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Health professionals' perspective on the applicability of AO Spine PROST (patient reported outcome Spine trauma) in people with a motor-complete traumatic or non-traumatic spinal cord injury

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Abstract

Purpose The AO Spine PROST (Patient Reported Outcome Spine Trauma) was developed for people with spine trauma and minor or no neurological impairment. The purpose is to investigate health professionals' perspective on the applicability of the AO Spine PROST for people with motor-complete traumatic or non-traumatic spinal cord injury (SCI), using a discussion meeting and international survey study.

Methods A discussion meeting with SCI rehabilitation physicians in the Netherlands was performed, followed by a world-wide online survey among the AO Spine International community, involved in the care of people with SCI. Participants rated the comprehensibility, relevance, acceptability, feasibility and completeness of the AO Spine PROST on a 1–5 point scale (5 most positive). Comments could be provided per question.

Results The discussion meeting was attended by 13 SCI rehabilitation physicians. The survey was completed by 196 participants. Comprehensibility (mean \pm SD: 4.1 ± 0.8), acceptability (4.0 ± 0.8), relevance (3.9 ± 0.8), completeness (3.9 ± 0.8), and feasibility (4.1 ± 0.7) of the AO Spine PROST were rated positively for use in people with motor-complete traumatic or non-traumatic SCI. Only a few participants questioned the relevance of items on the lower extremities (e.g., walking) or missed items on pulmonary functioning and complications. Some recommendations were made for improvement in instructions, terminology and examples of the tool.

Conclusion Health professionals found the AO Spine PROST generally applicable for people with motor-complete traumatic or non-traumatic SCI. This study provides further evidence for the use of the AO Spine PROST in spine trauma care, rehabilitation and research, as well as suggestions for its further development.

Keywords AO spine PROST · Outcome measure · Spinal cord injury · Health · Function · Spine trauma

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Introduction

Spinal cord injury (SCI) is a medically complex and life-disrupting condition. It can be caused by a trauma (such as fall from height) or by non-traumatic etiology (such as spinal degeneration, infection, or tumor). The consequences of SCI for the individuals' life affect body functions, activities, participation, and quality of life [1]. Individuals with SCI represent a small part of all people with spinal injuries [2, 3]. Nevertheless, the annual number of new cases was estimated between 250.000 and 500.000 worldwide [1].

Appropriate surgery, medical care and rehabilitation can have significant effect on disability in people with SCI [4, 5]. To learn what surgical and rehabilitation treatments are most effective and to compare them in a reliable and valid fashion, it is important to standardize classification and outcome measurements. To meet the requirements of a universal and multidisciplinary outcome instrument for the function of people with spinal trauma, the AO Spine Knowledge Forum Trauma developed the Patient Reported Outcome Spine Trauma (AO Spine PROST) [6]. It was developed for the use among spine trauma patients with mild, transient or no neurological impairment, represented in a score on the American Spinal Injury Association Impairment Scale (AIS) C, D, or E [6–8]. Validation studies in this specific diagnostic group showed satisfactory reliability and validity of the English, Dutch and Nepali language versions [8–10], that is recommended as outcome tool by the AO Spine community and already available in 17 languages [11]. However, individuals with motor-complete injuries (AIS A or B) are a significant part of the spine trauma population, ranging from 22.4 to 77.8% [12]. Moreover, hospitals and rehabilitation centers face growing populations of people with non-traumatic SCI due to degenerative, inflammatory, neoplastic or infectious conditions [1, 13–16]. Therefore, it is necessary to also investigate the applicability of the tool among motor-complete or non-traumatic SCI patients, to enhance the usefulness of the AO Spine PROST in clinical practice and research.

A recent study utilizing cognitive interviews showed that the AO Spine PROST was rated positively by individuals with complete traumatic or non-traumatic SCI, although some recommendations were made for improvement in instructions, terminology and used examples of the tool [17]. The perspective of health professionals is deemed relevant for assessing the clinical usefulness of the tool, as they are the users of the tool. Therefore, the aim of the current international study was to investigate the applicability of the AO Spine PROST for use in people with motor-complete traumatic or non-traumatic SCI, from the perspective of health professionals.

Methods

Study design and setting

An online survey followed by a discussion meeting was performed with Dutch rehabilitation physicians in October 2019. This was followed by an English-language, but otherwise identical, international online survey among health professionals in April-May 2021.

