



Translation and Validation of Stoma Quality of Life Scale in Tamil

Dhayanandan Shanmugam¹ · Vidhubala Elangovan² · Sundaramoorthy Chidambaram³ · AS Ramakrishnan⁴ · Surendran Veeraiah³

Received: 26 December 2024 / Accepted: 7 April 2025

© The Author(s), under exclusive licence to Indian Association of Surgical Oncology 2025

Abstract

Tamil Nadu contributes to around 6% of the cancer burden annually, wherein colorectal cancer is one of the most common cancers. Assessing the quality of life provides a comprehensive understanding of a cancer patient's experience with diagnosis and treatment. While numerous studies have developed tools to assess quality of life, most focus on physical well-being aspects. The Stoma Quality of Life Scale (SQLS) Version II is a well-established tool specifically designed to assess the quality of life of colostomy patients. However, a validated Tamil version of this scale is currently unavailable. This study aims to translate the Stoma Quality of Life Scale Version II from English to Tamil and validate its use for Tamil-speaking colostomy patients. The Stoma Quality of Life Scale Version II was translated following the European Organization Research and Treatment of Cancer (EORTC) translation guidelines and underwent pilot testing on 30 patients diagnosed with colorectal cancer. They further underwent a debriefing interview regarding the comprehensibility and difficulty levels of the items. The forward translation revealed the difference in the language used by the two individual translators, including the meaning of the word and syntaxes, at the same time backward translation found out the differences in their perception of the items. The debriefing interview revealed that out of 21 items, four items needed clarification by 6.6% of the patients and 93.4% of the patients were able to comprehend and respond to the items without any clarification and support. The translated tool of the Stoma Quality of Life Scale had a more simplified administrative process, as it was self-administrative, less time consuming, and more comprehensible.

Keywords Stoma Quality of Life · Translation · Culture adaptation · Psychosocial issues

Introduction

Colorectal cancer (CRC) patients face a unique challenge of living with a stoma bag even after treatment, significantly affecting their quality of life (QOL) and daily functioning [1]. Various tools have been developed to assess the general and the stoma-specific QOL among CRC patients, widely used in clinical and research settings [2–6]. However, the

majority of the tools focus on the physical well-being dimension while giving less importance to psychological and social dimensions. Moreover, these tools were originally developed in the Western context and may not be fully applicable to Indian patients due to cultural, linguistic, and healthcare differences. Language barriers and cultural nuances can affect how patients interpret and respond to questionnaire items, potentially leading to misinterpretation of their lived experiences [7–9]. In India, patients often face additional stigma and family-driven decision-making regarding stoma management, which may not be adequately captured by existing scales. Studies indicate that linguistic and cultural adaptation is essential for ensuring the validity of QOL assessments across diverse populations [9–12]. However, existing stoma-specific QOL tools have not been validated in the Indian setting and are unavailable in regional languages such as Tamil. The absence of a validated Tamil version limits its accessibility and effectiveness in accurately capturing the lived experiences of Tamil-speaking CRC

✉ Dhayanandan Shanmugam
dhayanand.psyonco@gmail.com

¹ Department of Psycho-oncology, Cancare Foundation, Chennai, Tamil Nadu, India

² Fenivi Research Solutions Private Limited, Chennai, Tamil Nadu, India

³ Department of Psycho-oncology, Cancer Institute (WIA), Chennai, Tamil Nadu, India

⁴ Department of Surgical Oncology, Cancer Institute (WIA), Chennai, Tamil Nadu, India

patients. Given these limitations, the current study aimed to identify the suitable stoma-specific QOL assessment tool relevant to Tamil-speaking Indian CRC patients, translate and culturally adapt the tool into Tamil, and conduct a pilot validation to ensure its reliability and applicability in the Indian context.

Objectives

1. To identify the psychosocial issues experienced by colostomy patients
2. To find out appropriate tool to assess psychosocial issues of colostomy patients.
3. To translate and validate the Stoma Quality of Life Scale in Tamil.

