

UCLA

UCLA Previously Published Works

Title

Preferences of adults with spinal cord injury for widely used health-related quality of life and subjective well-being measures

Permalink

<https://escholarship.org/uc/item/0nx5v5rv>

Journal

Journal of Spinal Cord Medicine, 42(3)

ISSN

1079-0268

Authors

Palimaru, Alina Ionela
Cunningham, William E
Dillistone, Marcus
et al.

Publication Date

2019-05-04

DOI

10.1080/10790268.2018.1474691

Peer reviewed



Preferences of adults with spinal cord injury for widely used health-related quality of life and subjective well-being measures

Alina Ionela Palimaru, William E. Cunningham, Marcus Dillistone, Arturo Vargas-Bustamante, Honghu Liu & Ron D. Hays

To cite this article: Alina Ionela Palimaru, William E. Cunningham, Marcus Dillistone, Arturo Vargas-Bustamante, Honghu Liu & Ron D. Hays (2019) Preferences of adults with spinal cord injury for widely used health-related quality of life and subjective well-being measures, The Journal of Spinal Cord Medicine, 42:3, 298-309, DOI: [10.1080/10790268.2018.1474691](https://doi.org/10.1080/10790268.2018.1474691)

To link to this article: <https://doi.org/10.1080/10790268.2018.1474691>



Published online: 23 May 2018.



Submit your article to this journal [↗](#)



Article views: 85



View Crossmark data [↗](#)

Research Article

Preferences of adults with spinal cord injury for widely used health-related quality of life and subjective well-being measures

Alina Ionela Palimaru ¹, William E. Cunningham^{1,2}, Marcus Dillistone³, Arturo Vargas-Bustamante¹, Honghu Liu⁴, Ron D. Hays^{1,2}

¹Department of Health Policy and Management, UCLA Fielding School of Public Health, Los Angeles, California, USA, ²Division of General Internal Medicine & Health Services Research, Department of Medicine, Geffen School of Medicine at UCLA, Los Angeles, California, USA, ³Royal Society of Medicine, Marylebone, London, UK, ⁴Division of Public Health & Community Dentistry, UCLA School of Dentistry, Los Angeles, California, USA

Objective: To describe preferences for survey instruments on health-related quality of life (HRQOL) and subjective well-being (SWB) among adults with spinal cord injury (SCI), and compare perspectives on the instruments between the United States and the United Kingdom.

Design: We conducted 20 in-depth interviews.

Setting: Participants were interviewed in their homes, some in person and some via Skype.

Participants: A convenience sample of 20 adults with SCI (10 in the US and 10 in the UK) were recruited via print and on-line advertisements.

Interventions: Not applicable.

Main Outcome Measures: Interviewees reviewed six instruments and rated how important it was for their medical providers to know answers to each survey. Two coders analyzed verbatim transcriptions independently using an inductive approach. Keyword-in-context (KWIC) analysis identified the most frequently used words by interviewees to discuss the merits of each instrument.

Results: Participants in both samples identified the Fatigue Severity Scale (FSS) as “vital” that their medical providers know about it. This was followed by the Spinal Cord Injury Independence Measure III, and a stand-alone Eudaimonic Well-Being question. The KWIC analysis showed that the most distinctive words used to discuss FSS were “fatigue” and “pain.”

Conclusions: Understanding what HRQOL and SWB measures are valued by adults living with SCI can lead to selection of informative instruments, which could help clinicians to complement and tailor established care and rehabilitation protocols for individual needs. Participants identified fatigue as a significant issue, and the FSS as a vitally important instrument to share with medical providers.

Keywords: Quality of life, Health-related quality of life, Subjective well-being, Spinal cord injury, Outcomes, Fatigue

Introduction

Spinal cord injury (SCI) is a life-changing event. In the United States, there are approximately 300,000 (out of about 319 million) individuals living with SCI, whereas the UK has approximately 40,000 cases of SCI (out of about 64 million).^{1–3} In both countries, SCI is

predominantly acquired through traumatic events (approximately 90%) such as vehicular accidents, falls, and violence.^{1–3} Long-term care for SCI should align with the goals advanced by the Institute of Medicine (2001) for patient-centered care that is “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (p. 6).⁴ One way to make care more patient-centered is to include patient-reported measures in clinical practice. Patient-reported measures include perceptions about quality of care, health behaviors, and