Participants

All 20 members of the Dutch-Flemish Spinal Cord Society (DUFSCOS) who were working in the Netherlands at the time of the study were invited for the Dutch online survey (using Survalyzer) and expert discussion meeting. The community of AO Spine International was invited to complete the international online survey (using Redcap). Additionally, the AO Spine Knowledge Forum (KF) Trauma Steering Committee members were asked to reach out to their local rehabilitation and physical therapy departments to increase participation of rehabilitation medicine specialists as well as physical therapists.

Study procedures and instruments

The AO Spine PROST (Fig. 1) is a patient-reported outcome measure that consists of 19 items on various aspects of functioning, e.g., household activities, changing posture and bowel function. Each item can be answered on a 0–100 numeric rating scale (NRS), in which 0 indicates no function at all and 100 the same functional level as before the accident that caused the spine injury, irrespective of how well the patient functioned before. Thus, the score reflects the level of experienced impact of the spine injury on the patients functioning.

Both the Dutch and English-language online surveys started with questions exploring the participants' demographic data. Next, the participants were asked to read the AO Spine PROST while imagining how one of their patients with a complete SCI would have responded to the questions. Thereafter, the applicability of the AO Spine PROST was assessed, including the comprehensibility, relevance, acceptability, completeness, feasibility as well as the added value in research and clinical practice. The ratings of relevance and completeness were asked separately for patients with traumatic complete SCI, traumatic incomplete SCI and non-traumatic SCI. The other aspects of the applicability were asked once, i.e., for SCI patients in general. All questions had a 5-point response scale that ranged from 1 (totally disagree) to 5 (totally agree). The aspects of applicability were defined as follows:

AO Spine PROST (Patient Reported Outcome Spine Trauma) Your function NOW compared to BEFORE the accident

This questionnaire contains 19 questions about aspects of your life after the accident that caused your spine injury. Please read the questions and the description of the scale carefully. Please answer ALL questions and answer each question with one cross ("X") on the scale. This should reflect how you function NOW compared to BEFORE the accident.

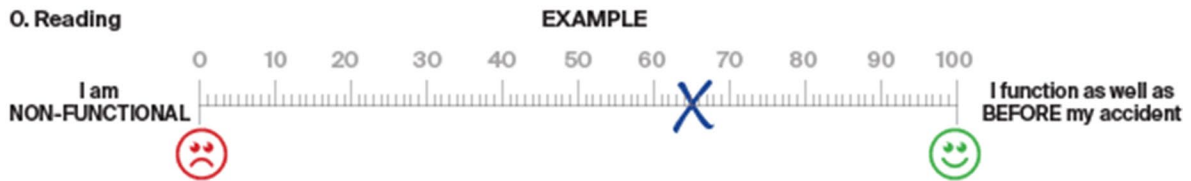
The scale ranges from 0 to 100. It is important to realize that 0 indicates a level at which you are NON-FUNCTIONAL. 100 indicates the level BEFORE the accident, no matter how well or poorly you functioned before the accident.

Below is an example.

Patient Name: _____

Date (MM/DD/YY): ____/____/____

Patient ID: _____
(to be filled in by the health professional)

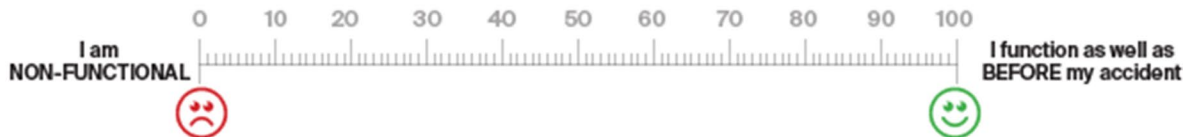


To be completed by the PATIENT

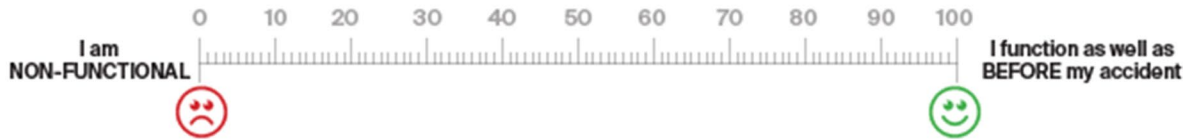
The questionnaire begins here.