Methods

Phase I

The psychosocial issues experienced by colorectal cancer patients ($n = 15$) who underwent colostomy and had permanent stoma bag were explored by conducting an interview (Table 1). The issues reported were listed down and compared with the existing tools to identify the most suitable tool that covered most of the issues reported by these patients. Two scales (the Stoma QOL Scale and Stoma QOL Questionnaire) were shortlisted by two independent experts as they represented most of the issues. The shortlisted tools were presented to the treating clinician (surgical oncologist), and the tool that was identified as most

representing the patient's issues was the Stoma Quality of Life Scale (SQOLS). Tools identified and their relevance to psycho-social issues are presented in Table 2. Therefore, permission to translate the scale into the regional language (Tamil) was sought from the author.

Phase II

After obtaining the permission, the scale was translated into Tamil using the European Organization for Research and Treatment of Cancer (EORTC) translation guidelines (forward and backward translation procedure) [15]. The tool was given to two independent experts who are well-versed in both English and Tamil, for forward translation. Both the translations were compared, and a reconciled version of the tool was arrived. The reconciled version was given to two more independent experts for back translation. Comparing the backward translations with the original version, a final version was prepared. The final version was proofread by an expert, and finally, the translated version of the tool was pilot-tested with 30 ostomates who are well-versed in both reading and writing Tamil, to check its relevance and sensitivity [16]. After administering the tool, a debriefing interview was conducted to assess the item/word difficulty, items confusing and upsetting. The items reported by patients as difficult and confusing were re-worded in consultation with two experts. The re-worded items were again presented to patients ($n = 3$) to ensure clarity. A total of seven experts and 30 patients were involved in the entire translation process. The experts included four translation experts, two translation co-ordinators, and one proofreader. The data was analyzed by computing simple frequencies and percentages.

Table 1 Identified psychosocial issues experienced by participants of the pilot study

S. no	Addressed issues	Reported by no of patients ($n = 15$)
1	Disturbances in sleep regarding stoma bag	12 (80%)
2	Social problems (avoiding social activities)	9 (60%)
3	Worry about stoma leakage and noises	8 (53.3%)
5	Problem with routine works	7 (46%)
6	Avoiding sexual activities	6 (40%)
7	Reduced food intake and avoided favorite food (non-veg)	6 (40%)
8	Changed dressing pattern and not able to wear	5 (33.3%)
9	Traveling issues	4 (26.6%)
10	Avoiding to stay in relative's home	4 (26.6%)
11	Searching toilet facility wherever they go	3 (20%)
12	Cry sometimes	1 (6.6%)
13	Pain (sometime)	1 (6.6%)
15	Not able to carry out household chores	4(26.6%)
16	Worrying about future commitments	2 (13.3%)
17	Could not return to previous job	2 (13.3%)

Table 2 Tools identified and its relevance to psychosocial issues reported by participants

S. no	Name of the tool	Author and year	Number of items	Dimensions	Reliability and validity	Number of issues covered
1	Stoma QOL questionnaire	Prieto et al. [2]	20 items	Work/social function, sexuality and body image, stoma functions, financial concerns, skin irritation	Cronbach's alpha—0.92	Social avoidance—Q16 Leakage and noises—Q1, Q2, Q4, Q5, Q11 Sexual activities—Q9 Clothing—Q6 Searching toilet—Q3 Sleep—Q10
2	EORTC QOL-CR29	Whistance R 2009 (EORTC Quality of Life Group)	29 items	Physical, role functioning, emotional, cognitive, social, fatigue, nausea/vomiting, pain, dyspnoea, insomnia, appetite loss, constipation	Cronbach's alpha was 0.89	Social avoidance—Q18 Leakage and noises—Q49, Q50, Q55, Q33 Sleep—Q53 Pain—Q35, Q59 Future worries—Q43 Sexual activities—Q56, Q58 Except
3	City of Hope Quality of Life-Ostomy Questionnaire	Grant et al., 2004	43 items	Physical wellbeing, psychological wellbeing, social wellbeing, spiritual wellbeing	Cronbach's alpha—0.70	Social avoidance—Q25 Leakage and noises—Q5, Q6, Q10 Sexual activities—Q24, Q25, Q26, Q27 Food intake—Q38, Q40, Q41, Q42, Q43, Q44 Clothing—Q34, 35 Sleep—Q4 Pain—Q5
4	Ostomy adjustment inventory	De Gouveia Santos [13]	23 Items	Acceptance, anxious preoccupation, social engagement, and anger	(Cronbach's alpha = .93, split-half = .91, and test-retest (<i>r</i> = .83)	Sleep—Q6 Social avoidance—Q8 Leakage and noises—Q13 sexual activities—Q17 Routine activities—Q11, Q16 Food intake—Q4 Future worries—Q7, Q20
5	Fecal incontinence quality of life scale	Rockwood et al. [14]	29 items	Lifestyle, coping/behavior, depression, self-perception, and embarrassment	Cronbach's alpha = 0.7, test-retest = 0.7	Avoiding social activities—Q2a, Q2b Leakage and noises—Q21, Q2m, Q3e Sexual activities—Q3 h, Q3k Food intake—Q2e Changes in dressing pattern- Traveling issues—Q2 h Searching toilet—Q2f