Correspondence to: Alina Ionela Palimaru, Department of Health Policy and Management, UCLA Fielding School of Public Health, 650 Charles E. Young Dr. S., Los Angeles, CA 90095, USA; Ph: 310-994-3620, 310-825-3317. Email: alinapalimaru@ucla.edu
Color versions of one or more of the figures in the article can be found online at www.tandfonline.com/yscm.

health outcomes.⁵ They can facilitate patient-physician communication, thereby helping clinicians target interventions that will improve outcomes.⁵

Quality of Life (QOL) is an all-encompassing concept that refers to a person's physical, psychological, social, spiritual, and economic well-being.⁶⁻¹⁰ Health-Related Quality of Life (HRQOL) is a subset of QOL and refers to perceived health. HRQOL domains include physical functioning, role functioning, social functioning, emotional well-being (depressive symptoms, anxiety, anger, positive affect), pain, energy, and general health perceptions.⁵

Subjective well-being (SWB) refers to global appraisals of life that include but go beyond health. There are three types of SWB measures: evaluative well-being --overall appraisal of one's life; experienced well-being--emotional status over short periods of time; and eudaimonic well-being (EWB)--perceived purpose in life.¹¹ Ravens-Sieberer *et al.* (2014) suggested that HRQOL measures could be enhanced with SWB measures that focus on "how well life is going for a person" (p. 208).¹²

Many studies on adults with SCI use outcome measures developed for the general population and may not reflect the needs of those with SCI.⁶ We examine which HRQOL and SWB measures are most valued by a sample of adults living with SCI in the United States and in the United Kingdom. We compare adults in the two countries to highlight potential cultural differences in valuing these measures.

Methods

Participants

Participants were eligible to be interviewed if they were 18 years or older, full-time wheelchair users, had a self-reported diagnosis of SCI, and could read and write in English. Exclusion criteria included inability to provide informed consent (including cognitive impairments such as dementia).

Recruitment occurred through (1) print advertisements through patient advocacy organizations in the UK (e.g. Spinal Injuries Association) and the US (e.g. veterans' support groups); (2) online advertisements through SCI fora, such as Apparelyzed (<http://www.apparelyzed.com/>) and Facebook wheelchair users' groups. Upon expressing interest in being interviewed, participants were sent an email with information about the study.

A total of 33 individuals responded to the advertisements, 15 in the US, and 18 in the UK. Of these respondents, 4 did not meet the inclusion criteria (age and full-time wheelchair use) and 7 decided not to continue with the study after reviewing the information package.

Twenty-two individuals were interviewed ($N_{US}=11$, $N_{UK}=11$).

Participants were offered \$10 / £7 remuneration for their participation, but only two accepted the offer. The Institutional Review Board of the University of California Los Angeles approved this study (Certified Exempt) (IRB#16-000229), and verbal informed consent was obtained from all participants.

Interview protocol

Semi-structured interviews were conducted by the first author (AP) to elicit in-depth views regarding HRQOL and SWB measurement among adults with SCI. We also collected demographic data from the sample.

The interview guide was developed using literature on SCI, and informal conversations with SCI rehabilitation professionals. We included six well-established self-report survey instruments [Eudaimonic Well-Being (EWB),¹¹ Short Form 36 (SF-36),¹³ Fatigue Severity Scale (FSS),¹⁴ Satisfaction with Life Scale (SWLS),¹⁵ Hedonic Well-Being-12 (HWB-12),¹⁶ and the Spinal Cord Independence Measure III (SCIM-III),¹⁷] and administered all of them to all participants. The first half of the interview (approximately 1 hour) focused on QOL in the context of SCI, whilst the second half (approximately 1 hour) focused on reviewing the instruments (Table 1). Methods and findings from the first half of the interviews are discussed elsewhere.¹⁸ The sequence in which the surveys were presented and discussed was varied randomly for each interviewee to control for order effects.^{19,20} The interview prompt for the review of the surveys was: "We are going to look at 6 surveys that have been used to assess health-related quality of life, and well-being in adults with SCI. Please answer each survey question as it applies to you, then please tell me how important it is for your medical provider to know your answer to each question, by choosing: vital, important, not important, or don't know." After completing each survey, participants were also asked to rate the overall importance of each survey using the same answer categories.

