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Title: Translation into Greek and initial validity and reliability testing of a modified version of the SCIM III, in both English and Greek, for self-use.

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Abstract

Purpose. To translate and culturally adapt the Spinal Cord Injury Measure version III (SCIM III) into Greek (GR-SCIM III). To conduct initial testing of psychometric properties of both measures by self-report.

Method. Forward-backward translation was conducted to produce the GR-SCIM III. Participants completed the English or Greek versions in 2008-2009. Both versions were examined for multidimensionality, internal consistency and concurrent/criterion validity with the EQ-5D.

Results. Forty five Greek adults with spinal cord injury (SCI) (23 males), mean age 61 (SD17) years; mean time since injury 11 (SD9) years, completed the GR-SCIM III. One hundred and seventy four English speaking adults with SCI (111 males), mean age 47 (SD12) years; mean time since injury 12 (SD11) years, completed the SCIM III. Unidimensionality was confirmed for both versions. Internal consistency was acceptable ($\alpha=0.78$ for both). Validity was strong for the “self-care” subscale (GR-SCIM III $\rho=-0.78$, SCIM III $\rho=-0.75$) and moderate for the “mobility” subscale (GR-SCIM III $\rho=-0.58$, SCIM III $\rho=-0.45$).

Conclusions. This has been the first function scale translated and validated in Greek for people with SCI. Both the GR-SCIM III and SCIM III are reliable for use by self-report. More studies are needed to further examine their psychometric properties and compare with observation or interview.

Introduction

The exact international incidence and prevalence of Spinal Cord Injury (SCI) is very difficult to evaluate due to lack of data but estimates place incidence between 10 and 83 per million people annually and prevalence between 223 and 755 per million people [1]. Despite data being incomplete, it is apparent that a large number of people live with a SCI around the world. The approach to rehabilitation in SCI has changed rapidly over the last few decades for a number of reasons. To begin with, the survival rate has increased significantly reaching as high as 95% in those sustaining an incomplete injury and being injured when aged under 25 years [2]. Life expectancy after SCI, if injured at the age of 20, can vary from 33 to 44 years [3] and the number of people who sustain an incomplete injury has increased [4]. People who live for longer than 20 years post injury are found to have good self-perceived health, be fairly independent and well integrated into the community [4].

As a consequence of the increase in the survival rate the “expert patient” programme, which is the adopted and adapted version of the Stanford Chronic Disease Self-Management Program [5, 6], has been promoted by the Department of Health in the UK [7-9] with the aim, supported by the International Classification of Impairment and Disability (ICF), to promote patient participation and community rehabilitation [7–11]. Standardised measures and assessment tools have been used widely in research and rehabilitation, promoted in guidelines and discussed in the literature [12-16]. The long term community rehabilitation models are calling for self-reported measures to assess function in SCI [17] which could help people with SCI become more self-aware, take responsibility for problem solving, and adjust to changes in their physical health [18-20].

Rehabilitation models are also adjusting to modern lifestyles. Globalisation, the ease of transport between countries and technological developments, both demand and facilitate the conduct of cross-national, cross-cultural or international research, which is rapidly increasing, and can raise questions about single-nation studies, can inform revisions and interpretation of results between countries [21-24]. Tele-rehabilitation is a recently suggested method for SCI, with encouraging early results, where patients give feedback electronically and are monitored via videophone sessions [25,26]. Function was assessed, in that study, using the Spinal Cord Independence Measure (SCIM) by observation before discharge from the SCI unit, and again at six months, but some functional tasks were assessed during the videophone sessions via interview [25,26]. Our study is the first attempt to present the people's with SCI perspective about their function rating while using a SCI-specific measure which may add to future tele-rehabilitation. Tele-rehabilitation could be conducted locally or internationally, which emphasises the importance of multiple language translations of the SCIM III.

The Spinal Cord Independence Measure (SCIM) is a “comprehensive ability rating scale that has been designed specifically for people with spinal cord lesions” [27]. SCIM III was tested internationally and it showed good validity making it a suitable measure for cross-cultural research [27]. It assesses function covering three principal areas: 1) self-care including feeding, bathing, dressing, and grooming; 2) respiration and sphincter management including respiration, bladder and bowel management, and use of a toilet; 3) mobility, which is divided into a) tasks in a room and a toilet, and b) tasks indoors and outdoors [28]. These subscales include 6, 4, and 9 items, respectively, consisting of 2 to 9 grades. The higher the grade the better the individual's performance/independence and the score ranges from 0 to 100 for the total score. SCIM III has

an intraclass correlation coefficient (ICC) of above 0.94 for the total score and for all individual subscales. It has improved inter-rater reliability compared to version II, internal Cronbach's α consistency for the overall SCIM III is above $\alpha=0.8$. Validity of the scale is $r=0.79$ [27].

