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Review

Self-reported functional status among spinal cord injury patients using the spinal cord independence measures III: Integrative literature review

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ABSTRACT

Increasing attention to engaging spinal cord injury (SCI) patients with their rehabilitation entails self-assessment of their functional status. The Spinal Cord Independence Measures Self-Report (SCIM-SR) was specifically developed to allow individuals with SCI to assess their functional status and report improvements or deficits. This review was done as a preliminary phase to examine the development process of the SCIM-SR and assess the advantages of using the SCI self-reported functional status measure in Qatar. An integrative literature review was conducted using Whittemore and Knafel's framework, searching three databases: CINAHL, Embase, and Medline. The initial search yielded 793 articles published between 2010 and 2022. After further evaluation of the literature, 12 articles were included in the subsequent analysis. This integrative literature review identified two major themes: SCIM-SR tool development and the advantages of using SCIM-SR. Tool development involved tool translation, language and cultural adaptation, and psychometric testing. Reported advantages included increased patient engagement, independence and convenience. This integrative review identified the required processes for translation, language and culture adaptation, and psychometric testing to facilitate the adoption of SCIM-SR in Qatar. To develop an Arabic version of the SCIM-SR, following a specific guideline as described in this integrative review is recommended. Before implementing the Arabic SCIM-SR tool, it is critical to evaluate its validity and reliability.

Keywords: rehabilitation, spinal cord injury, self-report/self-assessment, spinal cord independence measure III

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INTRODUCTION

Spinal cord injuries (SCIs) may have devastating impacts on individuals, families, and communities. An SCI comprises damage to any part of the spinal cord or nerves, which often causes permanent changes in strength, sensation, and other body functions below the injury site.¹ The estimated annual incidence of SCIs worldwide is 23 people per million.² Between 2010 and 2014, the estimated annual worldwide in-hospital mortality rate from SCIs ranged from 4% to 17%; following discharge, this rate is around 3.8% in the first year.¹ The estimated annual incidence of SCIs in the Arabian Gulf region is high. In Al Ain, the incidence rate was 170 per million per year between 2003 and 2006.³ In Qatar, 442 patients underwent trauma surgery due to SCIs between 2007 and 2009.⁴ The Qatar Rehabilitation Institute (QRI) at Hamad Medical Corporation (HMC), the largest healthcare provider in Qatar, admitted 120 SCI cases in 2021 (personal communication, October 30, 2022).

Effective rehabilitation programs aim to decrease the burden of illness while improving the quality of life for individuals with SCIs. The effectiveness of inpatient rehabilitation programs is evaluated by assessing patients' functional status.² The Spinal Cord Independence Measure (SCIM) was specifically designed for individuals with SCIs to measure their functional abilities.³ SCIMIII is now widely used in SCI rehabilitation facilities as a valid and reliable functional assessment tool.⁵ More efforts have been made recently to effectively engage SCI patients (SCIPs) in more actively participating in their treatment regimens, including the use of self-assessment of their functional status. The SCIM Self-Report (SCIM-SR) was developed to help individuals with SCIs be part of their rehabilitation planning and to report improvements or defects. SCIM-SR has been translated from English to other languages.⁵ However, it has not been translated into Arabic. This integrative literature review will explore and highlight the feasibility and applicability of adapting the SCIM-SR tool for individuals with SCIs in Qatar.

METHODOLOGY

Whittemore and Knaf's framework was chosen to guide this integrative literature review. This framework follows five steps: problem identification, literature search, data evaluation, data analysis, and presentation of the results.⁶

Problem Identification

Community rehabilitation models call for self-reported measures to assess function among SCIPs. Using self-assessment reports could help individuals with SCIs become more self-aware, problem-solve, and adjust to changes in their physical health.⁷ However, the application of the SCIM-SR in Qatar is limited without an Arabic version.

Literature Search

A comprehensive search was conducted using three databases: Cumulative Index to Nursing and Allied Health Literature (CINHAL), Embase, and Medline. The key terms were *rehabilitation*, *spinal cord injury*, *self-report/self-assessment*, and *Spinal Cord Independence Measure III*. The limiters were primary studies published in English from 2010 to 2022. The initial database search resulted in 793 articles.

