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#### Research article

## Validation of Bengali version of EORTC QLQ-SWB32: A standalone measure of spiritual wellbeing for advanced cancer patients receiving palliative care

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#### ARTICLE INFO

# Keywords: Bengali language Neoplasms Palliative care Quality of life Spiritual wellbeing

#### ABSTRACT

Background: Spiritual wellbeing (SWB) is one of the crucial components of holistic care for patients with terminal illnesses. The use of a validated instrument can help health professionals approach this difficult and subjective topic. There is no validated Bengali tool to measure this domain. Our study aimed to translate the EORTC QLQ SWB32 tool into Bengali, validate it among advanced cancer patients in Bangladesh, and compare the study's findings to international validation studies to determine its suitability as a measurement and intervention tool for these patients.

Methods: The original English version of the tool was translated in Bengali and back-translated by four independent translators with good command in both languages. After approval from the EORTC translation team and linguistic validation, the tool was further validated among 163 advanced cancer patients from palliative care units of four tertiary-level hospitals in Bangladesh. Reliability was tested with Cronbach's alpha, and construct validity was determined by exploratory factor analysis. Known group comparisons were performed by the Kruskal-Wallis H test and the Mann-Whitney U test.

Result: Ten adult cancer patients (two female and eight male, three Hindu and seven Muslim) participated in the linguistic validation. Six out of ten participants found the measure understandable and acceptable. A total of 163 advanced cancer patients participated in the psychometric validation phase. The majority of those participants were Muslims (94 %), with a slight male predominance. The internal consistency of each scale was satisfactory (0.7). Exploratory factor analysis also showed similarity to the original scale except item 12 (able to forgive others), which was loaded in both the EX and RO components (0.813 and 0.544, respectively). Older patients had a better relationship with themselves and a lower level of existential fulfilment than the younger group. Patients who tried to find comfort in their religion or spiritual faith, actively performed religious rituals, and had affiliations with religious or spiritual communities showed significantly higher global SWB.

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Conclusion: The Bengali version of the EORTC QLQ-SWB32 is a reliable and valid tool for measuring the spiritual wellbeing of advanced cancer patients receiving palliative care.

#### 1. Introduction

Spirituality is a fundamental part of human existence. It relates to each person's thought, their search for meaning of life, how they connect to self, others, nature, as well as transcendence [1,2]. Being diagnosed with a life-limiting illness like cancer invariably gives this spiritual process a new urgency, which may include a necessity to examine one's own beliefs and values that have been shaken and upended by life's experiences [3]. Patients often reflect on their lives, purpose, and experiences with the illness process, particularly at times of distress, suffering, loneliness, and deprivation, all of which challenge their values and beliefs and affect their quality of life [4].

The term "spiritual wellbeing" is used to indicate a quantifiable domain of quality of life in scientific literature (QOL) [5]. Addressing spiritual concerns and ensuring spiritual wellbeing are major components of end-of-life care [6]. As a multifaceted concept, spiritual wellbeing typically refers to a sense of value or purpose in life, inner peace and harmony, and the strength and peace found in faith [7]. In terminally ill patients, higher level of spiritual wellbeing reduces suicidal thoughts, hopelessness, and the desire for an early death. Furthermore, it increases their emotional happiness and life satisfaction, improves their coping mechanisms and acceptance of the prognosis, and thus ultimately improves their overall quality of life [8–10].

Unmet spiritual needs can cause painful spiritual distress in patients. Spiritual care is one of the crucial components of holistic care for patients with terminal illnesses. It is also an important intervention to improve their quality of life. The use of a validated instrument can help health professionals approach this difficult and subjective topic [11].

There are multiple instruments for measuring spiritual wellbeing (SWB) [12]. One widely validated tools for measuring spiritual wellbeing is the EORTC QLQ-SWB32 (SWB32), developed by the European Organization for Research and Treatment of Cancer (EORTC). This tool has five scales: Relationships with Self (RS), Relationships with Others (RO), Relationship with Someone or Something greater (RSG), Existential (EX), and Relationship with God (RG) for individuals who believe in God. This standalone questionnaire enquires into the spiritual concerns of palliative patients. It is a universal assessment tool that is not limited to a specific religious or spiritual belief. The EORTC QLQ-SWB32 is a unique instrument designed to assess participants' spiritual wellbeing and provide intervention during the questionnaire completion process. It also emphasizes the need for presence of the healthcare team during this process, offering emotional, psychological, and/or spiritual support as necessary [13,14].

There is currently no valid standalone tool to measure spiritual wellbeing for Bengali-speaking population. The EORTC QLQ-SWB32 is an internationally validated tool for assessing spiritual well-being. Our primary goal was to translate this tool into Bengali, validate it among advanced cancer patients in Bangladesh, and compare the study's findings to international validation studies to determine its suitability as a measurement and intervention tool for these patients.

#### 2. Methods

#### 2.1. Measure

#### 2.1.1. Instrument

A structured questionnaire divided into two sections, was prepared for data collection. The first section contained sociodemographic, clinical and spiritual variables like age, sex, marital status, education, monthly income, primary diagnosis, cancer stage, duration of getting palliative care, Eastern Cooperative Oncology Group (ECOG) performance status, religion, and use of religious or spiritual belief as coping mechanism. Religious/spiritual coping was assessed by three variables: trying to find comfort in religion/spiritual faith, actively performing religious rituals, and having affiliation with religious/spiritual communities.