Survey instruments

The surveys we reviewed with the participants were not selected following a systematic review of the literature, but with the exception of HWB-12 and the EWB question, these instruments are widely used in studies of adults with SCI.²¹⁻²⁹ We included the HWB-12 and the EWB instruments to assess their potential utility to SCI.²⁹ Four of the instruments (SF-36, SCIM III, FSS, EWB) have been assessed psychometrically in both the US and the UK.^{22,24,26-29} The psychometric

Table 1. Condensed version of interview guide (excluding follow-up questions & probes).

1. How did you come to need a wheelchair?
2. How did you feel when you were told you were spinal cord injured?
3. What do you remember about your initial rehabilitation?
4. What do you remember about the days immediately after coming out of rehabilitation?
5. How would you define "quality of life"?
6. Who is your primary source of medical advice when it comes to your injury?
7. Do you think your medical provider is interested in knowing about aspects of quality of life that matter to you? Why, why not?
8. When someone gives you medical advice, how important do you feel it is for them to know about other aspects of your life, such as those we have just discussed?
9. We are going to look at 6 surveys that have been used to assess health-related quality of life, and well-being in adults with SCI. Please answer each survey question as it applies to you, then please tell me how important it is for your medical provider to know your answer to that question, by choosing: vital, important, not important, don't know.
10. The first question of SF-36 is "In general, would you say your health is: Excellent, Very good, Good, Fair, or Poor". How would you answer this question?
11. Having answered this question, how important do you feel it is for [use their previous answer regarding their primary source of medical advice] to know your answer to this question?
12. How important do you feel it is for [use their previous answer regarding their primary source of medical advice] to know your answers to this [insert survey name] survey overall?
13. Overall, do you think that your medical provider's awareness of your answers to this survey might improve the overall quality of your rehabilitation care? If yes, how, if no, why not?

properties of the SWLS and the HWB-12 instruments have been evaluated in the US only.^{16,23} Table 2 summarizes the key properties of the instruments discussed with the participants, including how they are scored.

Data collection

The first two people who were eligible and agreed to be interviewed were selected for pilot interviews conducted by phone (N_{US}=1, N_{UK}=1) to test the interview guide,

Table 2. Key properties of the six HRQOL and SWB instruments discussed with participants.

Instrument	Target	Dimensions/domains	Scoring	Evaluated in SCI
Short Form 36 (SF-36)	General population	8 scale scores (physical functioning, role functioning, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, mental health); 2 summary scores (Physical Component Summary (PCS) score, Mental Component Summary (MCS) score); 1 preference-based score, SF-6D. Multiple types of answer ranges.	T scores, where mean is 50 and standard deviation is 10.	Yes
Hedonic Well-Being 12	General population	12 questions about well-being experiences the previous day. Answers range from 1 (Not at all) to 5 (Very).	Factor analysis.	No
Satisfaction with Life Scale	General population	5 questions assessing overall satisfaction with life (evaluative subjective well-being). Answers range from 1 (Strongly disagree) to 7 (Strongly agree).	Range 5-35. Benchmarks: 31-35 extremely satisfied; 26-30 satisfied; 21-25 slightly satisfied; 20 neutral; 15-19 slightly dissatisfied; 10-14 dissatisfied; and 5-9 extremely dissatisfied.	Yes
Eudaimonic Well-Being	General population	1 question about overall worth of life. Answer ranges from 0 (not at all worthwhile) to 10 (extremely worthwhile).	Overall score from 0 to 10.	No
Spinal Cord Independence Measure III	Adults with SCI	19 questions about overall level of independence. 1 self-care scale; 1 respiration and sphincter management scale; 1 mobility scale. Multiple types of answer ranges.	Overall independence score from 0 to 100. Self-care scale from 0 to 20. Respiration and sphincter management from 0 to 40. Mobility scale from 0 to 40.	Yes
Fatigue Severity Scale	General population	9 questions about overall fatigue severity. Answers range from strongly disagree (1) to strongly agree (7).	Overall score of fatigue severity, ranging from 9-63, higher score means higher fatigue severity.	Yes