In almost all questions, a number of situations or examples are shown in brackets. Please base your answer on the situation or example where you are most disabled.

1. Household activities (such as cleaning in and around the house, doing laundry or preparing a meal)



2. Work/study (if you were not working or studying BEFORE the accident, please skip this question)

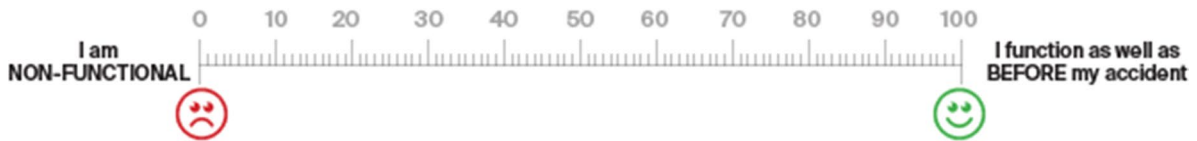


(To be filled out by the health professional)
Study identification code: _____

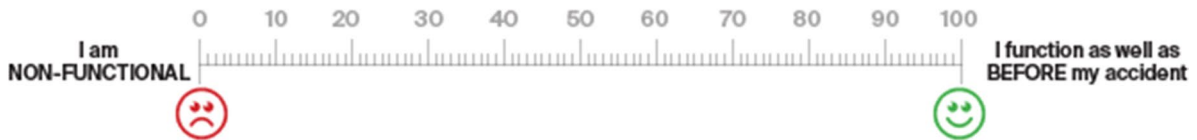
Source: Sadiqi et al. Development of the AO Spine Patient Reported Outcome Spine Trauma (AO Spine PROST): a universal disease-specific outcome instrument for individuals with traumatic spinal column injury. Eur Spine J 28(5): 1550-1557, 2017.

Fig. 1 AO spine PROST

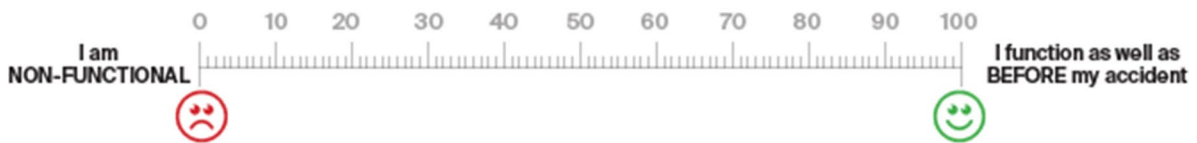
3. Recreation and leisure (such as hobbies or sports)



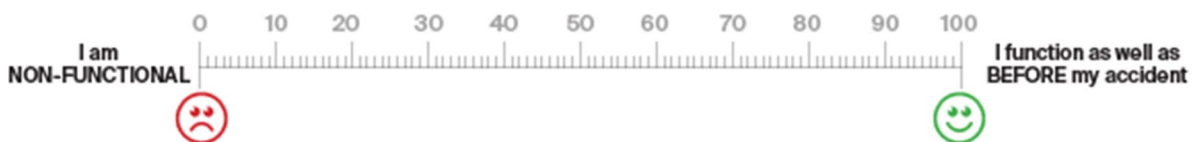
4. Social life (such as maintaining relationships with family, friends and acquaintances)



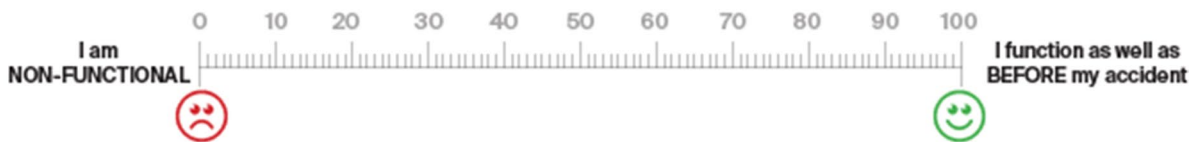
5. Walking (with or without an aid)



6. Travel (such as driving yourself, using public transportation or other means of transport)



7. Changing posture (such as lying down, sitting or standing)



8. Maintaining posture (such as lying down, sitting or standing, for as long as necessary)



(To be filled out by the health professional)