The second part included the EORTC QLQ-SWB32 questionnaire, which was originally validated with people receiving palliative care for cancer, and has since also been validated with people receiving curative cancer treatment. It is a validated measure for intervention and assessment of the key issues regarding respondents' spiritual wellbeing. It also acknowledges the necessity of consulting spiritual and mental health experts if required [13,14]. The QLQ-SWB32 includes 32 items, with 22 items forming four multi-item scales: RO (six items), RS (five items), RSG (five items), and EX (six items). RG and Global-SWB are single item scales. There are eight non-scoring items: two for screening belief in someone or something greater, and six for exploring clinically relevant concerns. Non-scoring items are retained in the measure because they prompt relevant and valuable discussions with the patients. Global-SWB scores range from 1 (very poor) to 7 (excellent) with 0 for don't know or can't answer. The other 31 items are scored from 1 (not at all) to 4 (very much). The sum scores from the four QLQ-SWB32 scales and Global-SWB are converted into scores ranging from 0 to 100, with 100 representing the highest possible score. Only the RS scale is reverse scored [13].

#### 2.1.2. Settings and criteria for patient recruitment

The translation process was done from March to July 2022. Linguistic validation was conducted from May to June 2023 at both the oncology and palliative care departments of Bangabandhu Sheikh Mujib Medical University (BSMMU). Data collection for the psychometric validation was carried out from July to November 2023. This phase of the study was conducted at the palliative care units of four tertiary-level hospitals in Bangladesh: Dhaka Medical College (DMC), National Institute of Cancer Research and Hospital (NICRH),

Bangabandhu Sheikh Mujib Medical University (BSMMU), and My Care Palliative and Geriatric Care Centre (MCPGCC). DMC and NICRH were government hospitals that had newly established palliative care units. BSMMU was the first hospital in Bangladesh to offer palliative care, while MCPGCC was a private hospital that recently started offering palliative care on a small scale.

For both linguistic and psychometric validation, we recruited stage III (cancer cells spread to adjacent lymph nodes or surrounding organs) and stage IV (cancer cells spread to distant organs) patients aged 18 years or older admitted to the oncology or palliative care units of the aforementioned hospitals, able to read Bengali, and receiving at least three days of care. This timing was selected because, in our practical experience, patients become well-oriented with their prognosis and treatment goals by the 3rd day of admission. We tried to keep our study inclusive of all existing religions of Bangladesh. So we made an effort to accommodate religious diversity, particularly among minority groups, by reaching out to them multiple times. We recruited participants through a consecutive sampling method and excluded those who were delirious, disoriented, or unable to communicate.

#### 2.2. Study procedure

#### 2.2.1. Translation

The translation process from English to Bengali was performed according to the EORTC translation guidelines [15]. After obtaining permission from the EORTC translation team, two independent translators (T1 and T2) produced the first Bengali translation. The translation underwent a thorough evaluation by a third researcher (T3), who collaborated with expert linguists to reconcile any existing discrepancies. All three translators were native Bengali speakers with a good command of English and were well familiar with palliative care. The reconciled version (Ts) had a few modifications to ensure it appropriately reflected local word use.

The reconciled version (Ts) was then back-translated by two independent translators (BT1 and BT2) with a good command of the English language and nonmedical backgrounds. Both translators were uninformed about the original version of the tool to avoid information bias. The back-translation process detected some inconsistencies with the original English text. Words such as "things I enjoy doing" (item 3), "felt able to forgive" (item 12), "people who are close to me" (item 8), "worthwhile" (item 15) "quietness" (item 20), "other people pray for me" (item 21), "belief" (items 24, 25), "live on" (item 27), and "spiritual wellbeing" (items 31, 32) were translated differently in the back-translated versions. The forward and backward translations were submitted to the EORTC translation team. The EORTC translation team again identified several grammatical and technical issues like wording, phrases, and synonyms in all versions. Back-translated versions revealed a few problems with presenting the deeper meaning of some of the items. After a detailed discussion with the EORTC team, necessary modifications were applied, and a revised Bengali version was made. The revised version again underwent another round of back-translation. Both the revised version and the back-translated version were resubmitted to the EORTC translation team. After the assessment of both versions, approval from the EORTC team was given, and an interim version was made. The EORTC team sent the interim version to an external proofreader. During proofreading, some grammatical issues were identified and corrected. After reviewing the proofread version by all the translators, EORTC, and the research team, the questionnaire was approved for pilot testing.

#### 2.2.2. Linguistic validation

The linguistic validation was carried out in two phases: Clinical review by the palliative care experts and Cognitive debriefing by a small sample from the target population.