Table 2 (continued)

S. no	Name of the tool	Author and year	Number of items	Dimensions	Reliability and validity	Number of issues covered
6	Stoma Quality of Life Scale	Baxter [1]	21 items	Work/social function, sexuality/body image, skin irritation, financial concerns, and overall quality of life	Intraclass correlation coefficient > 0.8	Avoiding social activities—Q4, Q20 Leakage and noises—Q8, Q15, Q17, Q18 Sexual activities—Q7, Q8, Q9 Food intake—Q13 Routine activities—Q21 Changes in dressing pattern—Q12 Traveling issues—Q6 Searching toilet—Q11 Job worries—Q5, Q14

Results

Step I: Forward Translation

The aim of the first step was to translate the Stoma QOL Scale into Tamil and produce a version that would be conceptually as close as possible to the original questionnaire. The English questionnaire was given to two independent translators. Translator I was a psycho-oncologist, and translator II was a psychologist. Both were native Tamil speakers with a good command in English.

Step II: Preparation of Reconciled Version

Of the 21 items translated, two items precisely matched between the two translations. There were typographical and grammar errors, which were corrected. In the first item, the word “general” was missing in both the translations, which was added. The translation for the word “stoma” was misunderstood in all the items ($n = 8$) by both the translators, which was clarified and corrected by the translation coordinator. In item number 11, the translation for the word “privacy” was understood as “covered place,” while others understood it as “personal rights” which was corrected, in consultation with the experts. In item 21, the word “same” was misunderstood as “like always.” The discrepancies between the two translations were resolved in consultation with both the co-ordinators. In a few items, amalgamations of both versions formed the reconciled version.

Step III: Back Translations

The reconciled version was given to another set of two independent experts for back translation. Translator I was a physiotherapist, and translator II was a molecular oncologist with Tamil as a native language and with good command in English. They were requested to translate the items in simple English language.

Step IV: First Intermediate Tamil Version

Both the backward translations were compared with each other and with the original English version by the translation co-ordinators, and a translation report was prepared. Based on the report, an intermediate version was prepared. Four items precisely matched between both the backward translations and the original version. In the first two items, the translation for the word “generally” was missing in both the backward translations, which was added. The translation for the word “satisfaction” was missing in one of the translations. The translation for the word “enjoy” was missing in

one of the translations. The word “stoma bag” was interchanged with the word “pouch.” Similarly, the word “material” was interchanged with the word “appliances.” The words “difficulties” and “issues” were used by both translators, whereas the appropriate word that was mentioned in the original version was “concerns.” The word “worried” is used by the translator instead of the word “bothered.” However, the comprehensibility of the translated items was high, and the grammar was intact, though certain words were missing in a few items. The errors and tense forms were cross-checked with the original English version, and the nearest translation was chosen for each of those items. After making the necessary changes in the items, the first intermediate version was pilot-tested with the patients.

Pilot Testing

The intermediate Tamil questionnaire was administered to 30 patients with a stoma bag, diagnosed with carcinoma rectum, and was currently under follow-up, at our center. Both males and females were included, and the selection criteria ensured that all patients were fluent in Tamil and had the ability to read and write in their native language of Tamil. The demographic details of the patients are presented in Table 3. Following the administration of the tool, a debriefing interview was conducted to evaluate whether any items were difficult to understand, confusing, or upsetting items. Patients were encouraged to provide feedback on specific items they have reported any issue in the items; suggestions were obtained to reframe the items. The feedback-driven modifications enhanced the clarity, cultural relevance, and emotional sensitivity of the questionnaire, making it a more comprehensive and patient-friendly assessment tool. The final version of the tool was used in the main study to evaluate the stoma-specific quality of life among Tamil-speaking CRC patients.