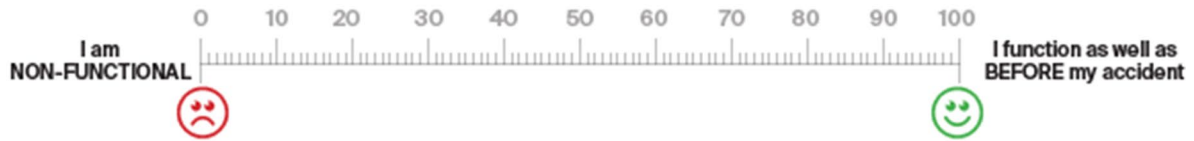
Study identification code: _____



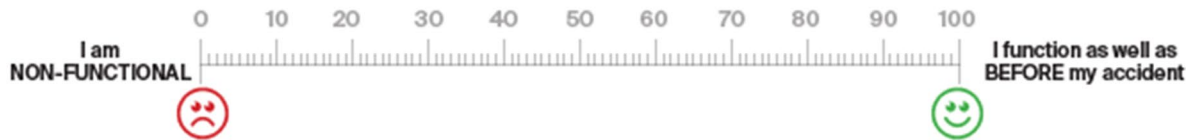
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Version 2.0, May 8, 2015. Form modified August 23, 2018 and September 7, 2020.

Fig. 1 (continued)

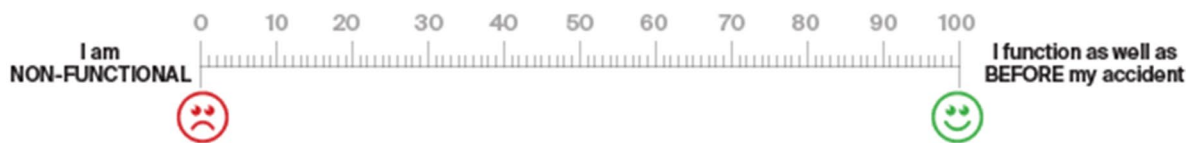
9. Lifting and carrying (such as lifting a bag of groceries or carrying a child)



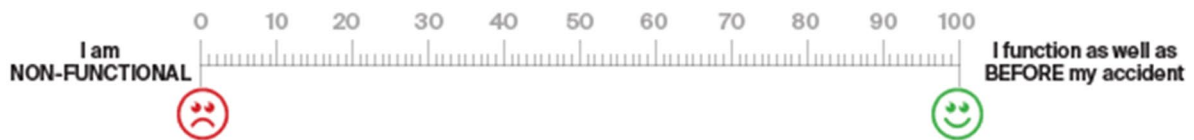
10. Personal care (such as taking a bath or shower, using the toilet or dressing and undressing)



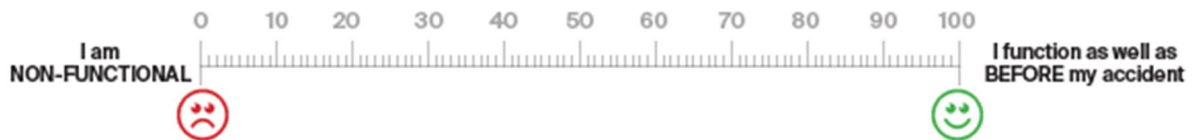
11. Urinating (are you able to urinate; can you hold your urine)



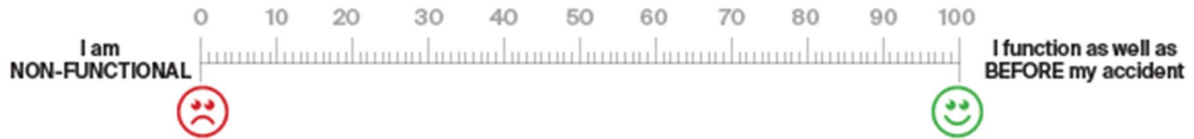
12. Bowel movement (are you able to have a bowel movement; can you hold your bowel movement)