- 1) Clinical review: This process was carried out by four palliative care experts (two from BSMMU, one from MCPGCCC, and one from DMC). They evaluated the clarity of the meaning of the questionnaire from the perspective of health-care practitioners.
- 2) Cognitive debriefing: This phase of the study was conducted among 10 adult cancer patients (3 from oncology and 7 from palliative care units of BSMMU) according to the EORTC guidelines. After explaining the purpose of the study, informed consent was obtained from the willing participants. All of them were interviewed for any difficult, confusing or upsetting words. We used a semi-structured and think-aloud method for this interview, which meant the patients spoke out their confusions or difficulties while filling out the questionnaire. They also talked about their difficulties after completing the questionnaire. Five open-ended questions were asked regarding each item for any difficulty, confusion, difficult or upsetting words, and how they would ask the question to others. In the case of difficult or confusing words or phrases, the researchers used several alternative words and explanations until suitable wording or phrases were found. Also, the patients' comments regarding how they would ask the questions themselves were noted down. The report, along with the necessary changes, was submitted to the EORTC office. After reviewing the revised questionnaire, the final version was officially approved by the EORTC team.

#### 2.2.3. Psychometric validation

After obtaining the finalized version from the linguistic validation process, the psychometric validation was conducted at the palliative care units of the above-mentioned hospitals in Bangladesh. For the psychometric validation, the required sample size was determined by a 5:1 sample-to-item ratio [16]. So our calculated number of patients was 160. But with the enthusiastic participation from our patients, our final sample size became 163. Fifty patients from DMC, 15 patients from NICRH, 65 patients from BSMMU and 33 patients from MCPGCC participated in this phase of the study.

Socio-demographic and medical data were collected from the hospital records. Data regarding spiritual history and EORTC QLQ-SWB32 were collected by the members of the research team via face-to-face interviews with the patients. Explanations regarding any question were offered when needed. Each questionnaire took 25–30 minutes to complete. The authorized members of the research team and palliative care team were accessible to all patients to provide emotional, psychological, and/or spiritual support as required

by each patient.

#### 2.2.4. Statistical analysis

Categorical and continuous data were summarized using descriptive analysis (i.e., frequency, percentage, means, medians, ranges, and standard deviations). Kaiser-Meyer-Olkin test (KMO) and Bartlett's test of sphericity were performed to assess the adequacy and suitability of the data for exploratory factor analysis. KMO value > 0.6 and Bartlett's test of sphericity at 0.00 are considered as the sample is adequate for factor analysis [17,18]. Exploratory factor analysis (EFA) was performed by using principal axis factoring with the varimax rotation method, setting the reference value for factor loading as >0.3. Cronbach's alpha reliability estimate was used to assess the reliability of the Bengali version of the measure. The threshold for Cronbach's alpha was set at  $\geq 0.7$  [19]. Kruskal Wallis H test, and Mann Whitney U test were performed to do the known group comparison. All statistical analysis were done using SPSS version 25. Statistical significance of the tests was set at p < 0.05.

#### 3. Result

#### 3.1. Linguistic validation

#### 3.1.1. Clinical review

Four palliative care professionals (three female and one male) from DMC, BSMMU, and MCPGCC took part in the clinical review. All of them agreed the language and content were understandable and appropriate in the context of palliative care (Table 1).

#### 3.1.2. Cognitive debriefing

Ten cancer patients, two female and eight male, three Hindu and seven Muslim, with a mean age of  $53.8 \pm 14.8$  years and educational levels ranging from "up to primary education" to "postgraduate", participated in the cognitive debriefing (Table 1). They were asked only to complete the EORTC QLQ-SWB32-Bengali questionnaire. These data were used only for linguistic validation, not to assess the psychometric properties.

Six out of ten participants found 28 items clearly understandable and acceptable. Four patients were confused with the concept of "feelings" in item 10. They could not point out what kind of feelings this term was referring to. So the term was elaborated as "feelings inside my mind". Six patients considered the statement "valued as a person" as unclear in item 13. So, we have simplified the term using the most commonly used word, "valuable as a person".

The most confusion and difficulty was faced regarding items 31 and 32. Nine out of ten patients had difficulty understanding the meaning of the word "spiritual". Most people associate this word with religion. There are two synonyms for the word "spiritual" in Bengali, among which one is not commonly used and another one is associated with religious faith. In Bengali, the word "spiritual" is derived from another word, "spirit". So we replaced the word "spiritual" with "soul". The soul is a person's spiritual essence, which contains their identity, personality, and memories. Thus, spiritual wellbeing is associated with the emotions and feelings (e.g., inner peace or strength, relationships with oneself, others, and/or God) perceived deep inside one's soul. As we stayed religion-neutral, we elaborated on the concept rather than going for a direct translation. We used the statement "feeling inside one's soul" to describe the term "spiritual" and "feeling well inside one's soul" for the term "spiritual wellbeing" in items 31 and 32, respectively.

During data collection, items 3 and 4 also required explanation. Many of the patients associate "things I enjoy doing" with active physical work. We had explained that things that bring enjoyment to one's mind do not always refer to the work done actively. Again, some patients thought "being able to forgive myself" was similar to the concept of "begging forgiveness to God". We needed to explain that the term "able to forgive myself" means forgiving oneself personally rather than asking forgiveness from God.

