluated in terms of qualitative face validity and quantitative face validity. Necessary changes were applied according to the panel of experts on (n=10 in 4 different specialties) and 7 moderately literate patients. To assess the content validity ratio (CVR) of each question, the questionnaire was delivered to the expert`s panel for classification, and they were characterized as three grades of significance including 3: necessary, 2: useful but not necessary, and 1:

unnecessary. A question that received a value of higher than 0.62 considered satisfactory for the study. In order to evaluate the content validity index (CVI) of the questions, the experts characterized each question into three scoring levels including 1: unrelated, 2: partially related, 3: related, and 4: completely related. In brief, content validity index was obtained from the sum of 3 and 4 points on the total number of experts.

The NCCN questionnaire assesses disorders in each of the areas of cardiac function, anxiety, cognitive function, fatigue, symptoms of hormone deficiency, pain, sexual function, sleep and health, and lifestyle. The heart area consisted of two questions and if the answer to any of the questions was "yes" it was considered a disorder. The anxiety area consisted of three questions that if each was "yes" the function in this area was considered impaired. The cognitive area had three questions that if any of them were "yes", the performance of the domain was considered impaired. The fatigue area had 3 questions entitled "fatigue coexistent with adequate night sleep", "fatigue intensity" and "fatigue score" which if answered "yes" to any of the questions or fatigue score of more than 3, disorder was considered. There were two questions related to hormone deficiency that if answered "yes" to any of the questions, it was considered a disorder. The pain domain included 2 questions entitled "pain feeling", and "pain score". The "yes" answer to pain feeling or pain score of more than 4 was considered disorder. The field related to sexual function had two questions that if answered "yes" to any of the questions, the function of the field was considered impaired. The field related to sleep had three questions that if answered "yes" to any of the questions, it was considered impaired. Healthy life style had four questions that if the answer to the questions "concern about weight", "exercise less than 3 times a week" and "consumption of fruits and vegetables less than 2.5 cups per day" was positive, it was considered a disorder. The health and lifestyle of taking or not taking supplements is not a disorder but refers to the side effects of treatment such as osteoporosis or poor diet that is compensated for with supplements.

Results

The original Cancer Survivors Assessment Questionnaire NCCN2.2020 (National comprehensive cancer network) was condensed from 27 to 24 questions during the customization process. Questions related to lymphedema, and immunization were eliminated from the survey, as a result of low content validity index, and scores. According to the panel of experts, ten questions including number 3, 5, 6, 9, 10, 13, 17, 18, 19, and 25 of the questionnaires were changed to a more suitable and comprehensible ones in Persian language. The original English version of 2020 NCCN Cancer Survivors Assessment Questionnaire and final customized Persian version is attached in Table 1.

Table 1. Final Persian version of the NCCN survivorship questionnaire Persian final translation after perceptive and contented validation and scoring of the original questionnaire

CVI	CVR	Impact score	Questions
1	1	4.4	1.Do you have shortness of breath or chest pain after physical activities (ex, climbing stairs) or exercise?
1	0.8	4.27	2.Do you have shortness of breath when lying flat, wake up at night needing to get air, or have persistent leg swelling?
1	1	4.6	3.In the past two weeks, have you been bothered more than half the days by little interest or pleasure in doing things?
1	0.8	4.47	4. In the past two weeks, have you been bothered more than half the days by feeling down, depressed, or hopeless?
1	0.8	4.47	5.Has stress, worry, or being nervous, tense, or irritable interfered with your life?
1	0.8	4.47	6. Does your thinking seem slow?
1	0.8	4.6	7.Do you have difficulties with multitasking or paying attention?
1	0.8	4.47	8.Do you have difficulties with remembering things?
1	0.8	4.53	9.Do you feel persistent fatigue despite a good night's sleep?
1	1	4.47	10.Does fatigue interfere with your usual activities?
1	1	4.47	11. How would you rate your fatigue on a scale of 0(none) to 10(extreme) over the past week?
1	1	4.53	12. Have you been bothered by hot flashes/night sweats?
1	1	4.47	13.Have you been bothered by other hormone-related symptoms(ex, vaginal dryness, incontinence)?
1	0.8	4.5	14. Are you having any pain?
1	1	4.47	15.How would you rate your pain on a scale of 0(none 0 to 10(extreme) over the past month?
1	1	4.33	16.Do you have any concerns regarding your sexual function, sexual activity, sexual relationships, or sex life?
1	0.8	4.14	17.Are these concerns causing you distress?
1	1	4.4	18.Are you having problems falling asleep, or waking up too early?
1	0.8	4	19. Have you been told that you snore frequently or that you stop breathing during sleep?
1	1	4.4	20.Are you experiencing excessive sleepiness (i.e., sleepiness or falling asleep in inappropriate situations or sleeping more during a 24-hour period than in the past)?
1	0.8	4.53	21. Do you engage in regular physical activity or exercise, such as brisk walking, jogging, weigh/resistance training, bicycling, swimming, etc.?
1	0.8	5	22.Excluding white potatoes, do you eat at least 2/5 cups of fruits and/or vegetables each day?
1	0.8	4.47	23.Do you have concerns about your weight?
1	1	4.47	24.Do you take vitamins or other supplements?