Dawson et al [17] identified the need for a new self-reported measure to assess function in SCI which would represent the patient's perspective. Self-assessment of function may help patients who, according to May et al [18], want to become self-aware and take responsibility for problem solving. When SCIM II was compared for use by observation versus interview [29] the differences between patients' ratings and observers appeared insignificant as correlations were high, ranging from $r=0.69-0.96$ [17, 29].

None of SCIM versions have, to our knowledge, been previously used by self-completion. We are aware of only one other study which translated SCIM III into Greek [30], following our translation [31], which has been published as a conference abstract, provides results for two patients only and where SCIM is used for therapist administration [30]. The aim of our current work was to develop a translation of SCIM III into Greek, to modify SCIM III for use by self-report and to conduct an initial test of the psychometric properties of this self-reported version in both English and Greek.

Materials and Methods

Translation of SCIM III into Greek

Permission for translation of SCIM III into Greek was obtained from Professor Amiran Catz (personal communication). Recommended methods for translation and cross-cultural adaptation [32-35] were applied. Five forward translations were conducted. All translators were of Greek

origin, four of who lived and worked in the UK. One was a surgeon urologist, one a professional translator with medical background and three were allied health professions University lecturers. The procedure of the forward translation is described in Figure 1. Two people of Greek origin, educated in English speaking Universities, living and working in the UK for many years, were used as the back-translators. Both were independent to the study and were not aware of the original English version of SCIM III. The back-translation procedure is described in Figure 2. The Greek version of SCIM III was piloted by five people with or without SCI all of Greek origin. Throughout the translation procedure, all translators were advised to consider conceptual equivalence taking into account culture, language and idiomatic differences.

Self-report version of SCIM III and adaptation into Greek

An adjustment to both the Greek and English versions of SCIM III, was that verbs in general were changed, where appropriate, from the third person to the first person. This was done because SCIM III was going to be completed by the respondents themselves and it would have been grammatically inappropriate and confusing to self-complete a questionnaire which uses third person language. Another change applied in the forward translation was that words, usually verbs, were translated from the third person (e.g. “requires”) into the passive voice, which is commonly used in Greek (e.g. “απατεείται”). In general, this was accepted as part of the Greek language culture, and as long as the meaning of the text was not altered it was followed throughout the questionnaire unless it was grammatically wrong to do so. Sometimes the translators used more than one word(s) or phrase(s) to describe the original word(s) or phrase(s). Study protocol guidelines were followed to resolve disputes (Figures 1 & 2) the most important of which can be found in Table 1.

Study design and data collection

In this study SCIM III was one of the measures to investigate low back pain (LBP), function and quality of life in incomplete SCI (iSCI) [31, 36].

People aged 18 years or older who lived in the USA, UK or Greece and who reported a diagnosis of iSCI were recruited primarily online (web survey) or via two hospitals and a medical centre (mail survey) in 2008 and 2009. People were excluded if: 1) they did not know the type of their injury, 2) they were not from one of the 3 participating countries, 3) they did not report iSCI, and 4) their returned questionnaires had more than 50% missing data. Participants completed a questionnaire pack which included the SCIM III. The online system was set up to accommodate taking breaks without losing data while securing anonymity for those participants who had agreed to participate anonymously. Both the paper and the online questionnaires had the same format and question sequence. A sample size calculation was conducted based on the primary outcome of the study (i.e. the presence of LBP) and the total number of participants needed for the whole study was 185; which was exceeded.

Ethical approval

The study was advertised on a number of websites including the Spinal Injury Association (SIA), the National Spinal Cord Injury Association (NSCIA) and “Disability Now”. Participants were also recruited from two general hospitals and one medical centre in the cities of Thessaloniki and Kavala (region of Macedonia, Greece). Ethical approval to conduct the study in all countries was obtained from Brunel University Research Ethics Committee, UK. In addition, local research and development approvals were obtained from the participating hospitals and the owners of all the websites/organisations which were used to assist in recruiting. All eligible participants were

informed that completion and return of the questionnaires was taken to indicate informed consent had been given.

Statistics

Cronbach's α coefficient was used to assess internal consistency. This coefficient produces an estimate of reliability coefficients. When Cronbach's α is higher it indicates that the items examined are strongly correlated with the common dimension that they are measuring [37].