Data Evaluation

The 793 articles were further evaluated to ensure the most relevant articles were included. After removing duplicates, screening titles and abstracts using the inclusion and exclusion criteria (Table 1), and reviewing the full text of 28 articles, 12 articles were found to be relevant for inclusion (Figure 1). The Mixed Methods Appraisal Tool (MMAT) version 2018 was used to critically appraise the included studies. All 12 studies were deemed to be of adequate quality for inclusion.

Table 1. Inclusion and exclusion criteria.

| Inclusion criteria | Exclusion criteria |
|---|--------------------------------------|
| Studies published from 2010–2022 | Studies earlier than 2010 |
| Traumatic and non-traumatic SCI studies | Studies on other diagnoses |
| Participants aged 14 years old and above | Participants aged under 14 years old |
| Primary studies | Secondary sources |
| Studies on the use of SCIM III self-assessment or self-report | Studies not about SCIM-SR |
| English language | Other languages |

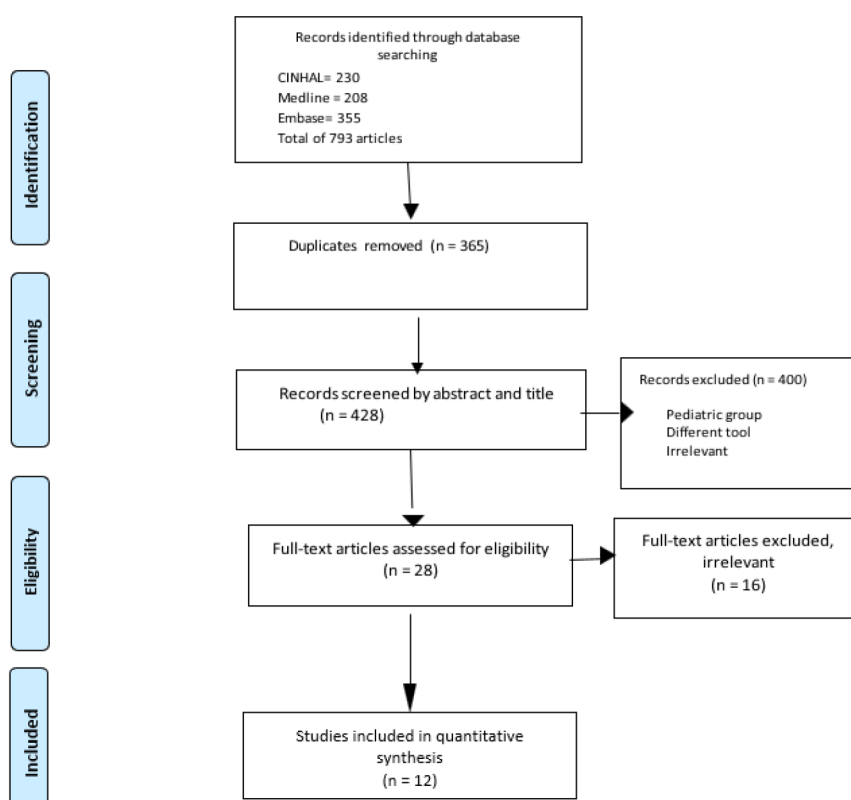


Figure 1. PRISMA flow diagram of literature search process.

Data Analysis

Data from the 12 articles was organized in a data extraction table. This process of reading, analyzing, and comparing information facilitated the finding of themes and the synthesizing of results.

RESULTS

All 12 articles reported on the process of translation and cultural adaptation of the SCIM-SR to different languages and cultural settings. The analysis process resulted in the identification of two salient themes: (a) SCIM-SR tool development and (b) the advantages of using SCIM-SR.

SCIM-SR Tool Development

The SCIM-SR has been through three main processes toward feasible and applicable adaptation as a self-reported functional status assessment tool in different contexts or different languages. These three processes are translation, language and cultural adaptation, and psychometric evaluation (Figure 2).

Translation

The studies included in this integrative review provided an overview of the different translation processes and guidelines that were followed to produce the SCIM-SR scale. Six studies used instrument translation guidelines that were reported in earlier SCIM-SR translation research (Table 2).⁸⁻¹³ Three articles did not mention any specific guidelines.^{5,7,14} While the guidelines followed in translating the SCIM-SR differed, eight of the included studies followed almost the same translation process.⁷⁻¹⁴ This process included the following steps: forward translation, backward translation, comparing and modifying, and piloting or pretesting the tool (Figure 2).