#### 3.1.3. Psychometric validation

Socio-Demographic, clinical and spiritual characteristics of participants of the psychometric validation: Among the 163 advanced cancer patients who participated in the psychometric validation of the study, the percentage of males was

**Table 1**Socio-demographic characteristics of the participants for linguistic validation.

| Variables                    | Clinical review (n = 4) n (%) | Cognitive debriefing (n $= 10$ ) n (%) |
|------------------------------|-------------------------------|--|
| Sex                          |                               |  |
| Male                         | 1 (25)                        | 8 (80)                                 |
| Female                       | 3 (75)                        | 2 (20)                                 |
| Education                    |                               |  |
| Up to primary                | 0                             | 5 (50)                                 |
| Secondary                    | 0                             | 4 (40)                                 |
| Graduation and above         | 4 (100)                       | 1 (10)                                 |
| Religion                     |                               |  |
| Muslim                       | 2 (50)                        | 3 (30)                                 |
| Hindu                        | 1 (25)                        | 7 (70)                                 |
| Buddhist                     | 1 (25)                        | 0                                      |
| Age in years (mean $\pm$ SD) | $33.1 \pm 2.4$                | $53.8 \pm 14.8$                        |

slightly higher (54 %) than the females (46 %). The mean age of the patients was  $49.8 \pm 14.7$  years, with the education level ranging from primary (41.1 %) to higher secondary and above (25.2 %). More than half (57.1 %) of them belonged to the lower middle-income group. More than two-thirds (68.7 %) of the participants had stage IV cancer. The median duration of getting palliative care was eight days. The majority of the participants (93.9 %) were Muslims. Only a few participants (6.1 %) followed Hinduism. All of the participants believed in God or a higher power. Most (84 %) participants actively practiced their religious rituals, but only 62.6 % sought comfort in their religious faith. Only 41.7 % were affiliated with religious communities (Table 2).

#### 3.1.4. Exploratory factor analysis (EFA)

The observed KMO value of 0.82 indicates the present data was adequate for the factor analysis. The Bartlett's test of sphericity ( $\chi$ 2 = 1418.26, df = 231, p < 0.001) revealed that the present sample was suitable for factor analysis.

EFA showed that items under each factor had adequate factor loading, ranging from 0.4 to 0.9. Similar to the original scale's factor structure, the Bengali version also extracted 23 items into five components. The Bengali version had shown the loadings of six items (items 1, 2, 3, 12, 14, 15, and 16) for the component EX, six items (items 8, 9, 10, 11, 12, 13) for the component RO, five items (items 5,

Table 2 Socio-demographic and clinical characteristics of the patients for psychometric validation (n = 163).

| Variables                                       | Frequency (%)              |
|---|----------------------------|
| Sex   |                            |
| Male  | 88 (54)                    |
| Female  | 75 (46)                    |
| Age (Years)                                     |                            |
| Up to 40  | 47 (28.8)                  |
| 41–60   | 86 (52.8)                  |
| >60   | 30 (18.4)                  |
| Mean age  | 49.8 ± 14.7 Years          |
| Educational status                              | _                          |
| Up to primary level                             | 67 (41.1)                  |
| Up to secondary level                           | 55 (33.7)                  |
| Higher secondary and above                      | 41 (25.2)                  |
| Marital status                                  | 12 (20.2)                  |
| Married   | 132 (81)                   |
| Single  | 31 (19)                    |
| Economic status (monthly income in BDT)         | 01 (12)                    |
| Low (<8000)                                     | 24 (14.7)                  |
| Lower middle (8000–30,000)                      | 93 (57.1)                  |
| Upper middle (>30,000)                          | 46 (28.2)                  |
| Median income (BDT)                             |                            |
|   | 20,000 BDT (1000-2,00,000) |
| Religion  | 152 (02.0)                 |
| Islam   | 153 (93.9)                 |
| Hinduism  | 10 (6.1)                   |
| Primary site of cancer                          | 16 (0.0)                   |
| Breast  | 16 (9.8)                   |
| Gastrointestinal system                         | 56 (34.4)                  |
| Head neck and oral cavity                       | 12 (7.4)                   |
| Respiratory system                              | 16 (9.8)                   |
| Urogenital system                               | 29 (17.8)                  |
| Unknown primary                                 | 15 (9.2)                   |
| Others  | 19 (11.7)                  |
| Stage of cancer                                 |                            |
| Stage III                                       | 51 (31.3)                  |
| Stage IV  | 112 (68.7)                 |
| Duration of getting palliative care (days)      |                            |
| <14 days  | 107 (65.6)                 |
| >14 days  | 56 (34.4)                  |
| Median duration                                 | 8 days                     |
| Eastern Cooperative Oncology Group (ECOG)       | Performance status         |
| Grade III                                       | 135 (82.8)                 |
| Grade IV  | 28 (17.2)                  |
| Trying to find comfort in religion/spiritual be | elief                      |
| Yes   | 102 (62.6)                 |
| No  | 44 (27.0)                  |
| Don't know                                      | 17 (10.4)                  |
| Actively performing religious rituals           |                            |
| Yes   | 137 (84.0)                 |
| No  | 26 (16.0)                  |
| Affiliation with religious/spiritual communit   |                            |
| Yes   | 68 (41.7)                  |
| No  | 95 (58.3)                  |

6, 17, 18, 19) for the component RS, five items (items 20, 21, 27, 30) for the component RSG, and one item (item 26) for the component RG. Unlike the original version where item 12 loaded in the RO component, item 12 (able to forgive others) loaded in both the EX and RO components (0.813 and 0.544, respectively) (Table 3).

