

Translation and pilot validation of Hindi translation of assessing quality of life in patients with primary brain tumours using EORTC brain module (BN-20)

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ABSTRACT

Aim: To translate and validate the European Organisation for Research and Treatment for Cancer (EORTC) brain cancer module (BN-20) into Hindi to make it available for patients and scientific community.

Methods and Results: The EORTC BN-20 was translated into Hindi using standard guidelines by EORTC. The process included forward translation by two translators, discussion with the translators in case of discrepancies and formation of first intermediate questionnaire. This questionnaire was then given to two more translators who translated this questionnaire back into English. These 2 questionnaires were then compared with the original EORTC questionnaire and the second intermediate questionnaire was formed. The second intermediate questionnaire was subsequently administered in 10 patients with brain tumors who had never seen the questionnaire before, for pilot-testing. Each of these 10 patients after filling up the questionnaire themselves was then interviewed for any difficulty encountered during the filling up of the questionnaire. These were in the form of specific modules including difficulty in answering, confusion while answering and difficulty to understand, whether the questions were upsetting and if patients would have asked the question in any different way. There were major suggestions in three questions, which were incorporated into the second intermediate questionnaire to form the final Hindi BN-20 questionnaire.

Conclusion: The final Hindi BN-20 has been approved by EORTC and can be used in clinical practice and studies for patients with brain tumors.

KEY WORDS: Brain tumours, BN 20, EORTC, quality of life, questionnaire

INTRODUCTION

Brain tumors can affect patient's physical and cognitive functions considerably. Patients during the course of diagnosis, treatment and follow-up go through physical, psychological, emotional and social problems. Quality of life (QoL) is a multidimensional concept consisting of physical, psychological and social issues and has been increasingly recognized as an important outcome measure in addition to classic endpoints of disease free and overall survival. The European Organization for Research and Treatment of Cancer QoL core questionnaire (EORTC-QLQ-C30) is one of the frequently used questionnaires in oncology practice, but is broad and generalized without addressing specific issues pertaining to patients with brain tumors. In this regard, a specific brain tumor scale, the Brain Module (BN-20), has been formulated to be used along with the general questionnaire [Table 1]. However, the

module is in English language and since the questionnaires are self-administered they cannot be used in a large majority of patients seen in our set-up. The aim of this work therefore was to formulate an appropriately translated Hindi questionnaire as per recommended guidelines, with the ultimate objective to make it available for the clinicians and scientific community dealing with Hindi speaking patients for day-to-day practice and research.

MATERIALS AND METHODS

We adopted the suggested guidelines for translation procedure as given by EORTC. One of the authors (AB) acted as the local project manager and liaison person for identifying and coordinating with the translators. The suggested step methodology was as follows:

Forward translations involved translation of the original BN 20 English questionnaire into Hindi by

Table 1: EORTC. QLQ BN20 Questionnaire

Patients sometimes report that they have the following symptoms. Please indicate the extent to which you have experienced these symptoms or problems during the past week.

During the past week:		Not at all	A little	Quite a bit	Very much
31.	Did you feel uncertain about the future?	1	2	3	4
32.	Did you feel you had setbacks in your condition?	1	2	3	4
33.	Were you concerned about disruption of family life?	1	2	3	4
34.	Did you have headaches?	1	2	3	4
35.	Did your outlook on the future worsen?	1	2	3	4
36.	Did you have double vision?	1	2	3	4
37.	Was your vision blurred?	1	2	3	4
38.	Did you have difficulty reading because of your vision?	1	2	3	4
39.	Did you have seizures?	1	2	3	4
40.	Did you have weakness on one side of your body?	1	2	3	4
41.	Did you have trouble finding the right words to express yourself?	1	2	3	4
42.	Did you have difficulty speaking?	1	2	3	4
43.	Did you have trouble communicating your thoughts?	1	2	3	4
44.	Did you feel drowsy during the daytime?	1	2	3	4
45.	Did you have trouble with your coordination?	1	2	3	4
46.	Did hair loss bother you?	1	2	3	4
47.	Did itching of your skin bother you?	1	2	3	4
48.	Did you have weakness of both legs?	1	2	3	4
49.	Did you feel unsteady on your feet?	1	2	3	4
50.	Did you have trouble controlling your bladder?	1	2	3	4

two native speakers with Hindi as mother tongue and fluent in the English language as well.

First intermediate Hindi questionnaire was to be formed from the two forward translations where the local project manager discussed each question with the translators after personal meetings and telephonic conversations and finally an intermediate Hindi questionnaire was to be formed.

Back translation

The first intermediate Hindi questionnaire was to be then given to two independent translators, fluent in English and Hindi, to back translate it to English. The second intermediate questionnaire: This back translation was then to be compared with the original English questionnaire to form the second intermediate questionnaire.

Pilot testing

This second intermediate questionnaire was then to be administered to 10 patients with brain tumors who had never seen the questionnaire to form the final questionnaire.