Discussion

Gynecological cancer survivors have been growing as a result of advancements in national cancer screening strategies, resulting in early-stage diagnosis, and cancer treatments developments; thus, general mortality to incidence ratios have been declined from 2000 to 2015. For all cancers combined, in cancer statistics (2018), the 5-year relative survival rate during the most recent time period (2007-2013), in females, was estimated to be 90% for female breast cancer, and 22% for uterine corpus cancer. The incidence of five-year survival for stage I, uterine cancer as the most frequent gynecologic cancer, is approximately 80-90%. Luckily, 75% of the patients present with early-stage disease. For stage II, the survival has become 70-80%, and 20-60% for stage III and IV **(1, 9-15)**. However, lack of a valid documented assessment tool to measure their requirements for supportive care is detected **(16)**. Health givers often dismiss the importance of cancer survivors` distress and require to be trained and have skills to deliver ideal management **(4)**.

The NCCN Survivorship Guidelines deliver broadcast estimation, assessment and management references to the consequences of cancer and its treatment, in order to help cancer survivors` professional care givers improve patients' health and quality of life. Applied guidelines embrace

recommendations by specialists created by means of research to modify medical care for each individual. The NCCN Survivorship Assessment addresses general survivor`s issues, late and long-term effects of treatment (7).

Researchers are usually looking for tools that cover the anticipated impressions as accurately and completely as possible. The effectiveness of interventions and treatment programs is affected by the measures and clinical conclusions that the assessment tool has provided. It is essential to perform not only the clinical evaluation in order to quantify, categorize, and enterprise a suitable treatment, but also conceive the patients' subjective expressions. Cultural factors have long been recognized to influence patients' perception and discernment of their problems. To facilitate the multicultural evaluation of cancer survivor`s complications and receive information on epidemiology and etiology of the problems, the practice of consistent assessment tools is critical. The preferred assessment tool involves the definitions of terminologies for the interested language, to give appropriate principles, and indicate indispensable correct information. The translated version will empower us to examine for equivalence of scores through groups with varied customary beliefs, to attain further information about the quality of life in these patients, and develop culturally proficient structures of care. It is ideal to practice identical assessment tools to enable the inclusive contrast of the problem, and receive information about incidence, distribution, and origins of the subject. Accordingly, modifying the survey is required to assess its assets in reliability, rationality, frankness, and practicability among concerned subjects, as a considerable reference, and make it culturally suitable for a nation's population. In spite of being an internationally practical objective assessment instrument, the NCCN survivorship questionnaire has not been translated and culturally adapted for assessing cancer survivors in the Iranian female population (8, 17-20).

Cultural interactions affect people's perceptions and health practices and are areas of interest and study by health professionals. Due to the cultural diversity of many countries, culturally sensitive assessment methods are needed, but there are many challenges in achieving a valid and reliable measurement. This is especially important in cancer care. The translation of the questionnaire for intercultural research is fraught with methodological problems (21). The translation of the questionnaire for intercultural research is full of methodological problems related to colloquial expressions, specialized terms, idiomatic expressions, word clarity and word meanings. It cannot be assumed that a particular concept has the same relationship between cultures. Merely translating an English version into another language is not enough to explain linguistic and cultural differences. Ideally, one should first study the culture's view of the concept of interest, but often a practical alternative is to find and translate a tool developed in another culture (22-24).

The original Cancer Survivors Assessment Questionnaire needs to be translated into other languages for the reason that they have been multicultural modified and validated in a unlike sociocultural atmosphere. In order for the results of a study to be related to another nation, the questionnaire should be applied by cultural, religious, or compatible principal standards (7). Furthermore, it is important to evaluate the assets of the authorized instrument to the target population, in our case, Iranian gynecologic cancer survivors. This study aimed to develop a Persian version of NCCN Guideline survivorship assessment to support Iranian clinicians in defining suitable and effective ways of care in the Iranian population. The Persian form of NCCN Guideline survivorship assessment could be considered a decent cross-cultural correspondent for the original English version. The questionnaire was a consistent and valid tool in terms of internal reliability, test-retest consistency, and dimensionality.

Conclusion

The Persian version of cancer survivors' assessment questionnaire (based on NCCN 2.2020 survivorship guideline) can be used as a consistent, effective, approachable, and practicable instrument for evaluating complications in Iranian gynecologic cancer survivors. It can support Iranian clinicians to have a multidimensional understanding of the difficulties that Persian language gynecologic cancer survivors meet and can be practiced for both clinical and research purposes. We suggest that the Persian version of cancer survivors' assessment questionnaire be applied in populations with Persian language and that its sensitivity to variation be measured.

Acknowledgments

Conflict of Interest

There is no conflict of interest.

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