#### 3.1.5. Reliability analysis

The internal consistency of each scale was measured using Cronbach's alpha, and for all scales, the values were satisfactory. All scales (RO, RS, RSG, and EX) had Cronbach's alpha values between 0.7 and 0.8. Our findings showed that the Bengali version of SWB32 had good reliability [19] (Table 4).

#### 3.1.6. Known group comparison

There were some statistically significant differences observed for some of the known-group comparisons. There was a statistically significant difference in RS, EX, and Global SWB scores among the age groups. Patients over 60 had significantly higher RS but lower EX than younger groups. This finding indicated that, older patients had a lower level of relationship with themselves than younger patients. On the other hand, patients under 40 years had significantly lower Global SWB than older groups. Patients who actively performed religious rituals had significantly higher RSG, RG, and Global SWB scores. Patients who tried to find comfort in their religion/spiritual faith had significantly higher RS, RSG, RG, and Global SWB. Meanwhile, those who didn't try to find comfort in their religious faith had higher RO scores. A significant difference was found in RG and Global SWB regarding affiliation with religious/spiritual communities. Patients with religious community affiliations had higher RG and Global SWB scores. We found no association between sex, economic status, educational level, stage of the disease, and SWB scores (Table 5).

#### 4. Discussion

The EORTC QLQ 32 tool has been validated for the assessment of spiritual wellbeing of cancer patients in multiple countries internationally. Our study was conducted in Bangladesh, where the study participants differed in terms of culture, tradition, education, and religious background from other countries where the tool has been validated [8,13,14,20–22].

#### 4.1. Linguistic validation

During linguistic validation, six out of ten patients found most of the items clearly understandable and acceptable. The majority of our participants had difficulty understanding the words "spiritual" or "spirituality", which they identified as religious. The reason behind this confusion might be the socio-cultural structure of our country, where religion is deeply integrated with one's thought process and dominates their spiritual domains. Also, most of the synonyms for 'spirituality' in Bengali are related to religion. In our experience, Bengali people often perceive a person as spiritual only when he or she follows certain rituals or behaviors directed by his

**Table 3** Exploratory factor analysis (n = 163).

| Scale item                                      | EX     | RO     | RS     | RSG    | RG     |
|---|--------|--------|--------|--------|--------|
| Eigenvalue                                      | 8.08   | 2.11   | 1.88   | 1.69   | 1.51   |
| Variance (%)                                    | 33.29  | 7.96   | 6.79   | 6.37   | 5.68   |
| Q1.Able to deal with problems (EX)              | 0.566  | 0.306  | -0.237 | 0.068  | 0.032  |
| Q2.Peace with myself (EX)                       | 0.587  | 0.159  | -0.178 | 0.057  | -0.013 |
| Q3. Find things I enjoy (EX)                    | 0.597  | 0.182  | -0.265 | 0.060  | 0.053  |
| Q5. Feeling Troubled (RS)                       | -0.352 | -0.194 | 0.595  | -0.064 | 0.059  |
| Q6. Feeling Lonely (RS)                         | -0.281 | -0.385 | 0.603  | -0.110 | 0.011  |
| Q8. Share thoughts with those close to me (RO)  | 0.301  | 0.617  | -0.139 | 0.105  | 0.022  |
| Q9. Loved by those important to me (RO)         | 0.211  | 0.714  | -0.223 | 0.107  | -0.008 |
| Q10.Someone to talk about my feelings (RO)      | 0.091  | 0.706  | -0.105 | 0.153  | -0.024 |
| Q11. Able to trust others (RO)                  | 0.127  | 0.420  | 0.032  | 0.180  | 0.072  |
| Q12. Able to forgive others (RO)                | 0.813  | 0.544  | -0.057 | 0.150  | 0.055  |
| Q13. Valued as a person (RO)                    | 0.389  | 0.486  | -0.210 | 0.094  | -0.038 |
| Q14. My life is fulfilling (EX)                 | 0.647  | 0.153  | -0.208 | 0.210  | 0.064  |
| Q15. My life is worthwhile (EX)                 | 0.754  | 0.172  | -0.176 | 0.171  | 0.044  |
| Q16. Planning for the future (EX)               | 0.658  | 0.128  | -0.049 | 0.095  | 0.078  |
| Q17. Worries/concerns about the future (RS)     | -0.190 | -0.129 | 0.639  | -0.050 | -0.056 |
| Q18. Can anything be done for me (RS)           | -0.093 | 0.117  | 0.669  | -0.005 | -0.053 |
| Q19. Unfair that I am ill (RS)                  | -0.165 | -0.227 | 0.481  | -0.256 | -0.052 |
| Q20. Time for quietness/prayer/meditation (RSG) | 0.204  | 0.129  | -0.069 | 0.684  | 0.220  |
| Q21. Important that others pray for me (RSG)    | 0.081  | 0.342  | -0.160 | 0.625  | 0.055  |
| Q26. Connected to God/someone greater (RG)      | 0.174  | 0.096  | 0.118  | 0.344  | 0.910  |
| Q27. Live on through words, deeds (RSG)         | 0.189  | 0.325  | -0.259 | 0.511  | 0.043  |
| Q30. I believe in life after death (RSG)        | -0.012 | 0.064  | 0.081  | 0.592  | 0.069  |
| Q31. I have spiritual well-being (RSG)          | 0.515  | 0.143  | -0.351 | 0.513  | -0.070 |

Extraction method: Principal component analysis.