RESULTS

The result of carrying out the above methodology in our testing and validation was as follows:

Step 1: Forward translations

The aim of this first step was to translate the BN-20 into Hindi and produce a version that would be conceptually as close as possible to the original questionnaire. The English questionnaire was given to the two translators. Translator I was an occupational therapist (TJ) with Hindi as the native

language and had very good command over English. The translator II was a radiation oncologist (RJ) who also was a native Hindi speaker and had extremely good command over English.

Steps II and Step III

Difficulties encountered and the first intermediate Hindi questionnaire

The two questionnaires were evaluated by the project co-coordinators. There were no differences for the first seven questions. In question eight, both questions had similar meaning but word आँखें meant eyes compare to नजर meaning vision as done by the translator II. Hence the question by translator II was considered for the intermediate questionnaire. Translator I used the word बीमारी in question eight which means illness while the translation by translator II appeared more correct. In question 15, the word समन्वय used by translator I is used in written language more. It is difficult to understand the meaning of this word for the layperson. On the other hand the word तालमेल used by the translator II is routinely used in the spoken language. Hence the question by the translator II was considered for the first intermediate questionnaire.

Wherever there were discrepancies between the two, the points were discussed with the translators either personally or over the telephone. Based on the two forward translations and individual discussion with the translators, a first intermediate questionnaire was formed which was an amalgamation of appropriate questions from the two translations depicting the nearest translation to the questions contained in the original English questionnaire. This was done by the two project co-coordinators.

Step IV: Back translations

The intermediate questionnaire was given to the two translators working who had never seen the original EORTC BCM-20 questionnaire before. They were given information regarding the questionnaire explaining that it was a quality of life assessment tool specific for brain tumors. They were requested to formulate the questions in simple English language understandable to every one.

Translator I (DS) was an official translator working at our hospital. Translator II (TG) was another radiation oncologist working at our hospital. Both of them had good command over both English as well as Hindi languages.

Step V: Second Intermediate Hindi questionnaire

The two back translations were compared to each other and also to the original questionnaire. All questions by both the translators were similar to each other and to the original questionnaire.

As the translations by both the translators were almost same, the first intermediate Hindi translation did not need any modification and was taken as the second intermediate Hindi questionnaire.

Step VI: Pilot testing

The second intermediate Hindi questionnaire was then administered to 10 patients diagnosed to have a brain tumor. These patients had never seen the questionnaire before and were all native Hindi speakers. Patient population comprised of six males and four females with a median age was 40 years (range 22-54 years). The histopathological subtypes of brain tumors included three high-grade gliomas, two glioblastoma multiforme, one low-grade glioma, two pituitary adenoma, one pineoblastoma and one schwannoma. The native language (mother tongue) of all patients was Hindi. The educational status was elementary school in one, junior high school in two, senior high school in five, college and above in two patients. All patients had undergone some sort of surgical procedure for their brain tumors. Each patient after filling-up the questionnaire was then interviewed, in which questions were asked directing the each module with respect to difficulty in answering, confusion while answering and difficulty to understand, whether the questions were upsetting and if the patients would have asked the question in any different way.

Difficulties encountered in the pilot testing

Minor difficulties encountered are not discussed over here. There were significant problems for 3 questions for which the questions needed amendment. Q5 Patient 1 (SK), patient 2 (RS) and patient 5 (FD) found the word दृष्टीकोन difficult and suggested the word नजरिया for it. Patient 6 (PT) and patient 9 (HB) also found the word दृष्टीकोन difficult but could not suggest any alternative for the same. As 5 patients had difficulty in

understanding the word दृष्टीकोन, we modified our question replacing it with नजरिया and the final question was kept as: क्या आपका भविष्य के बारे में नजरिया बिगड़ा?

Q13 Four patients had difficulty in understanding this question. Patient 1 (SK) suggested: क्या आपको खयालत बताने में तकलिफ होती थी? Patient 4 (JL) and patient 9 (HB) found the word आदान प्रदान difficult and suggested लेन देन in its place. Patient 5 (FD) had difficulty in understanding this question and suggested: क्या मैं बोलती हो वो आपके समझने में या आप बोलते हो वो मुझे समझने में तकलिफ होती थी? We felt that the word आदान प्रदान used by our translators is used more in written language and is relatively difficult to understand for the lay people. The word लेन देन suggested by them appears more understandable and useful in day-to-day practice and therefore was modified in our final questionnaire.

Q15 four patients had a bit of difficulty in understanding this question. Patient 2 (RS) found this question difficult to understand. No single word was difficult for her. She suggested: क्या आपको कोई काम करने में कठनाई होती थी? Patient 3 (RS) and (10) had a bit of difficulty in understanding this question but could not suggest any simpler question. Patient 9 (HB) also found some difficulty in understanding this question and suggested: कुछ काम काज करने में तकलिफ होती थी?

The questions suggested by the two patients do not convey the same meaning as in the original questionnaire. Therefore we felt that the question in our intermediate questionnaire was more correct and retained the same. The suggestions made by the patients were incorporated in the three questions and the final Hindi BN-20 questionnaire was formed, which was subsequently submitted to EORTC for ratification and acceptance.