13. Sexual function



14. Emotional function (such as gloomy, worried or anxious feelings)

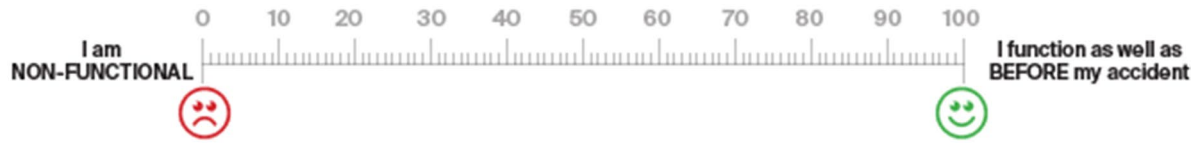


(To be filled out by the health professional)
 Study identification code: _____

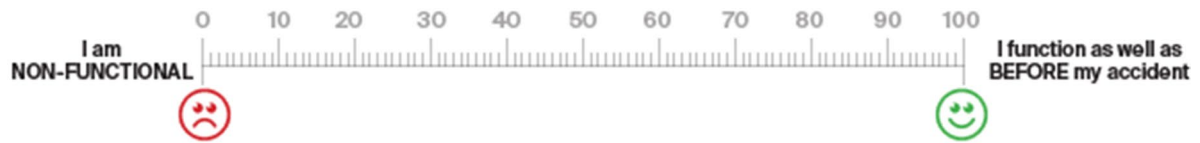
Source: Sadiqi et al. Development of the AO Spine Patient Reported Outcome Spine Trauma (AO Spine PROST): a universal disease-specific outcome instrument for individuals with traumatic spinal column injury. *Eur Spine J* 28(5): 1550-1557, 2017.

Fig. 1 (continued)

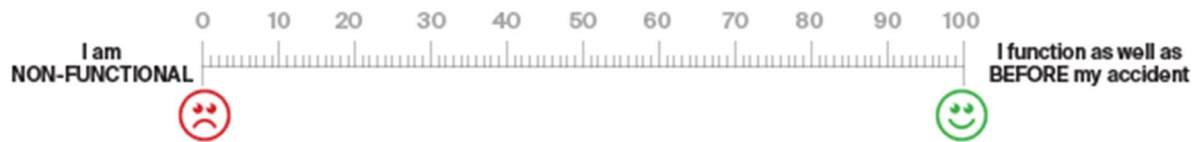
15. Energy level (such as fatigue or listlessness)



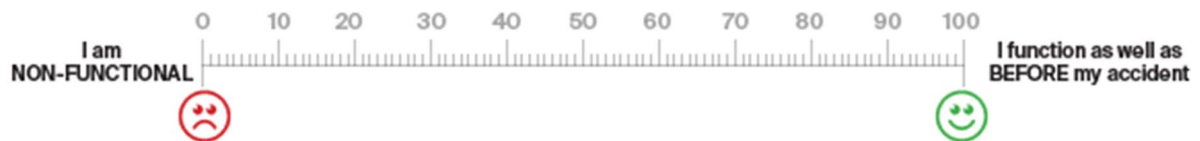
16. Sleep (such as number of hours and quality)



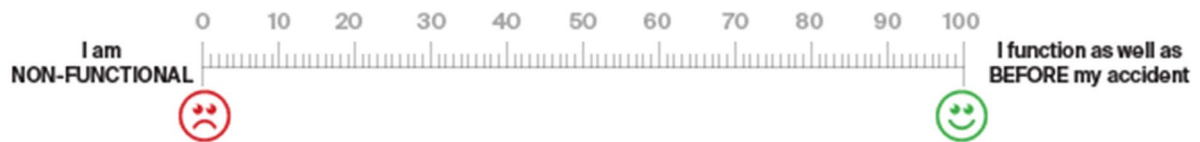
17. Stiffness of your neck and/or back (in terms of disability in overall performance)



18. Loss of strength in your arms and/or legs (in terms of disability in overall performance)



19. Back and/or neck pain (in terms of disability in overall performance)



(To be filled out by the health professional)

Study identification code: _____

Fig. 1 (continued)

- **Comprehensibility:** All items are understandable for the average patient with SCI. Average means without brain damage, no illiteracy, able to read in your language’.
- **Relevance:** All items are relevant to rate the consequences of SCI on patients’ lives; meaning none of the items need to be removed because these are not relevant.
- **Acceptability:** All items are acceptable for the average patient with SCI; meaning none of the items need to be removed because patients might experience these as obtrusive.
- **Completeness:** All items together provide the necessary information to understand the experience of living with SCI. Meaning there are no items that need to be added because these are relevant to at least part of the patients with SCI.
- **Feasibility:** Administration of the AO Spine PROST instrument is feasible in clinical practice.
- **Added value:** The AO Spine PROST is a valuable addition to existing measures for use in SCI research and/or clinical practice.