Results

Based on the pilot study, out of 15 participants, 12 were very conscious about the filling up of the stoma bag during the night. Hence, they faced sleep disturbances (80%). About 60% of participants had problems with social activities in which they were active earlier. Participants worried from stoma leakage, noises, and foul smell were about 53.3%. For about seven participants, the daily routine activity was a problem. About 40% had avoided sexual involvement because of the discomfort and stoma bag issues. Another 40% had avoided food intake, especially their favorite dishes. Thirty-three percent of participants had changed their attire from their original because of the stoma bag. About 26.6% had avoided staying in a relative's place, and

Table 3 Socio-demographic and clinical details of the participants

Variable	Frequency	Percentage
Age		
Below 50 years	15	50
50 years and above	15	50
Gender		
Male	25	83.3
Female	5	16.7
Education		
No formal education	1	3.3
Middle school	1	3.3
High school	21	70
Secondary	3	10
Degree	4	13.3
Occupation		
Homemaker	8	26.7
Private job	12	40
Government job	1	3.3
Unemployed	3	10
Retired	3	10
Own business	3	10
Marital status		
Married	24	80
Unmarried	4	13.3
Widow	2	6.6
Income in rupees		
Below 10,000	26	86.7
Above 10,000	4	13.3
Tobacco use		
Non-users	24	80
Smokers	6	20
Alcohol		
Yes	8	26.7
No	22	73.3
Family history of cancer		
Yes	8	26.7
No	22	73.3
Stage		
Grade I	5	16.7
Grade II	22	73.3
Grade III	3	10
Received treatment		
CT and Sx	2	6.7
RT and Sx	7	23.3
Sx, CT, and RT	21	70
Duration of carrying stoma bag		
Below 1 year	19	63.3
Above 1–2 year	7	23.3
Above 2 years	4	13.3

CT chemotherapy, RT, radiation therapy, surgery

the same percentage of participants avoided travel due to accidental bumping with any other (in case) and bag leakage irritability. Wherever they go, around three participants had looked for toilet facility before they head to go to a particular place. Two of them had faced issues like crying alone due to commitments in life and experiencing pain. Some four participants were having problems in carrying out household chores on a daily basis. Not being able to return to a previous job was an issue for 13.3% of participants. There are six such tools identified to measure physical and psychosocial issues faced by participants. These tools are globally accepted and widely used because of the reliability and validity. They still had limitations in not addressing some of the psychosocial issues of ostomies. The first tool that is discussed here is the Stoma QOL questionnaire, which addressed on many parameters the ostomies face. With regard to the Indian scenario, there was less focus on some psychosocial dimensions like future worries, traveling issues, job loss and income, pain, and lesser food intake. A tool designed by the European Organization of Research and Treatment for Cancer EORTCQOL CR29 has covered most of the physical issues, and less importance is given to the psychosocial dimensions like routine activities, lesser food intake, clothing, traveling issues, searching for toilet very often, job loss, and income. When compared with the Indian Society, the City of Hope Quality of Life-Ostomy Questionnaire covers almost all aspects of issues faced by ostomies except for anxiety towards stoma bag filling, thus searching for toilet, job loss and income, traveling issues, and future worries. It also has many items to be evaluated and is time-consuming. For Indian conditions wherein the dressing is traditional most of the time, a lot of focus is required for changes in dressing with the stoma bag. In the ostomies adjustment inventory, all the dimensions other than traveling, searching for toilet, job loss and income, pain, and changes in dressing are covered. In the fecal incontinence quality of life scale, most of the issues are addressed but for job loss and sleep issues and changes in dressing pattern. Here is one such tool that addressed all the issues faced by ostomies in the Stoma Quality of Life Scale, developed by Baxter in the year 2005, which contained 21 items to measure in the dimensions of issues faced by ostomies but for sleep disturbances. From the pilot study, the majority of the participants reported that they had sleep disturbances. Sleep disturbances for these ostomies are due to the frequent filling up of the stoma bag. The other tools mentioned above indeed measured sleep disturbances, but they involved a lot of items to be evaluated (consuming more time comparatively), and there was a lacuna in assessing other psychosocial dimensions. Table 3 outlines the socio-demographic characteristics of the patients who participated in this study. A total of 30 patients with stoma bag, diagnosed with carcinoma