Rotation method: Varimax with Kaiser normalization.

**Table 4** Analysis of scale reliability.

| Scale  | No of item in the scale | Cronbach's Alpha | Median | Range  |
|--|-------------------------|------------------|--------|--------|
| Relationship with others (RO)                        | 6                       | 0.7              | 33.3   | 0–88.8 |
| Relationship with self (RS) <sup>a</sup>             | 5                       | 0.7              | 46.6   | 0-100  |
| Relationship with someone or something greater (RSG) | 5                       | 0.7              | 26.6   | 0-100  |
| Existential (EX)                                     | 6                       | 0.8              | 50.0   | 0-100  |
| Relationship with God (RG)                           | 1                       | _                | 36.8   | 0-100  |
| Global-SWB   | 1                       | _                | 57.1   | 0-85.7 |

<sup>&</sup>lt;sup>a</sup> Reversely scored; higher score means lower relationship.

Table 5 Known group comparison: Associations between participants' scores on the SWB32 scales and participants' socio-demographic characteristics and clinical parameters (n = 163).

| Variables                      | RO                     | RS#          | RSG          | EX            | RG           | Global SWB  |
|--------------------------------|------------------------|--------------|--------------|---------------|--------------|-------------|
|                                | Median (range)         |              |              |               |              |             |
| Age                            |                        |              |              |               |              |             |
| Upto 40                        | 33.3 (0-88)            | 33.3 (0-93)  | 26.6 (0-87)  | 55.5 (16-100) | 66.6 (0-100) | 42.8 (0-86) |
| 40-60                          | 27.7 (0-83)            | 43.3 (0-100) | 26.6 (0-100) | 50 (0-100)    | 66.6 (0-100) | 57.1 (0-85) |
| >60                            | 22.2 (0-83)            | 60 (0-100)   | 23.3 (0-80)  | 44.4 (0-83)   | 66.6 (0-100) | 57.1 (0-86) |
| P value <sup>a</sup>           | 0.2                    | 0.01         | 0.3          | 0.02          | 0.7          | 0.01        |
| Sex                            |                        |              |              |               |              |             |
| Male                           | 27.7 (0-83)            | 46.6 (0-100) | 26.6 (0-100) | 50 (0-100)    | 44.4 (0-100) | 42.8 (0-85) |
| Female                         | 33.3 (0-89)            | 40 (0-100)   | 26.6 (0-87)  | 50 (0-100)    | 66.6 (0-100) | 42.8 (0-86) |
| P value <sup>b</sup>           | 0.1                    | 0.3          | 0.5          | 0.4           | 0.4          | 0.3         |
| Economic status                |                        |              |              |               |              |             |
| Low                            | 41.6 (0-77)            | 40 (0-100)   | 26.6 (0-100) | 44.4 (0-100)  | 66.6 (0-100) | 57.1 (0-86) |
| Lower middle                   | 33.3 (0-89)            | 40 (0-100)   | 26.6 (0-87)  | 50 (0-100)    | 66.6 (0-100) | 42.8 (0-86) |
| Upper middle                   | 22.2 (0-83)            | 50 (0–100)   | 26.6 (0-87)  | 50 (0-100)    | 66.6 (0–100) | 42.8 (0–86) |
| P value <sup>a</sup>           | 0.05                   | 0.5          | 0.9          | 0.1           | 0.3          | 0.8         |
| Religion                       |                        |              |              |               |              |             |
| Islam                          | 27.7 (0-89)            | 46.6 (0-100) | 26.6 (0-87)  | 50 (6-100)    | 50 (0-100)   | 50 (0-86)   |
| Hinduism and Christianity      | 41.6 (16–72)           | 33.3 (13–87) | 33.3 (6–100) | 50 (6–100)    | 50 (0–100)   | 50 (0–86)   |
| P value <sup>b</sup>           | 0.1                    | 0.3          | 0.4          | 0.7           | 0.2          | 0.8         |
| Education level                |                        |              |              |               |              |             |
| Upto primary                   | 38.8 (0-83)            | 46.6 (0-100) | 26.6 (0-73)  | 50 (6-100)    | 66.6 (0-100) | 57.1 (0-86) |
| Secondary                      | 27.7 (0-89)            | 40 (0-100)   | 33.3 (0-100) | 50 (0-100)    | 66.6 (0-100) | 42.8 (0-86) |
| Higher secondary/above         | 27.7 (0-83)            | 60 (0-100)   | 20 (0-100)   | 50 (0-100)    | 66.6 (0-100) | 57.1 (0-86) |
| P value <sup>a</sup>           | 0.2                    | 0.6          | 0.8          | 0.9           | 0.2          | 0.1         |
| Actively performing religiou   | s rituals              |              |              |               |              |             |
| Yes                            | 33.3 (0-89)            | 40 (0-100)   | 40 (7-100)   | 50 (0-100)    | 66.6 (0-100) | 57.1 (0-86) |
| No                             | 33.3 (0–83)            | 50 (0–100)   | 26.6 (0-87)  | 55.5 (11–100) | 33.3 (0–100) | 28.5 (0–86) |
| P value <sup>a</sup>           | 0.6                    | 0.5          | 0.01         | 0.2           | 0.01         | 0.02        |
| Staging of disease             |                        |              |              |               |              |             |
| Stage III                      | 33.3 (0-83)            | 40 (0-100    | 26.6 (0-67)  | 50 (0-100)    | 66.6 (0-100) | 57.1 (0-86) |
| Stage IV                       | 30.5 (0-89)            | 46.6 (0–100) | 26.6 (0–100) | 50 (0–100)    | 66.6 (0–100) | 57.1 (0-86) |
| P value <sup>a</sup>           | 0.8                    | 0.4          | 0.8          | 0.8           | 0.3          | 0.8         |
| Trying to find comfort in rel  | igion/spiritual belief |              |              |               |              |             |
| Yes                            | 27.7 (0–89)            | 36.6 (0-100) | 40 (0-80)    | 66.6 (0-100)  | 100 (0-100)  | 57.1 (0-86) |
| No                             | 38.8 (0–83)            | 53.3 (0–93)  | 20 (7–100)   | 44.4 (11–100) | 33.3 (0–100) | 28.5 (0–86) |
| P value <sup>a</sup>           | 0.01                   | 0.01         | 0.01         | 0.01          | 0.01         | 0.01        |
| Affiliation with religious/spi |                        |              | ***          |               | ***          |             |
| Yes                            | 27.7 (0–89)            | 46.6 (0-100) | 20 (0-80)    | 47.2 (0-100)  | 100 (0-100)  | 57.1 (0-86) |
| No                             | 33.3 (0–83)            | 40 (0–100)   | 33.3 (0–100) | 50 (0–100)    | 66.6 (0–100) | 42.8 (0–86) |
| P value <sup>a</sup>           | 0.4                    | 0.2          | 0.03         | 0.1           | 0.04         | 0.01        |