Analyses

The discussion meeting was audio taped, transcribed, and analyzed theoretical thematically by three of the authors (AH, MP, SS) [18]. Therefore, a coding scheme was developed based on the 5 statements. The results of both online surveys were merged, and compared with the results of the discussion meeting. The comprehensibility, relevance, acceptability, completeness and feasibility of the AO Spine PROST were analyzed by calculating frequency tables using IBM SPSS Statistics (Version 27).

Results

Out of the 20 DUFSCOS members, 10 (50%) completed the online questionnaire. The discussion meeting was attended by 13 physicians (65%). The online survey among the AO Spine International community was completed by 186 participants, resulting in a total survey sample of 196. Participant characteristics are presented in Table 1. Most of them were male (83.4%) and aged between 35 and 44 years. Almost half of them were orthopedic surgeons (47.8%). The large majority of the survey participants either agreed or strongly agreed with each statement (Table 2). Comments regarding the statements together with frequencies are shown in Table 3 and detailed in the text below.

The mean score for comprehensibility of the AO Spine PROST was 4.1. Comments included that it was unclear what the terms ‘functional’ or ‘non-functional’ (anchors on both ends of the NRS) mean in Q12 (bowel movement), Q13 (sexual function), Q14 (emotional function), and

Table 1 Characteristics of the professionals participated in the DUF-SCOS survey and international survey ($N=196$).

	<i>n</i> (%)
Male	171 (83.4)
<i>Age (in years)</i>	
25–34	34 (16.6)
35–44	85 (41.5)
45–55	45 (22.0)
55–64	32 (15.6)
≥65	8 (3.9)
<i>Region</i>	
North America	13 (6.3)
Latin America	32 (15.6)
Europa and South Africa	71 (34.6)
Middle East and Northern Africa	27 (13.2)
Asia and Pacific	62 (30.2)
<i>Work setting</i>	
University hospital	113 (57.7)
Community hospital	33 (16.8)
Private practice	25 (12.8)
Rehabilitation, in- or outpatient	29 (14.1)
Other	5 (2.4)
<i>Specialty</i>	
Orthopedic surgery	98 (47.8)
Neurosurgery	46 (22.4)
Trauma surgery	7 (3.4)
Doctor of physical and rehabilitation medicine	17 (8.3)
Physical therapist	27 (13.2)
Other	10 (4.9)
<i>Years in practice</i>	
0–5	29 (14.1)
6–9	32 (15.6)
10–14	53 (25.9)
15–19	33 (16.1)
≥20	58 (28.3)

n—number of participants

Q16 (sleep). Participants also indicated that some items may be interpreted differently. For example Q2 (work/study): as having a job, but also as occupational self-fulfillment. Further, participants noticed overlap between recreation and leisure (Q3) with social Life (Q4) and/or travel (Q6), between changing posture (Q7) and maintaining posture (Q8), or between urinating (Q11) and bowel movement (Q12).

Participants rated the AO Spine PROST generally as relevant, for all subgroups (complete, incomplete, or non-traumatic SCI), as indicated by mean scores of 3.9, 4.0 and 3.9, respectively. A first series of comments mainly concerned the irrelevance of items about the function of lower extremities in people with complete SCI. Mostly concerning Q5 (walking), but also Q7 (changing posture, example

Table 2 Completeness and feasibility of the AO Spine PROST according to health professionals.

Question (<i>N</i> =196)	Mean \pm SD (range 1–5)	Agree/ strongly agree <i>n</i> (%)
Comprehensible	4.1 \pm 0.8	165 (84.2)
Relevant for T and complete SCI	3.9 \pm 0.8	159 (81.1)
Relevant for T and incomplete SCI	4.0 \pm 0.7	168 (85.8)
Relevant for NT	3.9 \pm 0.7	160 (81.6)
Acceptable	4.0 \pm 0.8	164 (83.7)
Completeness for T and complete SCI	3.9 \pm 0.8	154 (78.6)
Completeness for T and incomplete SCI	3.9 \pm 0.8	163 (83.1)
Completeness for NT	3.9 \pm 0.8	151 (77.0)
Feasible in research	4.1 \pm 0.7	165 (84.2)
Feasible in clinical practice	4.0 \pm 0.7	163 (83.1)
Valuable addition	4.0 \pm 0.7	167 (85.2)