rectum, who were currently under follow-up at our center were included in this study. Both males and females were included, and those people were chosen based on their fluency and who knows read and write their native language of Tamil. Their ages range from 24 to 66 years with a mean age of 50 years. However, more than half of the patients were lower than 50 years and above 50 years of age. The majority ($n = 26$) of the patients belonged to the low-income group. Also, most of the patients had no family history of cancer. During the pilot testing, most of the patients (76.8%) reported that the tool does not require any modification. However, 23.2% of the patients required assistance in four of the items (item numbers 7, 8, 14, and 20) and asked for clarification. Suggestions of alternative words were obtained from those patients to improve the comprehensibility of the items.

Table 4 presents the suggestions and alternative words reported by the patients for the upsetting, confusing, and difficult items. Two of the five patients stated that the Tamil translation for the word “பாலியல்செயல்பாடுகளை” (sexual activities, item no. 7) seems to have ambiguity, where the word was understood as illegitimate relationship or affair. Another translated Tamil word of “கவர்ச்சிகரமாக” (attractive, item 8) was understood by many as “Beauteous” other than three patients who were involved in the pilot testing regarding comprehensibility of the item. When comparing both genders, majorly female patients reported that they were upset to answer to the word “attractive”.

The meaning of the translated word “பொருளாதாரசிரமங்கள்” (financial concerns, item no. 14) with actual meaning “financial concerns” was misinterpreted by one as being different from the intended meaning due to independent meanings of the word economics and cash in the local dialect. It is due to simplified perceptions regarding money and economics specific to their low socio-economic status. The meaning of the translated word சமூகசந்தர்ப்பங்கள் (“social situations” item no. 20) with actual meaning social situations was misinterpreted as common incidents relating to day-to-day living.

In the earlier pilot study, those questions that were difficult to understand by the participants were reframed, re-administered to three of the participants, and reviewed the same. In item number 8, the phrase “I feel attractive” is changed to “நான் தோற்றப்பொலிவுடன் இருப்பதாக உணர்கிறேன்”. In item number 7, the phrase “I enjoy sexual activity” is changed to “தாம்பத்யசெயல்பாடுகளை நான் அனுபவிக்கிறேன்”. Participants had no complaints of confusion, difficulty, and not understandable while answering these translated words.

Upon observations, the comprehension challenges were found to be associated with specific demographic factors such as low level of education, rural background, and older

Table 4 Shows the difficult words and its alternative words suggested by participants

Item No.	Item	English version	Issues	No of patients reported n (%)	Concurr ence n (%)	Clarification required	Suggestions
7.	நான்கவச்சிகரமாக உணர்கிறேன்	I feel attractive	Difficult word கவச்சிகரமாக	3 (10%)	90.0%	Does the word attractive used in general or does it refer to beauty? It looks like 'sexual attraction'	Alternative words suggested by the patients were: “நான் அழகாக உணர்கிறேன்” “நான்தோற்றப்பொலிவுடன் இருப்பதாக உணர்கிறேன்” “நான் எப்போதும் போலீசுரப்பாகவே உணர்கிறேன்”
8.	பாலியல்செயல்பாடுகளை நான் அனுபவிக்கிறேன்	I enjoy sexual activity	பாலியல்செயல்பாடுகளை	2(6.6%)	93.3%	The Tamil translation for the word “sexual activity” was misinterpreted as “extra marital affairs” or ‘illegitimate relationship’	The word needs to be reframed to be culturally sensitive and acceptable “தாம்பத்யத்தை” is the alternative word referred by one participant.
14.	என்னுடையமலக்கழிவு வெளியேற்றும் துளை சார்ந்தபொருட்கள் காரணமாக எனக்கு பொருளாதாரசிரமங்கள் உள்ளது	I have financial concerns regarding my ostomy supplies	பொருளாதாரசிரமங்கள்	1(3.3%)	96.7%	The word “financial concerns” regarding buying of stoma bag was confused with “general financial concerns”	Patient reported question needed clarification and did not need reframing. No modifications done.
20.	சமூகசந்தர்ப்பங்கள் என்னை பதட்டமடைய செய்கிறது	Social situations makes me feel anxious	சமூகசந்தர்ப்பங்கள்	1(3.3%)	96.7%	Does the word “social situations” mean “common incidents relating to day to day living”	Patients suggested the item to be reframed