Cronbach's α can be affected by multidimensionality which affects its precision, thus it should be used when there is only one single common factor in order to measure the strength of this factor [38]. Therefore unidimensionality should be established first by principal component analysis (PCA) [38]. PCA using the Kaiser-Meyer-Olkin (KMO) and Bartlett's test was conducted on both the English and the Greek versions of SCIM III.

Criterion/concurrent validity examines if the measure actually measures what it intends to do and this is done by comparing it with another already validated measure [39]. Previously, SCIM III was validated against the Functional Independence Measure (FIM), however, to our knowledge a Greek version of FIM was not available. Therefore, validity was examined for two of the subscales of SCIM III which were similar to two of the subscales in the EQ-5D [24]; self-care and mobility. The two tests are scored in opposite directions, i.e. in EQ-5D the higher the score the worse the health outcome whereas in SCIM the higher the score the better the outcome. Therefore the two measures should be inversely (negatively) correlated to indicate a good concurrent validity and the closer this correlation to -1 the stronger the relationship. Spearman's rho (ρ) was used to examine these correlations.

Results

Sample characteristics

Fifty eight (58) people with SCI from Greece self-completed the questionnaire and data from 45 which met the inclusion criteria were eligible for analysis. There were more men (56%), the mean age was 61 (SD17) years and the mean time since injury was 11 (SD9) years. Most people reported incomplete paraplegia (67%) and the cause of injury was mainly non-traumatic (60%). Two hundred and twenty four (224) people self-completed the English version of SCIM III and data from 174 met the inclusion criteria for analysis. There were more men (64%), the mean age was 35 (SD15) years and the mean time since injury was 12 (SD7) years. Incomplete paraplegia and tetraplegia were equally present (50%). Finally, the cause of injury was mainly traumatic (79%).

Reliability

Unidimensionality was confirmed for both versions of SCIM III as one factor was extracted while conducting PCA. For the GR-SCIM III none of the KMO test results were below acceptance value (<0.50). The Bartlett test was significant in all (Table 2). Both tests confirmed the data were suitable for principal component analysis (PCA). Similarly, for the English version of SCIM III all KMO test results were above acceptance value (≥ 0.50) indicating that data were appropriate for PCA. The strength of correlations justified further analysis as the all correlations examined with the Bartlett test were highly significant.

Having ensured unidimensionality, reliability was examined with Cronbach's α which for the overall self-reported GR-SCIM III was 0.78 (Table 3). For the "self-care" subscale it was found

to be “excellent” ($\alpha=0.90$). The “feeding” item within this subscale was the weakest ($\alpha=0.54$). For the “respiration and sphincter management” subscale it was “poor” ($\alpha=0.59$). Within this subscale two items had below acceptable alpha; “respiration” ($\alpha=0.17$) and “bowel management” ($\alpha=0.39$) and if deleted then Cronbach’s α increased to $\alpha=0.65$ and $\alpha=0.51$ respectively. For the “mobility in the room and toilet” subscale, Cronbach’s α was “good” ($\alpha=0.83$). The item “mobility in bed” in this subscale had the lowest alpha ($\alpha=0.73$). For the “mobility indoors and outdoors” subscale, Cronbach’s α was “excellent” ($\alpha=0.91$). The item “transfer ground-wheelchair” within this subscale was the lowest ($\alpha=0.77$). The subscale “respiratory and sphincter management” was the weakest subscale within the total GR-SCIM III which rated as “poor” ($\alpha=0.57$) and if deleted Cronbach’s α for the total scale increased to $\alpha=0.74$. Finally, the subscales “self-care” and “mobility indoors and outdoors”, were the strongest subscales and, if deleted, then α for the total scale dropped (Table 3).

For the English self-reported version of SCIM III, overall, Cronbach’s α was very similar to that of the Greek version ($\alpha=0.79$). Cronbach’s α for the “self-care” subscale was “excellent” ($\alpha=0.92$). The “feeding” item was the weakest within the subscale, similar to GR-SCIM III. Cronbach’s α for the “respiration and sphincter management” subscale was below an acceptable level ($\alpha=0.40$). “Bowel management” was the weakest item within the subscale ($\alpha=0.19$) which, if deleted, would increase α to $\alpha=0.37$ which is still not above acceptable level. The subscale “mobility in room and toilet” had acceptable validity ($\alpha=0.77$). The subscale “mobility indoors and outdoors” had good validity ($\alpha=0.87$). Finally, when examining the sum of the subscales, two out of the four subscales had Cronbach’s α of acceptable levels and two were poor (Table 3).