 $<sup>^{\</sup>mathrm{a}}$  Mann-Whitney U test.

or her religion. So, the distinction between spirituality and religion becomes blurred for them, and the idea of spirituality outside of religion becomes incomprehensible [23].

We aimed to stay religion-neutral, so we elaborated on the concept rather than using a direct word-to-word meaning. We replaced the word "spirit" with "soul", which is clearly understood by Bengali people. Thus, "feelings inside one's soul" was used to describe the term "spiritual" and "feeling well inside one's soul" to describe the term "spiritual wellbeing". The difference between "soul" and "religion" is clear in Bengali, while the word "spirituality" carries a narrower meaning and is often linked with religious issues. Our approach is similar to the Finnish version, where they also used conceptual meaning for "spirituality" rather than academic translation [21].

<sup>&</sup>lt;sup>b</sup> Kruskal-Wallis H test; #\*reversely scored; higher score means lower relationship.

#### 4.2. Psychometric validation

The primary aim of our study was to assess the psychometric properties of the Bengali version of SWB32. We found that the Bengali version has similar validity to the other versions [8,13,14,20–22]. Cronbach's alpha coefficients for the scales were higher than the threshold of acceptance of 0.6. This indicates that the Bengali-translated version is broadly equivalent to other translated versions [8, 13,14,20–22].

Construct validity was assessed by exploratory factor analysis. The Bengali version had 22 items which was arranged in the RO, RS, RSG and EX scales and one item in RG scale. This finding was equivalent to the original version [13].

The main difference between our quantitative findings and those of the international validation study was a different factor loading for item 12. In our study, we found that item 12 (being able to forgive others) grouped most strongly in EX and less strongly in RO, as in the international validation [13]. The concept of forgiveness is closely related to religion across many faiths and cultures [24,25]. One study found that the ability to forgive others partially mediates the relationship between religion and health [26]. The practice of forgiveness is one of the positive indicators of mental and spiritual wellbeing as well as existential fulfilment [27,28]. It also improves the person's relationship with his surroundings. Thus, this item conceptually relates to both EX and RO. The difference in our results indicates a difference between the sociocultural characteristics of our participants and those in other studies [8,13,14,20–22].

We also performed a known group comparison to detect the difference in SWB32 scale scores between the known independent groups among our study participants.

In our study, older participants had a better relationship with themselves and a lower level of existential fulfilment than the younger group. Our finding is similar to that of the international validation study, where a positive association between self, SWB, and older age was found [13,14]. In contrast to our findings, one study reported that younger participants scored higher on the Global SWB scale, while another study found no age-related difference in SWB scores [8,20]. This discrepancy may be explained by the religious and cultural trends in our country. In Bangladesh, as people age, they tend to place greater importance on the afterlife and become more inclined towards religious beliefs. This trend might contribute to higher level of spiritual wellbeing among older participants in our study.