Forward Translation

The forward translation process was followed in nine studies.^{5,7-14} The number and type of forward translators provided for each SCIM-SR translation differed among the studies (Table 2). Translators were familiar or unfamiliar with SCIMIII, such as other healthcare providers or professional translators, respectively. For example, Takeuchi et al. included translators who were familiar with SCIMIII, while Aguilar-Rodríguez et al. used professional translators who were not familiar with the tool.^{8,10}

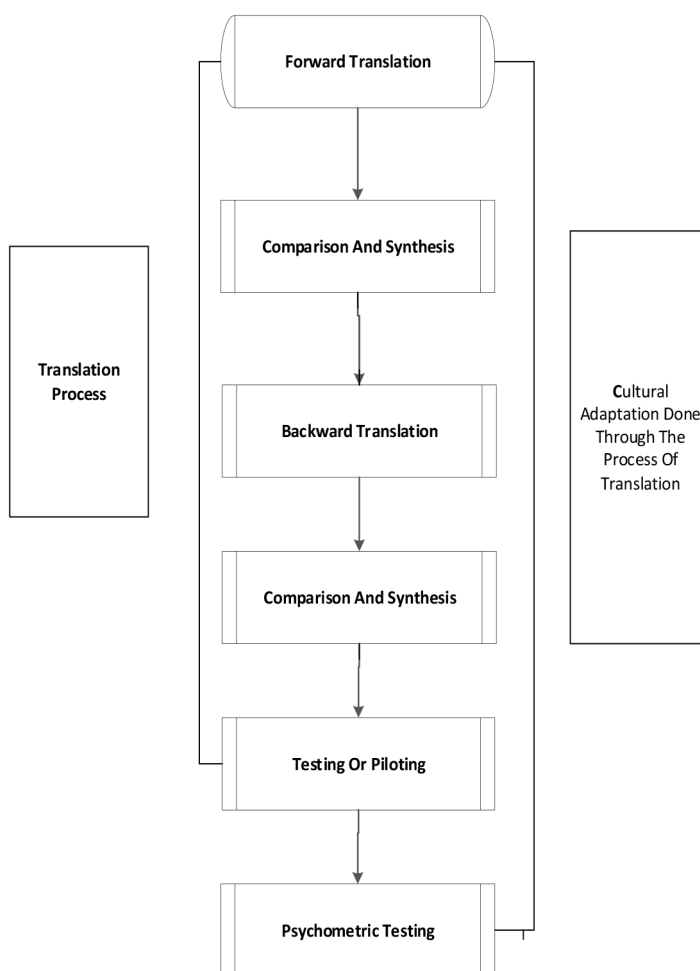


Figure 2. Tool development process.

Backward Translation

Backward translation to English was done in seven studies.^{7–13} The backward translation process was conducted by either the same translators as in the forward translation phase or by new translators who were blinded to the original tool. Four of the studies used translators who were blinded to the original English version of SCIM-SR.^{7,8,11,13} However, Wang et al. used healthcare providers who were familiar with SCIM-SR to translate the tool.¹²

Comparing and Modification

In the comparing and modification process, the English SCIM-SR and the version resulting from backward translation were compared for equivalency in seven studies.^{7–13} For example, Takeuchi et al. recruited 30 medical students proficient in English to compare the two scales.¹⁰ In cases of disagreement in their study, reconciliation meetings were held by the translators until the final copy of the SCIM-SR was approved.¹⁰

Piloting or Pretesting

Seven studies reported the last stage as pretesting or piloting of the translated, modified tool (prefinal SCIM-SR).^{5,7–9,11–13} Testing of the prefinal SCIM-SR allowed additional corrections to suit the language of the context and facilitate the usage of these tools by SCIPs.^{5,7–9,11–13} Table 1 presents the different participants in the pilot stage of SCIM-SR within these seven studies.