patients. Patients with lower levels of formal education (particularly those with only primary or no formal schooling) required assistance in understanding certain items. Patients from rural areas reported more difficulty with comprehension than those from urban areas, particularly for items that involved technical or medical terms. Older patients (aged 50 years and above) were more likely to encounter challenges in understanding certain items compared to their younger counterparts. The alternative words suggested by participants were incorporated into the final version to make the tool more linguistically and culturally relevant.

Discussion

Stoma Quality of Life Scale (SQLS) Version II, a culture-specific tool, was translated into the local language (Tamil) using the forward-backward translation guidelines of EORTC in this study. The forward translation process revealed that language variations exist among patients, as inferred from differences in word choice and sentence structures used by the two translators. The pilot test results revealed that most of the items were comprehensible and were able to elicit the response.

The words such as “stoma,” “privacy,” “appliances,” and “sexual activities” could not comprehend the same meaning when translated into Tamil. There is no appropriate word found in the dictionary for these words to accurately convey the meaning. The Tamil word for “stoma” was literally read as “micro-hole bag” which could not be comprehended as intended. Therefore, this word was translated in simple language for the easy understanding of the local people.

During the pilot testing, several comprehensibility related issues arose due to patient’s understanding of the items, particularly regarding their psycho-physiological concerns. Some factors are interfering with difficulty to understand and answer the items.

According to the patient’s understanding, the subject (“IP”) reported that the word “sexual activities” (item no 7) was conveying the meaning as both “sexual affairs as well as “prostitution activities.” In the local context and cinematic perception, the word “பாலியல் செயல்பாடுகளை” was comprehended by the subject (“IP”) as still maintaining an immoral sexual relationship with other people other than their spouses and that the translated word of “பாலியல் செயல்பாடுகளை” was misunderstood from the actual meaning of “spouse sexual activities.”

Such demographic factors might influence their understanding, where people with lesser educational qualifications may have difficulty answering those items when compared to highly educated patients. Simultaneously, another factor that contributed to comprehensibility was

for the people who hailed from rural background. Misapprehension issues may differ when comparing both rural and urban patient which depends upon their awareness and sensitivity towards the word or item. Older patients (aged 50 years and above) were more likely to encounter challenges in understanding certain items compared to their younger counterparts. Older participants took longer to process and interpret the questions, particularly those that required abstract reasoning or subjective assessment of emotions.

Another translated Tamil word of “கவர்ச்சிகரமாக” (attractive, item 8) was understood by many as “Beauteous” other than three patients (R.N, E.V, S.V) who were involved in the pilot testing regarding comprehensibility of the item. When comparing both genders, majorly female patients reported that they were upset to answer to the word “attractive.” Those patients reported that the word “கவர்ச்சிகரமாக” was deciphered to have a sexual connotation and having an indirect meaning of showing genitals or it might indicate looking as a conspicuous actress. Various reasons were interfering in this muddle. In the common dialect, the translated word of attractive conveys as sexually attractive and particularly indicates female patients to exhibit sexual interest towards others than male patients; the above reason was misperceived as it depends upon the cinematic culture where commercial cinema has wrongly conveyed the meaning of the translated Tamil word with sexual connotations. Of the three subjects, two of them were in their senescent periods of life where their orthodox view towards the meaning of attractiveness has inhibited them from truly understanding the meaning of the word.

All three patients hailed from rural background and low-income group. It might also be the reason for misunderstanding of the item, which has to be answered, and they expected clear clarification from the researcher.

The meaning of the translated word “பொருளாதாரசிரமங்கள்” (item no. 14) with actual meaning “financial concerns” was misinterpreted by one subject (A.R.) as being different from the intended meaning due to independent meanings of the word economics and cash in the local dialect. It is due to simplified perceptions regarding money and economics specific to their low socio-economic status.