We observed no association between the sex, economic or educational status of the patients, clinical staging of the disease, and SWB scores. Our finding regarding sex and SWB score is consistent with the Vietnamese study [20]. However, contrary to our findings, the international validation study and a Croatian study found that women scored higher in all four scales of SWB [8,13,14]. Additionally, the Croatian study found a significant difference regarding the stage of the disease and SWB scores, with patients in Stage I disease scoring higher than those in advanced stages. Since all our participants were in advanced stages of their disease (stages III and IV), we found no significant difference in SWB scores among them [8].

The majority (94 %) of our study participants were Muslims, and the rest were Hindus. The EORTC QLQ SWB32 has been validated in different geographical areas among various religious faiths, such as Christian, Buddhist, Muslim, and no religion [13]. We did not find any significant differences in scale scores for religion. However, since most of our participants (93.9 %) were Muslims, and only ten (6.1 %) were Hindus, we cannot say whether the Bengali version of this measure is equally applicable to both religions.

Also, people who actively performed religious rituals had significantly higher RSG, RG, and global SWB in our study. Our findings are analogous to the Vietnamese version, where there is a statistically significant difference in the RSG score between people who practice religious rituals and those who do not [20]. In the present study, participants with affiliation with religious communities had a higher score in the RSG and EX scales, while in China, 90 % of participants with no religious belief scored lowest in the RSG scale [26, 281.

We assessed religious/spiritual coping via three variables: trying to find comfort in religion/spiritual belief, actively performing spiritual rituals, and having affiliation with religious/spiritual communities. Those who tried to find comfort in their religion/spiritual faith scored significantly higher on all scales. Also, patients who actively performed religious rituals and had affiliations with religious/spiritual communities scored higher on the Global SWB scale. In a previous study among Bangladeshi breast cancer patients, it was found that religion is the most commonly adopted coping mechanism by advanced cancer patients [29]. Religion plays an important role in spiritual coping. It has been proposed that non-believers need more spiritual care than those who believe in formal religions [30].

#### 4.3. Strength and limitations

One of the strength of our study was that, it found the Bengali version of EORTC QLQ SWB32 is a comprehensive, reliable and valid tool to measure the spiritual well-being of advanced cancer patients receiving palliative care. However, this study had a few limitations. We did not evaluate the translated tool's test-retest reliability or convergence validity. Most patients were nearing the end of their lives, so completing a lengthy questionnaire was difficult for them. They were exhausted after answering 32 questions from the SWB32 tool, so we did not include another tool in our questionnaire to assess convergence validity. Furthermore, this study only involved patients receiving palliative care, which limited the results of the known-group analysis, as they may differ for patients undergoing curative treatment. We used the conceptual meaning of spiritual wellbeing rather than a direct translation, which may have influenced the outcome to some extent. We also did not go into great detail about religious coping, the nature and scope of the beliefs involved, or how those beliefs aided the coping process. This study was conducted in a mostly Muslim country; most of our participants were Muslims (153; 93.9 %), and only ten (6.1 %) were Hindus. We were unable to find participants from other religions within the time frame of our study. Due to the small number of Hindu participants and the lack of participants from other religions, we were unable to determine whether this questionnaire is equally applicable to all existing religions in Bangladesh.

#### 5. Conclusion

The Bengali version of EORTC QLQ SWB32 has been found to be a reliable and valid tool for measuring the spiritual wellbeing of advanced cancer patients. Its validity and reliability are similar to those of other translated versions. These findings indicate that, although the definition of spiritual wellbeing differs from person to person, the conceptual framework of the EORTC QLQ-SWB32 is applicable to Bengali culture and language, as well as the other cultures and languages in which it has been validated to date.

#### **Ethical considerations**

Ethical approval for both the research and consent procedure (approval number: CeNoR/EA/2301) was obtained from the Ethical Review Committee, Centre for Noncommunicable Diseases Prevention, Control, Rehabilitation, and Research. Written informed consent was obtained from all eligible patients.

#### Financial disclosure

The authors of this study received no funding from any profit or non-profit source.

#### Data sharing statement

All data relevant to the study are accessible in Mendely data, https://doi.org/10.17632/6xggt8tdz9.1.

#### CRediT authorship contribution statement

Jheelam Biswas: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. Nashid Islam: Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Formal analysis, Conceptualization. Nahid Afsar: Writing – review & editing, Writing – original draft, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Formal analysis. Wai Wai Mroy: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Data curation, Conceptualization. Palash Chandra Banik: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Methodology, Formal analysis, Conceptualization.

#### **Declaration of competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Acknowledgements

The authors gratefully acknowledge Dr. Md. Maruf Ahmed Molla, Fellow, Department of Microbiology and Immunology, SUNY Upstate Medical University, Syracuse, NY, United States of America, and Ms. Audity Nowshin, Dept. of English Literature, BRAC University, Dhaka, Bangladesh-for their contribution in the translation process.

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