Language and Culture Adaptation

Language and cultural adaptation throughout the translation process was conducted in 10 studies (Table 1).^{5,7–14} In three studies, the wording was changed from third to first person as the patients

Table 2. SCIM-SR tool development.

| References | Translation guidelines | Forward translation | Synthesis | Backward translation | Synthesis | Pilot | Language and culture adaptation |
|---------------------------------------|--|--|---|---|--------------------------|--|--|
| Aguilar-Rodríguez et al. ⁸ | Sperber et al. ²³ guidelines. | Two professional translators. | Compared and compiled by the author. | Done by two different professional translators. | Compiled by the authors. | Tested on 20 SCI to reach the pre-final SCIM-SR. | Linguistic validation by 30 reviewers (professional translators); two versions compiled to reach approved version. Likert scale used to measure comparability. |
| Bonavita et al. ⁵ | Not mentioned. | Done by professional scientific translator. | Not applicable. | Not applicable. | Not applicable. | 5 Italian-speaking experts commented on the SCIM-SR. | Tested on 5 SCIPs for cognition interview to check if they understood the wording. |
| Fekete et al. ¹⁵ | Not applicable. | Not applicable. | Not applicable. | Not applicable. | Not applicable. | Not applicable. | During wording adaptation, some items were omitted as they were not known to patients. Complex terms were replaced with simpler ones to facilitate self-reporting. Scoring algorithm changed. External expert reviewed the final draft. |
| Jørgensen et al. ¹⁴ | Not clearly identified. | Done by two translators, one expert in SCI rehabilitation; both native Swedish speakers proficient in English. | Both translators agreed on one common version, then an expert committee met and graded each item. | Not applicable | Not applicable. | Two independent bilingual Swedish and English healthcare professionals with experience in SCI rated each item for clarity and cultural adaptation. | |

(Cont.)

Table 2. (Cont.)

| References | Translation guidelines | Forward translation | Synthesis | Backward translation | Synthesis | Pilot | Language and culture adaptation |
|---------------------------------|---|--|--|--|--|--|---|
| Khatri et al. ⁹ | Beaton et al. ¹⁹ guidelines. | Two translators (one medical physiotherapist and one non-medical Nepali language expert). | One common translated document was produced from the two forward translations. | Done by two native English speakers (non-medical). | Expert committee (physiotherapist, physiatrist, methodologist). | Cognitive interview with five SCI individuals. | Semantic, idiomatic, experimental, and conceptual equivalence between English version and Nepali version of the SCIM-SR. |
| Michailidou et al. ⁷ | Not clearly identified. | 5 Greek translators (1 urologist, 3 allied health professionals, 1 professional translator). | Compared to produce one report. | 2 Greek people residing in the UK. | Compared and discussed to produce final report. | 5 people with or without SCI. | All translators considered conceptual equivalence, taking culture and language into consideration. Verbs changed from third to first person. Accepted words used and many other words removed and changed during translation. Sometimes the translator used more than one word to semantically explain situations. |
| Takeuchi et al. ¹⁰ | Sperber et al. ²³ guidelines | 2 medical experts translated the English SCIM-SR into Japanese. | Compared and compiled in one version by another translation expert. | Professional translators. | Recruited 30 medical students studying in English to compare the two scales. | Not done. | Two rounds of corrections in Japanese SCIM-SR to get the best scoring for the wording. |

(Cont.)

Table 2. (Cont.)

| References | Translation guidelines | Forward translation | Synthesis | Backward translation | Synthesis | Pilot | Language and culture adaptation |
|----------------------------------|---|---|--|---|---|---|--|
| Tongprasert et al. ¹¹ | Beaton et al.'s ¹⁹ guidelines. | Two drafts were independently translated by a Thai physiatrist (an expert in spinal cord rehabilitation medicine), and a native Thai non-medical English language specialist. | Drafts were compared by the authors to produce one report, assisted by a physiotherapist and occupational therapist. | Independently translated back into two English versions by a non-medical native English speaker fluent in the Thai language, and a non-medical English professional translator. Both translators were unaware of the original version of the questionnaire. | The two back-translated versions were sent to Professor Christine Fekete and another native English speaker by email for feedback on understanding and discrepancy. The draft version of the SCIM-SR-Thai was revised into the pre-final version of the SCIM-SR-Thai. | Completed by five participants with SCI. | The interview and feedback from participants revealed that items in the questionnaire were understood, with minor suggested adjustments. The final version of the SCIM-SR-Thai was obtained after revision based on all the suggestions. |
| Wang et al. ¹² | Brislin guidelines. ²⁴ | Two graduate nurses. | Compared by the same two nurses. Experts were consulted in cases of disagreement. | Two nursing graduates with bilingual literacy in Chinese and English, with SCI research experience. | The two nurses who conducted the forward translation compared the back-translated with original English SCIM-SR. | Tested on 20 SCIPs. | Seven language professionals checked the wording and used Likert scale wording scoring to further adjust the wording to reach comparability. |
| Wilaratrami et al. ¹³ | Beaton et al.'s ¹⁹ guidelines | Spine surgeon and 1 non-medical professional translator. | Two copies assessed and adjusted by the investigator. | A bilingual translator speaking Thai as a second language. | Compared the back-translation version with English SCIM-SR. Reconciliation meeting to reach the pre-final version. | 10 health volunteers completed the pre-final Chinese SCIM-SR. | Cross-cultural adaptation was done during the translation process. Adaptions were made using personal pronouns, changing complex topics, and avoiding technical terms. |