The meaning of the translated word (item no. 20) with the intended meaning being “சமூகசந்தர்ப்பங்கள்” (social situations) was misinterpreted by subject (A.D) due to the vast generality associated with the meaning of the word and hence suggested a change which would denote a specific meaning such as translated words which would imply daily activities and social functions. This was due to the subject’s perception that the translated word had a vague meaning and did not denote any particular

meaning or a specific situation to which the subject could easily comprehend.

The challenges encountered during the Tamil adaptation of SQLS align with those faced in similar cross-cultural validation studies in other languages. In Spanish and Portuguese adaptations of stoma-related quality of life tools, researchers encountered difficulties in translating culturally sensitive terms, such as “sexual activities,” which required adjustments to align with local linguistic and cultural norms [7]. Similarly, Chinese and Arabic adaptations found that words related to bodily functions, hygiene, and social stigma were difficult to translate directly, necessitating context-based modifications to maintain the intended meaning [8, 9]. A French adaptation of a colorectal cancer QOL questionnaire highlighted the need to restructure terms related to intimacy and psychological distress to avoid misinterpretation [17]. In India, regional language translations such as Hindi and Kannada revealed that rural participants often struggled with medical terminologies, leading to the inclusion of simplified, colloquial expressions to enhance comprehension [18]. The Tamil adaptation of SQLS underwent similar modifications to ensure cultural relevance and ease of comprehension, particularly for rural and elderly populations. The necessity to refine translations based on local dialects, socio-cultural perceptions, and linguistic variations is crucial to ensure the validity and reliability of the adapted tool [8, 9, 17–20].

Conclusion

The patients reported that the Stoma QOL tool was relevant. The translated tool had a more simplified administrative process and was self-administrative, less time-consuming, more comprehensible, and patient-friendly. The translated tool will help in the self-assessment of the quality of life of patients in a more comprehensive manner. This would give a detailed understanding of the subjective well-being of the patients, which would help the psycho-oncologists to offer appropriate interventions, for both temporary and permanent colostomies. It is not necessary for a psycho-oncologist to be present during assessments.

Acknowledgements The authors extend their heartfelt gratitude to the cancer patients and their caregivers in the ward and stoma clinic at the Cancer Institute (WIA), Chennai, for their invaluable contributions to this study. We also wish to acknowledge Mrs. Selvi, Senior Stoma Therapist, and Mrs. Brindha, Staff Nurse from the Stoma Clinic, Cancer Institute (WIA), for their dedicated support in sample collection and overall assistance.

Data Availability Data of the study will be shared by the authors upon request.

Declarations

Conflict of interest The authors declare no competing interests.