n—number of participants, *SD*—standard deviation, *SCI*—spinal cord injury, *T*—traumatic, *NT*—non-traumatic

standing), Q8 (maintaining posture, example standing) and Q18 (loss of strength in your arms and/or legs). Other comments specifically concerned people with non-traumatic SCI: the introduction, response scale and the name PROST all refer to a traumatic etiology, and therefore, would not apply to people with non-traumatic SCI. A third series of comments concerned the relevance of the items on work/Study (Q2), travel (Q6) and sexual function (Q13) when scored early after the onset of SCI, as often no endpoint would have been reached yet. On the other hand, one participant noted

that the items may not be scored long after the onset of SCI, due to the comparison with before the onset.

The AO Spine PROST was generally rated as acceptable, with a mean score of 4.0. Only sexual function (Q13) was flagged as potentially offensive by 2 participants, more specifically that this may depend on the age of the patient.

Completeness was given a mean score of 3.9 for all subgroups. Some missing items were indicated (Table 3). Mentioned complications were spasticity, pressure sores, infection, deep venous thrombosis, brainstem nucleus, swallowing and cardiac capacity. One survey participant commented on the lack of examples in Q13 (sexual function).

The AO Spine PROST was considered feasible in research (mean 4.1) as well as in clinical practice (mean 4.0). However, it was expected to be time-consuming for use in clinical practice. Comments mentioned once were that the instructions and the NRS response scale could be complicated for patients, and how to complete the tool if someone is not able to do this themselves due to physical limitations.

Discussion

Health professionals rated the AO Spine PROST as generally comprehensible, relevant, acceptable, complete and feasible, regardless of etiology (traumatic or non-traumatic) and severity (complete or incomplete) of SCI. With the AO Spine PROST, a wide range of consequences of spine trauma or SCI is covered. Compared to more familiar measures of functional status, secondary health conditions and quality of

Table 3 Comments made in the online surveys and discussion meeting

Statement	Comments
Comprehensibility	--Terms 'functional or non-functional' can be confusing (<i>n</i> =5, D). --Some questions can be multi-interpreted (<i>n</i> =4). --Some questions overlap (<i>n</i> =2, D). --Unclear how the use of assistive devices should count in the rating (<i>n</i> =2) --Unclear how (in) dependency should count in the rating (<i>n</i> =3).
Acceptability	--Question to sexual function could be offensive; (<i>n</i> =2)
Relevance	--Questions on function of lower extremities for participants with complete SCI (<i>n</i> =6, D). --Terminology implies a traumatic cause (<i>n</i> =2). --Regards some questions no endpoint may have been reached (<i>n</i> =3, D).
Completeness	--Missing questions on: --respiration/breathing (<i>n</i> =8) --complications (<i>n</i> =7) --separate question(s) needed for arm/hand and leg function (<i>n</i> =5) --financial situation (<i>n</i> =3) --other types of pain (<i>n</i> =1, D) --Other: care for children, coping, mood, moving short distances, acceptance by the society, temporal and spatial orientation (<i>n</i> =1).
Feasibility	--Completion could be time consuming (<i>n</i> =3). --Instructions and NRS response scale are complicated (<i>n</i> =1)

n = number of participants making this comment in the online surveys, *D* = mentioned in the discussion meeting of Dutch SCI rehabilitation physicians

life in SCI research, the AO Spine PROST combines items of such measures in a single scale. It is also considered as unique because of the scores reflect a comparison of current functioning with the pre-injury situation.

A frequent comment on the comprehensibility of the AO Spine PROST concerned the use of the word ‘function’ in some items, and ‘functional’ or ‘non-functional’ as anchor-terms in the response scale. In the first translation and cross-cultural study of the AO Spine PROST the same issue was discussed at length [19]. The decision to use these terms was made to bring the phrasing of the questions and response scale in line with the overall aim of the AO Spine PROST, i.e., to measure the patients’ functioning. This also matches the terminology of the International Classification of Functioning, Disability and Health (ICF), the basis of the development of the AO Spine PROST [6].