Abbreviation: SCIM-SR, Spinal Cord Independence Measures Self-Report.

themselves needed to use the SCIM-SR.^{7,13,15} Participants in three studies were interviewed to check their understanding of the questions.^{5,7,11} The results of these interviews indicated that participants were confused by some descriptions that were subsequently omitted.⁷

Psychometric Evaluation

Psychometric evaluation is essential to assessing the validity and reliability of the translated SCIM-SR. The SCIM-SR was found to be valid and reliable (Table 3). However, the sphincter management subscale was removed from the subscale analysis in five studies as results for bladder sphincter management affected the overall validity and reliability results.^{7,10,12,13,16}

Validity

Studies in this integrative review used different approaches to assess the validity of the SCIM-SR (Table 3). Different statistical tests were also used to assess validity, including correlation coefficients and the Bland–Altman test. Correlation coefficients were computed between patients' scores using SCIM-SR and healthcare providers' scores using SCIMIII, which demonstrated a strong correlation between SCIMIII and SCIM-SR.^{5,7,8,10–12,15} The Bland–Altman test was done in the same studies, and the results showed no bias or minimal differences between the two scales.

Reliability

Reliability was tested using different types of tests, including internal consistency and test-retest reliability (Table 3). Cronbach's α was computed to check the internal reliability of SCIM-SR.^{7,9–14} In addition, Möller et al. assessed the test-retest reliability of SCIM-SR and reported no influence of time on the results of SCIM-SR.¹⁷ Except for the bladder and sphincter subscales, the psychometric evaluation of the SCIM-SR indicated high reliability.

Advantages of SCIM-SR

The translation of the SCIM-SR was found to be advantageous to both patients and healthcare providers. The use of the SCIM-SR has allowed patients to be more independent and more involved in evaluating their functional development.⁷ SCIM-SR has been more convenient for SCIPs and their families because it requires less time and effort to administer, and it is applicable independently in outpatient or community settings.^{5,8–12,14,15} Similarly, healthcare workers have found SCIM-SR to be convenient because SCIMIII is limited to inpatient settings and can be time-consuming to complete.^{9,12,14,15}

DISCUSSION

The goal of this integrative review was to understand the process required to develop the SCIM-SR. Self-reporting is critical in assisting SCIPs to be more self-reliant and capable of assessing their daily living functions.⁵ A self-reported tool in the languages and contexts of patients is required for SCIPs to understand the scale's content.

SCIM-SR Tool Development

Based on the findings of this review, the successful implementation of SCIM-SR in diverse languages and cultures requires a specific translation process. This process must follow forward translation, backward translation, and testing of the translated tool. This finding is supported by Maneesriwongul and Dixon as well as Beaton et al. who stated that an agreed-upon guideline for tool translation is required to have a valid translation process.^{18,19} Based on the translation process followed within the articles included in this review, a standardized and specific number and type of experts are required in each translation stage. Beaton et al. and Hall et al. also reported that having a standardized number of experts and types of professionals will improve the uniformity and quality of the translation process.^{19,20} This integrative review showed that the translation process must follow a standardized cultural and language adaptation process as well as standardized validity and reliability measures. Hall et al. also recommended having a clear and standardized cultural and language adaptation process.²⁰ Poor cross-cultural adaptation may compromise the equivalence of instruments and introduce measurement bias.^{18,20} In addition, existing research has affirmed that validity and reliability are the essential components of psychometric testing following the translation and adaptation of a tool.^{20,21}