References

1. Baxter NN, Novotny PJ, Jacobson T, Maidl LJ, Sloan J, Young-Fadok TM (2006) A stoma quality of life scale. *Dis Colon Rectum* 49(2):205–212. <https://doi.org/10.1007/s10350-005-0264-8>
2. Prieto L, Thorsen H, Juul K (2005) Development and validation of a quality of life questionnaire for patients with colostomy or ileostomy. *Health Qual Life Outcomes* 3:62. <https://doi.org/10.1186/1477-7525-3-62>
3. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, Brannon J (1993) The functional assessment of cancer therapy scale: development and validation of the general measure. *J Clin Oncol* 11(3):570–579. <https://doi.org/10.1200/JCO.1993.11.3.570>
4. Grant M, Ferrell BR, Dean GE, Uman G, Chu D, Krouse R (2004) Revision and psychometric testing of the City of Hope Quality of Life-Ostomy Questionnaire. *Qual Life Res* 13(8):1445–1457. <https://doi.org/10.1007/s11136-004-5952-8>
5. Rockwood TH, Church JM, Fleshman JW et al (2000) Fecal incontinence quality of life scale: quality of life instrument for patients with fecal incontinence. *Dis Colon Rectum* 43(1):9–16. <https://doi.org/10.1007/BF02237236>
6. Taylor C, Morgan L (2011) Quality of life following reversal of temporary stoma after rectal cancer treatment. *Eur J Oncol Nurs* 15(1):59–66. <https://doi.org/10.1016/j.ejon.2010.05.002>
7. Silva AG, Pereira MG, Lopes C (2020) Cross-cultural adaptation and validation of a stoma-related quality of life scale in Portuguese-speaking patients. *J Wound Ostomy Continence Nurs* 47(5):505–512. <https://doi.org/10.1097/WON.0000000000000689>
8. Lee CH, Wang WL, Chen HY (2019) Challenges in translating health-related quality of life measures: a Chinese adaptation study. *Qual Life Res* 28(3):845–857. <https://doi.org/10.1007/s11136-018-2046-9>
9. Al-Shboul M, Al-Smadi A, Tawalbeh L (2021) Arabic translation and cultural adaptation of the ostomy quality of life questionnaire: a validation study. *Int J Nurs Pract* 27(2):e12980. <https://doi.org/10.1111/ijn.12980>
10. Canova C, Giorato E, Roveron G, Turrini P, Zanotti R (2013) Validation of a stoma-specific quality of life questionnaire in a sample of patients with colostomy or ileostomy. *Colorectal Dis* 15(11):e692–e698. <https://doi.org/10.1111/codi.12361>
11. Zhang J, Wong FKY, Zheng M, Hu A, Zhang HQ (2015) Psychometric evaluation of the Ostomy Adjustment Scale in Chinese cancer patients with colostomies. *Cancer Nurs* 38(5):395–405. <https://doi.org/10.1097/NCC.0000000000000213>
12. Abbasi G, Zadeh SS, Janfaza E, Assemi A, Dehghan SS (2012) Language, translation, and culture. *Int Conf Lang, Media, Culture* 33:83–87
13. de Gouveia Santos VLC, Nascentes CC, de Oliveira Freitas N, de Oliveira MW, de Castro DLV (2020) Cultural adaptation and validation of the ostomy adjustment inventory-23 for Brazil. *Wound Manag Prev* 66(9):32–40
14. Rockwood TH, Church JM, Fleshman JW, Kane RL, Mavrantonis C, Thorson AG, Wexner S, Bliss, Donna RN, Lowry AC (2000) Fecal incontinence quality of life scale: quality of life instrument for patients with fecal incontinence. *Dis Colon Rectum* 43(1):9–16. <https://doi.org/10.1007/BF02237236>
15. Nowak W, Adamczyk BT, Brzyski P, Satowka J, Kulis D, Richter P (2011) Adaptation of the quality of life module EORTC QLQ-CR1 for Polish patients with rectal cancer: initial assessment

- of validity and reliability. *Pol J Surg* 83(9). <https://doi.org/10.2478/v10035-011-0078-5>
16. Smylie J, Martin CM, Kaplan-Myrth N, Steele L, Tait C, Hogg W (2004) Knowledge translation and indigenous knowledge. *Int J Circumpolar Health* 63(Suppl 2):139–143. <https://doi.org/10.3402/ijch.v63i0.17877>
 17. Dupont A, Bourion-Bédès S, Michel P (2018) Adaptation and validation of a French version of a colorectal cancer quality of life questionnaire. *Eur J Cancer Care* 27(6):e12910. <https://doi.org/10.1111/ecc.12910>
 18. Chandrashekaraiyah B, Swapna N, Belliappa MS (2024) Cross-cultural adaptation, translation and validation of Kannada Version of the Swallowing Quality of Life Questionnaire (KSWAL-QOL). *Indian J Otolaryngol Head Neck Surg* 76:351–357. <https://doi.org/10.1007/s12070-023-04162-w>
 19. Omara MTA, Al-Malkia MH, Bindawas SM, Alnahdia AH, Alje-hand GH, Al-omaria BNM, Alhammada SA (2024) Cross-cultural adaptation and validation of the Arabic version of McGill quality of life: revised questionnaire in the patients with cancer. *Disabil Rehabil* 46(9):1878–1887. <https://doi.org/10.1080/09638288.2023.2207220>
 20. Rao S, Narayanan V, Scior K (2023) Cultural adaptation and validation of the Autism Family Experience Questionnaire (AFEQ) for use in India. *Int J Dev Disabil* 69(4):228–238. <https://doi.org/10.1080/20473869.2023.2280808>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.