Ceiling effects were noticed in the analysis of GR-SCIM III. Of the 19 items, included in the four subscales, 11 had a ceiling effect (58%). The subscale with the highest ceiling effect was “mobility in room and toilet” (100%) followed by “respiration and sphincter management” (75%), “self-care” (33%) and finally “mobility indoors and outdoors” (17%) (Table 4). There were no floor effects. Ceiling effects were also noticed in the results of the English self-reported version of SCIM III; of the 19 items included in the four subscales, seven had a ceiling effect (37%). The subscale of “mobility in room and toilet” had the highest ceiling effect (100%). It was followed by “self-care” (66.6%), and then by “mobility in room and toilet” (17%). No ceiling effect was noticed for “respiration and sphincter management” and no floor effects were noticed (Table 4).

Validity

When examining validity for the GR-SCIM III self-reported version, correlations with the “self-care” and “mobility” subscales of the EQ-5D resulted in a strong correlation for “self-care” ($\rho=0.78, p\leq 0.01$) and a moderate correlation for “mobility” ($\rho=-0.58, p\leq 0.01$). Similarly, when examining validity for the English self-reported version of SCIM III correlations with the “self-care” and “mobility” subscales of the EQ-5D resulted in a strong correlation for “self-care” ($\rho=0.75, p\leq 0.01$) and a moderate correlation for “mobility” ($\rho=-0.45, p\leq 0.01$).

Discussion

This study showed that both GR-SCIM III and SCIM III are valid and reliable when used by self-report.

Reliability

Reliability was examined by firstly confirming unidimensionality via PCA and then examining internal consistency. For both versions, using Cronbach's α coefficient, internal consistency was found to be above the minimum acceptance level of $\alpha=0.70$. When examining each subscale separately only "respiration and sphincter management" did not pass the acceptance level. This was lower for the English version. This could imply that the respondents, who, in our study, were the people with iSCI themselves, may have had difficulty understanding the meaning of the questions and gave an approximate answer. However, the same item did not pass the acceptance level for the Italian version of SCIM III [41] or for the English version when examined in the UK population [42] when the scale was not completed by self-report but was administered by observation. In the original SCIM III study [43] and the Turkish version [44] Cronbach's α was lower for this particular item but just above the accepted level. This finding may indicate some difficulties with the wording of this item and simplification is needed. In our study, where SCIM was completed by people with iSCI, this item had lower Chronbach's α than all previous SCIM studies, thus this item needs further attention particularly if it is to be used by the people with iSCI themselves to report on their situation and progress during their rehabilitation as reliability related questions can be raised.

Items in the GR-SCIM III and the English version of SCIM III in our study had similar or slightly lower α values than the Italian version [41], better or similar values than the Turkish version [43] and slightly better than the original multicentre study [43]. If any of the items within the subscales were deleted then Cronbach's α was reduced for the GR-SCIM III and the SCIM III, which shows that the items contribute to the homogeneity of the scale. These results are promising for the reliability of the scale which could enable its use in the long term rehabilitation programme of people with SCI. A future study to include a test –retest reliability examination is, however, needed.

Validity

Validity was examined by comparing concurrent/criterion validity with part of the EQ-5D and not the FIM as done in previous studies [41,43,44]. For both versions, the correlation between the two scales on the self-care subscales was strong though not as strong as for the other studies when the FIM was used for comparison [41,43,44]. For both versions the correlations for the mobility subscale were moderate and lower than identified in previous studies comparing with FIM [41,43,44]. This finding may be attributed to the different items used in the EQ-5D and FIM subscales. Researchers in the future may wish to translate FIM into Greek and use it in new comparison studies with GR-SCIM III.

Ceiling effects

The high level of ceiling effects found for both SCIM versions, which were beyond the recommendations for a good health measure [45], need to be reflected upon. There have been other studies in the literature reporting similarly high ceiling effects of measurements [45]

including the SF-36 [46], SCIM III [47] and the SCIM II [48], which may flag up concerns about the suitability of a tool for usage with certain patient groups. The high percentage of ceiling effects found here could be attributed to the fact that the respondents were less impaired as they all had incomplete SCI. Ackerman et al [47] used SCIM III to study people with complete SCI and found a higher percentage of ceiling effects among people with less impairment, which is in line with the findings of the current study. SCIM III has been found to respond to change when tested on people with complete injury and within the first year of their injury [47,48]. A future study using the English or Greek version of SCIM III should test its ability to discriminate change for people with incomplete SCI only and for long-term follow-up after their injury.