Advantages of SCIM-SR

This integrative review highlighted several advantages of translating the SCIM-SR across diverse cultures and languages for patients, healthcare providers, and organizations, which have also been

Table 3. Validation and reliability.

| References | Validity type/test | Validity result | Reliability/test | Result |
|------------|---------------------------------------|---|--|--|
| 1 | Aguilar-Rodríguez et al. ⁸ | Lin's concordance correlation. Lin's concordance correlation. Bland-Altman. | Lin's concordance correlation. Coefficient of total score = 0.998. Self-care ($r = 0.988$). Respiration and sphincter management ($r = 0.992$). Mobility ($r = 0.997$). The Bland-Altman plot showed a small bias - 0.32. Bland-Altman plot shows few outliers. | Not tested. |
| 2 | Bonavita et al. ⁵ | Criterion validity. Pearson's correlation. Bland-Altman. Intraclass correlation. | Total Pearson's correlation coefficient score shows a strong correlation ($r = 0.934$). Intraclass correlation ($r = 0.933$). The lowest correlation result was for respiration and sphincter management ($r = 0.806$). Mobility correlation ($r = 0.906$). Self-care correlation ($r = 0.918$). Pearson's r for the total score was 0.87. Correlation coefficients result ($r = 0.90$). Bland-Altman method scores showed that patients rated their functional status higher than professionals. Bland-Altman revealed no systematic changes between evaluation points. | Not tested. |
| 3 | Fekete et al. ¹⁵ | Criterion validity. Pearson correlation. Bland-Altman. | | Not tested. |
| 4 | Jørgensen et al. ¹⁴ | Criterion validity. Bland-Altman. | | Test-retest. Internal consistency. |
| | | | | Cronbach's α total score = 0.89. For self-care ($\alpha = 0.92$). For respiration and sphincter management ($\alpha = 0.37$) (the lowest). For mobility ($\alpha = 0.86$). |

(Cont.)

Table 3. (Cont.)

| References | Validity type/test | Validity result | Reliability/test | Result |
|------------|---------------------------------|---|---|--|
| 5 | Khatiri et al. ⁹ | Not tested. | – | Intraclass correlation coefficient = 0.96. Cronbach's α total score = 0.80. Self-care ($\alpha = 0.959$). Mobility ($\alpha = 0.838$). Respiration and sphincter management ($\alpha = 0.506$) (lowest). |
| 6 | Michailidou et al. ⁷ | Concurrent/criterion validity. Spearman's rho. | Strong correlation for self-care ($p = 0.78$). Moderate correlation for mobility ($p = -0.58$). | Internal consistency. Cronbach's α total score = 0.78. Self-care ($\alpha = 0.90$) (excellent). Respiration and sphincter management ($\alpha = 0.559$) (poor). Mobility ($\alpha = 0.91$) (good). Deleting sphincter management increased Cronbach's α . |
| 7 | Möller et al. ⁷ | Criterion validity. Spearman's rho correlation. | SCIM-SR scores showed a significant correlation with the selected items of the WHO-QoL-BREF ($p = 0.01$), with moderate to strong influence. | Not tested. Linear regression showed no influence of time passed on functional status assessment using SCIM-SR except for the bladder and sphincter examination (slight decrease). |
| 8 | Prodinger et al. ¹⁶ | Construct validity. Rasch analysis using intraclass correlation. | Intraclass correlations with SCIMIII sub-scale scores were (0.90). | Values of approximately 0.70 and greater (acceptable). Person Separation Index (PSI). |
| 9 | Takeuchi et al. ¹⁰ | Criterion validity. Bland-Altman. Spearman's rank correlation coefficients. | Bland-Altman revealed no significant proportional bias (-0.02). Spearman's correlation coefficient total = 0.95. Sub scores: Self-care ($r = 0.98$). Respiration and sphincter management ($r = 0.83$). Mobility ($r = 0.89$). | Internal consistency. Cronbach's α for total JSCIM-SR score above 0.88. Self-care ($\alpha = 0.92$). Respiratory and sphincter management ($\alpha = 0.7$). Mobility ($\alpha = 0.89$). |

(Cont.)