ensuring the questions were understandable and the length of the interview was reasonable. Because of the structural changes resulting from these pilot interviews (changes in the order of questions, phrasing of several questions, and addition of three questions) these were not included in the final analysis. In total, 20 participants were interviewed ($N_{US}=10$, $N_{UK}=10$) between April and June 2016. In both countries participants resided in a mix of urban, suburban, and rural areas. In the UK, participants were interviewed in their homes in the following geographic areas: Merseyside, South Devon, Hampshire, West Kent, Northumberland, Staffordshire, Leicestershire, and Wales. In the US, participants were interviewed in their homes in the following geographic areas: Southern California (Los Angeles, San Diego), Southwest Pennsylvania, Southeast Pennsylvania, Wisconsin, Central Florida, North Texas, Maryland, Upstate New York, and Alabama. Of the 20 interviews considered for this analysis, 12 were conducted face-to-face ($N_{US}=2$, $N_{UK}=10$), and 8 via Skype/FaceTime ($N_{US}=8$). To minimize travel costs and represent geographic distribution of US participants, most of the US interviews were conducted via Skype. Interview length ranged between approximately 80 minutes to 4 hours (median time was 103.5 minutes). None of the participants decided to end the interview early. All interviews were audio recorded, and transcribed verbatim.

Analysis

Transcripts were uploaded to Atlas.ti³⁰ to facilitate management, coding, analysis and interpretation of complex qualitative data, using grounded theory. These transcripts included both the first half of the interview, regarding QOL in the context of SCI,¹⁸ and the second half, regarding survey preferences. Coding was performed in two rounds, each consisting of two coders coding independently. The process was driven by inductive reasoning based on the interview content, and included both open coding (codes identify dimensions emerging from the data) and in-vivo coding (codes are assigned directly from the text, when interviewees' own words are compelling). Inter-coder reliability was estimated using Cohen's kappa,^{31–34} with software from the University of Pittsburgh's Coding Analysis Toolkit.^{35,36} The initial kappa on a random sample of 5 transcripts was 0.75. After reconciliation, coding was done on the remaining 15 transcripts, with kappa of 0.82. The codebook is available upon request. The survey results and group comparisons were analyzed using STATA version 14 for Windows.³⁷

To further understand the motivation behind the respondents' ratings of each survey, we conducted a

Keyword in Context (KWIC) analysis. Using freely available Web-based text processing software, *Voyant Tools*,³⁸ we analyzed the verbatim transcripts of the comments that all participants made in relation to each of the 6 surveys; the comments were divided into six different text files, one for each survey. *Voyant Tools* produced a raw frequency of distinctive words (i.e. it excluded prepositions, conjunctions, etc) used by each participant to explain their survey rating. Through the KWIC function, the most frequently used distinctive words were selected and analyzed in context—that is, 15 words preceding and 15 words following each frequently used word.

Results

Table 3 shows participant demographic and clinical characteristics. The two groups were similar in terms of levels of injury, but they differed significantly at $P < 0.05$ based on independent group t-tests on median age at injury (38 versus 20 years for US and UK, respectively), time since injury (8 versus 32 years for US and UK, respectively), and post-acute rehabilitation weeks (14 versus 40 weeks for US and UK, respectively).

For each participant, we collected answers to all 6 surveys (82 questions in total), ratings of importance for each survey question (82 in total), as well as overall ratings of the importance of each of the 6 instruments. Table 4 summarizes results of participant reviews of the six surveys with illustrative quotes. The findings are presented in the order of survey importance, starting with the least important. Table 5 summarizes participant ratings of how important they felt it was for their medical provider to know their answers to each of the 6 survey instruments overall and the individual survey items. Of the 6 surveys, the only scores that differed significantly between the two country groups were those for the FSS. FSS scores are summary scores, ranging from 9 to 63, where higher scores indicate higher fatigue. The mean scores were 37.8 in the US group ($SD = 5.43$), and 42.1 in the UK group ($SD = 4.95$), t statistic = 2.29, $P < 0.05$. Table 6 provides a summary of themes relating to identified survey problems, and suggested improvements. The improvements in Table 6 are a summary of participant feedback.

Figure 1 displays the most frequently used words by survey importance rating (vital/important/not important) for each of the 6 surveys. For the FSS, the most distinctive words used were “fatigue” and “pain.” Pain was described as bodily pain in relation to wrists, elbows, shoulders, and bones. Of the 32 occurrences of the

Table 3. Demographic and clinical characteristics of the sample.