Some health professionals questioned the relevance of administering the AO Spine PROST when further improvement is expected, i.e., regards work/study. However, as the AO Spine PROST measures the patient’s current functional status, repeated administration can be useful to reveal patterns of recovery of functional status after spinal injuries. The first studies on the AO Spine PROST were conducted within 13–24 months post-onset [8, 17, 19]. This time frame was chosen because the score has to reflect the patients’ current function compared to before the accident, taking into account that memories fade over time [20]. However, a recent study in which the AO Spine PROST was administered at a median follow-up of 94.5 months since onset did not show lower reliability and validity of the instrument compared to the results from the previous studies [21]. Another series of comments was about the feasibility. Health professionals expected that completing the questionnaire could be a time-consuming process. This might be the case if the AO Spine PROST is administered as an oral interview. A mean completion time of only 7.0 min was found for an online self-report version [8].

Limitations of this study

Main limitations of this study are that only one discussion meeting with Dutch rehabilitation physicians was performed, and the group of participants in the online survey may not be a representative sample of all health professionals involved in the treatment of individuals with SCI. In the online questionnaire there was an overrepresentation of surgeons and participants working in a university hospital, possibly reflecting the AO Spine International network. Nevertheless, these surgeons have various relevant specialties. Also, the rehabilitation perspective was granted as the discussion meeting was attended by rehabilitation physicians. Although the discussion

meeting was conducted in the Netherlands, results of the worldwide online questionnaire do not suggest diverging opinions according to nationality. Finally, the AO Spine PROST was included in the survey and participants were asked to make themselves familiar with the instrument before answering the evaluative questions. However, it is unknown to which degree participants were truly familiar with the AO Spine PROST, which may have influenced the validity of the results.

Modifications

In the development and validation phase, cognitive interviews were performed among people with spine trauma or SCI. Most comments made by health professionals regarding the comprehensibility, acceptability, relevance and completeness were also flagged by people with SCI. However, some comments were not flagged by people with SCI, for example the missing items about respiration and complications and the acceptability of an item on sexual function [7, 17]. Different perspectives from health professionals and people with SCI on the AO Spine PROST have to be carefully considered when making decisions on future revisions of the AO Spine PROST, if desired.

Based on the results of the cognitive interview study among people with SCI and the current study among health professionals, a few minor adjustments seem desirable to make the AO Spine PROST more suitable for people with motor-complete traumatic and non-traumatic SCI. We proposed adjustments after the cognitive interview study [17]. However, based on the current study including the perspective of health professionals the proposed adjustments are not complete. To adapt the tool to the users’ needs, we propose to add a separate manual for the health professional, including options about how to complete the AO Spine PROST (on paper or digitally, by person themselves or with help from someone else). Also, the time point post-onset of patients’ spine injury to which the instrument may be applied can be inferred from the recent validation study²¹. Second, the instructions could become more appropriate for people with non-traumatic SCI by removing the words ‘accident’ and to clarify how the use of assistive devices could be taken into account. Finally, some adjustments could be made to the description of items and examples, namely: Q5 (walking), such as adding a note to score a zero when walking is not possible. By removing specific body parts (Q17 ‘neck and/or back’, Q18 ‘arms and/or legs’) the questionnaire would become more applicable for people with complete SCI. The same applies to Q19, by deleting the words ‘back and/or neck’, all other pain types would be included.

Conclusion

In conclusion, health professionals rated the AO Spine PROST is a comprehensive, relevant, not-offensive, complete, and feasible tool in the clinical practice and research. Satisfactory results were seen for its applicability in adults with a motor-complete traumatic or non-traumatic SCI. Based on the results of the current study together with the aforementioned cognitive interview study, we supposed a few minor adaptations in order to further enhance its usefulness as patient-reported outcome measure in the entire spine trauma and SCI population. In the next phase the adapted AO Spine PROST will be validated in an international multicenter study.

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Author contributions AH collected the data, conducted the data analysis and drafted the paper. MP designed the study, provided feedback on data analysis and the paper. TVD provided feedback on the paper. FCO, KS, LB, FK SR, GS, AV designed the study and provided feedback on the paper. SS designed the study, contributed to data collection and provided feedback on the paper.

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Data availability The data analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Conflicts of interest The authors declare that they have no conflict of interest.

Ethical approval The study received approval from the local Research Ethics Committee of De Hoogstraat Rehabilitation. The manuscript submitted does not contain information about medical device(s)/drug(s).

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