DISCUSSION

EORTC questionnaire consists of a core questionnaire and a site-specific questionnaire. The core questionnaire consists of 30 questions of which two questions are for global quality of life. BN-20 is a specific brain cancer module and consists of 20 items grouped in four domains and seven single items. The four domains consist of various items concerning future uncertainty, visual disorder, motor dysfunction and communication deficit. The symptoms scale consists of various symptoms related to the neurological problems. The questionnaire is administered to the patient and the patient has to answer the questions himself. Therefore it is very important to have the questionnaire in patient's own language so that they can understand and answer in a better way. Translation of the BN- 20 module in different languages has been done previously.^[2,3] It is difficult for common people in India to understand English as the national language in our country is Hindi. The EORTC QLQC30 has previously been translated into Hindi at our hospital and is used generally in

the research protocols and clinical trials in the Hindi-speaking communities.

The cultural adaptation of QOL questionnaire encompasses two essential steps: a translation stage ensuring linguistic validity of the questionnaire in the new language and evaluation of the psychometric properties of the questionnaire and psychometric validation. The two are complementary and indispensable in demonstrating the equivalence between the original and translated questionnaire. With a population of one billion and the national language being Hindi, a majority of people speak Hindi in India. Apart from India there are large numbers of Indians who are settled in various parts of the world and have Hindi as their mothertongue. It was therefore very necessary to provide a translation of the Brain cancer module in Hindi so that it could be used for clinical trials by clinicians in India as well as abroad for the Hindi-speaking patients.

We adopted the suggested guidelines for translating and validating the Hindi translation of BN-20 questionnaire. The final completed translation was submitted to EORTC where it was evaluated for the accuracy in translation as well as method of translation. A few queries related to the translation were discussed with the translators and incorporated in the final version, which has been approved by EORTC with the requisite

copyright and can now be used in various clinical trials of brain tumors as well as in routine QoL assessment for Hindi-speaking patients [Table 2].

CONCLUSIONS

Quality of life is an important outcome measure especially in brain tumors and is being increasingly used in clinical trials. EORTC QLQ is the most commonly used QoL questionnaire. The cultural adaptation of QLQ is a rigorous and complex process. The main objective is to obtain a conceptual equivalence between the original and translated versions which then allows comparison amongst various international trials. The translation of EORTC BN-20 was carried out as per the EORTC guidelines for translation and within the confines of internationally accepted methodologies. The pilot-testing of the questionnaire showed some difficulties in three questions which were then modified as per the spoken language. EORTC BN-20 now (Hindi) has been approved by the EORTC and can be used in the clinical trials involving brain tumors with permission from the EORTC QLQ unit (www.eortc.be/home/qol).

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Table 2: EORTC QLQ- Translated final Hindi questionnaire EORTC QLQ - BN20

मरीज कुछ बार नीचे लिखे हुई तकलीफें बताते हैं कृपया आप हमें बताएं कि आप को पिछले सप्ताह में किस हद तक तकलीफ हुई

क्र.	पिछले एक सप्ताह/हफ्ते में	बिलकूल नहीं	थोड़ासा	जादा	बहुत जादा
१.	क्या आपको अपना भविष्य अनिश्चित लगा?	१	२	३	४
२.	क्या आपको लगा की आपकी स्थितियों में कुछ रुकावटें आयीं?	१	२	३	४
३.	क्या आपको अपने परिवारिक जीवन के टुटने की चिंता हुई?	१	२	३	४
४.	क्या आपको सिरदर्द था?	१	२	३	४
५.	क्या आपका भविष्य के बारे में नजरिया बिगड़ा?	१	२	३	४
६.	क्या आपको कोई वस्तु दो (दुगनी) दिखती थी?	१	२	३	४
७.	क्या आपको धुंधला दिखता था?	१	२	३	४
८.	क्या आपको नजर के वजह से पढ़ने में कोई दिक्कत हुई?	१	२	३	४
९.	क्या आपको कोई मिरगी / झटका आया?	१	२	३	४
१०.	क्या आपको शरीर के एक तरफ के भाग में कोई कमजोरी थी?	१	२	३	४
११.	क्या आपको अपने विचार प्रगट करने में उपयुक्त शब्द ढुंढने में कठिनाई होती है?	१	२	३	४
१२.	क्या आपको बोलते समय तकलीफ होती थी?	१	२	३	४
१३.	क्या आपको विचारों के लेन देन में कठिनाई होती थी?	१	२	३	४
१४.	क्या आपको दिन में सोने जैसा लगता है?	१	२	३	४
१५.	क्या आपके तालमेल में कठिनाई आयी?	१	२	३	४
१६.	क्या आप बाल झड़ने से परेशान होते थे?	१	२	३	४
१७.	क्या त्वचा कि खुजली ने आपको परेशान किया?	१	२	३	४
१८.	क्या आपको दोनों टांगों में कमजोरी थी?	१	२	३	४
१९.	क्या आपको पैरों में असंतुलन महसूस होता था?	१	२	३	४
२०.	क्या आपको पेशाब नियंत्रण करने में तकलीफ होती थी?	१	२	३	४

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