Table 3. (Cont.)

| References | Validity type/test | Validity result | Reliability/test | Result |
|------------|--|--|---|--|
| 10 | Tongprasert et al. ¹¹ Construct concurrent validity. Bland-Altman. Pearson correlation. Intraclass correlation. | Three-factor-model and unidimensional model of the SCIM-SR-Thai were analyzed using confirmatory factor analysis (CFA). The three-factor-model had an acceptable fit to the data, but the unidimensional model fit the data better. Pearson correlation = 0.97. Bland-Altman showed a few outliers (P -value = 0.048). | Internal consistency. | Cronbach's α total score = 0.98. Self-care ($\alpha = 0.96$). Mobility ($\alpha = 0.96$). Respiratory and sphincter management ($\alpha = 0.97$). |
| 11 | Wang et al. ¹² Content validity. Criterion validity. Intraclass correlation coefficient. Bland-Altman. | Correlation coefficient for total = 0.935. For self-care ($r = 0.899$). For mobility ($r = 0.942$). For respiration and sphincter ($r = 0.760$). Bland-Altman analysis showed no significant difference. | Internal consistency. Test-retest. Reliability. | Cronbach's α total score = 0.908. Self-care ($\alpha = 0.913$). Respiration and sphincter management (0.581). Mobility ($\alpha = 0.895$). Test-retest result after 2weeks. Spearman coefficient total score = 0.73. |
| 12 | Wiaratrasami et al. ¹³ Construct validity/concurrent. Bland-Altman. Pearson's correlation coefficient. | Pearson's correlation coefficient subscales demonstrated strong correlations (0.859–0.960). The Bland-Altman result indicated that patients rated their functionality similar to medical therapists. Bland-Altman results ranged from 0.063 to 1.56 ($p < 0.05$). | Test-retest. Internal consistency. | Cronbach's α total score = 0.91. Self-care ($\alpha = 0.94$). Respiration and sphincter management ($\alpha = 0.75$). Mobility ($\alpha = 0.90$). |

found in the literature. Hunter et al. found self-reporting helped patients with long-term needs to be part of evaluating their abilities.²² Self-reporting tools enhance patients' engagement in their plan of care, which promotes their self-efficacy and resilience and is associated with improved quality of life and clinical outcomes in many health contexts.²⁰ Doma et al. stated that self-reporting is a resource-efficient, low-cost way to reduce the burden of conventional assessment on patients.²¹ Moreover, Hall et al. found that self-reporting tools might include elements that assess patients' satisfaction and improve the quality of care.²⁰ Using self-reporting tools thus enhances patient-centered care and improves the quality of services provided, which reduces healthcare costs.²²

Strengths and Limitations

The main strength of this review is that the SCIM-SR was found to be a valid and reliable tool. The main limitation of this integrative review is that no studies assessed patients' experiences while using self-report tools. In addition, no literature on this topic includes Arabic-speaking individuals with SCIs. Furthermore, the implementation of the SCIM-SR has limitations related to sphincter assessment.

Implications and Recommendations

This integrative review has several implications and recommendations. The translation of the SCIM-SR at the QRI to the Arabic language should follow specific guidelines. Therefore, formal SCIM-SR training sessions for nurses and other professionals are required. Future studies need to consider the long-term outcomes of using SCIM-SR, particularly in terms of patient outcomes as well as patient experience and satisfaction with the SCIM-SR. The cost-effectiveness of the tool should also be evaluated. Other methods that allow SCIPs to conduct sphincter control assessments need to be explored in future studies as the reviewed studies indicated a lack of adequate sphincter control self-assessment by participants due to their inability to properly assess bladder residue.

CONCLUSION

This integrative review aimed to explore the feasibility of translating the SCIM-SR to Arabic for adoption in Qatar. The results of this integrative review highlight the development of the tool and its advantages as a self-assessment tool. The development of the tool includes translation, language and cultural adaptation, and psychometric measure testing. The advantages of the SCIM-SR as a self-assessment tool include empowering patients to be part of the plan of care and being more engaged with their rehabilitation goals. The tool also reduces pressure on healthcare professionals and facilities, which can be particularly useful in cost-effectively delivering assessments with less inconvenience for patients. To develop an Arabic version of the SCIM-SR for use in Qatar, it is recommended to follow the same steps outlined in the review and to assess the validity and reliability of the Arabic SCIM-SR tool before implementation as an evidence-based practice solution.

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