Practical relevance

The current study provides Greek researchers and therapists with a new measurement tool by having translated a function scale for use with the SCI group into Greek. This development method used both published protocols for translation [32,35,49,50] and the advice of the original authors of the SCIM III (personal communication). The translations were not problematic, all translators were bilingual and had educational achievements to at least tertiary level. The advantage of the back-translation ensured the integrity of the items and, together with the use of an external panel, acted as a check for the preservation of face validity.

The availability of this measure will have positive implications for the assessment and rehabilitation of functional independence for people with SCI in Greece as it can be used by Greek health professionals and policy makers for further testing, research and data collection. It can be used by clinicians worldwide who need to assess people with SCI whose first language is

Greek. Comparisons between Greek groups and other groups who have used the English version of SCIM III will be allowed, enhancing research and assisting therapists in following the best treatment approaches suggested in the wider literature. Explaining to the patient the value of using a widely used and accepted measure could also have a positive impact on the relationship between therapist and patient as the latter could feel that he/she is more accurately assessed and significant attention is paid to treatment planning.

Clinical relevance

An original contribution of this study is the use of SCIM III and GR-SCIM III as self-completed measures. The validity and reliability of the English version were examined using a large sample, similar to or larger than other studies in which other measures were translated and validated [51-55]. Unidimensionality was confirmed and reliability was acceptable for both versions. Validity was better for the Greek version.

While this study does not imply replacing the functional assessment done by the health professional via observation, it provides new and positive implications for the care of the patient in two ways. First of all, it builds on the call made by Dawson et al [17] for the need for a new self-reported measure to assess function in SCI which would represent the patient's perspective. Patients want to become self-aware and take responsibility for problem solving [18] and self-assessment of function will help them in this direction. The fairly recently developed FIM self-report measure provides a measure of perceived functional independence [56]. Although SCIM III, as used here, is not a new self-reported measure but an adaptation of a current measure, it is the first attempt to present the person's living with SCI perspective while using a SCI-specific

measure. The participants in this study managed to complete the scale without problems proving that function in SCI can be assessed via self-report. Future studies may need to include new items in this particular scale, aiming to capture the cognitive aspects of the functional challenges and the behavioural outcomes as perceived by the patient. National level contributors and cultural behaviours may be identified as a result enhancing the multinational applicability of this scale.

The second positive implication of using this self-reported measure links to a realistic structure in long-term rehabilitation. Patients request improvement in long-term rehabilitation [57], the “expert patient” and Chronic Disease Self-Management Program (CDSMP) models promote empowering of patients, teaching them skills while seeking to reduce the socioeconomic cost of injury and rehabilitation [8,9,57,58]. The continuous process of rehabilitation requires constant identification of problems that need to be addressed [59], and patients want to know practical information like for their “bladder and bowel” problems [18], thus the patients’ self-assessment of their function will help them to “keep an eye” on any changes while growing older with SCI. They will then be able to feed back to their therapists with the aim of responding quickly and in an appropriate manner to the changes noticed. Consequently, community rehabilitation will be enhanced and upcoming methods like tele-rehabilitation may benefit from using this scale by self-report.

Study limitations

This study had a few limitations that need to be taken into consideration. Firstly, information about the participants’ characteristics was primarily self-reported. It cannot be guaranteed that

the questionnaires were completed by the respondents themselves but there is no reason to believe otherwise. A small percentage of people did not know the completeness of their injury but the lack of physical examination or access to medical records to confirm their level of injury based on the ASIA classification of types and levels for a SCI could be considered as a limitation. This resulted in excluding twenty eligible participants.

The Greek respondent group may be small, however, the results reported on validity and reliability should be regarded as initial testing of the self-reported psychometric properties of GR-SCIM III. A future study on a larger sized group is encouraged.

In conclusion, this study showed that both GR-SCIM III and SCIM III are reliable for self-report which when used will better promote implementation of long term rehabilitation. However, the psychometric properties of the scale, including a test retest, should be further explored in future studies which should involve people with both complete and incomplete SCI. Further testing of the Greek SCIM by observation is need and studies to compare usage of the measure by the different ways of completing it in a before and after intervention design are desirable. More attention will need to be given to the “respiration and sphincter management” subscale for both versions. This study shows that consideration needs to be given to the participants’ type of injury which may affect the results of SCIM III. When a measure is used under different conditions from that originally intended its characteristics may be different [17]. Future researchers need to examine SCIM III in incomplete SCI only and if similar findings to this study emerge, then adaptations to the SCIM III may be required to reflect the completeness of the injury of the

respondent. Availability of this scale in Greece is expected to have a positive implication in both assessment and treatment for people with SCI.

Conflict of interest

The authors declare that no conflicts of interest exist.

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