Characteristic	US (N = 10)		UK (N = 10)		Sample total (N = 20)	
Sex (N / %)						
Male	6	(60)	9	(90)	15	(75)
Race/Ethnicity (N / %)						
White	8	(80)	9	(90)	17	(85)
Black/African-American	1	(10)	1	(10)	2	(10)
Pacific Islander	1	(10)	-	-	1	(5)
Education (N / %)						
High school or GED	2	(20)	5	(50)	7	(35)
Some college or 2-year degree	2	(20)	1	(10)	3	(15)
Four-year college	3	(30)	3	(30)	6	(30)
More than 4-year college	3	(30)	1	(10)	4	(20)
Employment (N / %)						
Full-time (30 hrs/week or more) for pay	2	(20)	5	(50)	7	(35)
Part-time (less than 30 hrs/week) for pay	1	(10)	1	(10)	2	(10)
Volunteer (no pay)	-	-	1	(10)	1	(5)
Disabled (not working)	3	(30)	2	(20)	5	(25)
Retired	4	(40)	1	(10)	5	(25)
Living with Partner at time of interview (N / %)						
Yes	6	(60)	6	(60)	12	(60)
Age (Median / Range)						
Chronological Age	57	(23-69)	51	(31-62)	53	(23-69)
Age at Injury*	38	(9-64)	20	(0-49)	21	(0-64)
Time since Injury*	8	(2-50)	32	(11-47)	18	(2-50)
Level of Injury (N / %)						
Incomplete Paraplegia	4	(40)	3	(30)	7	(35)
Complete Paraplegia	2	(20)	3	(30)	5	(25)
Incomplete Tetraplegia	2	(20)	-	-	2	(10)
Complete Tetraplegia	2	(20)	4	(40)	6	(30)
Etiology (N / %)						
RTA (car, motorcycle, pedestrian, off-road)	3	(30)	5	(50)	8	(40)
Disease (e.g. Spinal infarct, Myelitis)	4	(40)	2	(20)	6	(30)
Leisure (Riding, swimming, diving)	2	(20)	2	(20)	4	(20)
Sport/Rugby	-	-	1	(10)	1	(5)
Work (Fall from height)	1	(10)	-	-	1	(5)
Rehabilitation (Median / Range)						
Post-acute Rehabilitation (Weeks)*	14	(2-34)	40	(12-72)	27	(2-72)

GED, general education diploma; RTA, road traffic accident. *Statistically significant differences between the two groups ($P < 0.05$) based on two-sample t-tests.

word “pain” in 12% of instances pain was described as causing physical and mental fatigue.

For the SCIM III, in 16% of 25 occurrences “know” was used to refer to knowledge by the respondent about their own needs, deficiencies, problems, etc. The rest referred to the importance that doctors know a patient, their lifestyle, and medical and non-medical needs. In 41% of occurrences of the word ‘wheelchair’ participants talked about problems with wheelchair use: armrest being broken, inability to do push-ups in the chair, risk of falling out of the chair, and sitting tolerance.

For EWB, overall, “family” was mentioned in 33% of the occurrences of the “worthwhile,” while the rest related to work, contributions to society, and pursuit of pleasures. When “doing” was used, 25% of the mentions related to work, 13% related to self-care activities, and the rest were about doing things in general. In the context of the SWLS, more than half (64%) of the

occurrences of “health” relate to mental health. In the comments about SF-36, occurrences of “health” were related to physical and mental health, both for those who rated the survey “important” and those who thought it was “not important.”

Discussion

This study examined preferences of adults with spinal cord injury for widely used HRQOL and SWB instruments in two small samples in the US (N = 10) and the UK (N = 10). The respondents’ scores for SF-36, SWLS, SCIM-III, EWB and FSS were similar to those found in other studies, including SF-36 mental component scores being higher than physical component scores.²¹⁻²⁸ However, only for the Fatigue Severity Scale scores is there a statistically significant difference between the two groups. Because the HWB-12 has not been used on SCI adults, comparisons were unavailable.

Table 4. Summary of participant reviews of the six surveys with illustrative quotations.

Survey instrument	Summary of reviews	Illustrative quotations
Short Form 36 (SF-36)	<p>In answer to the first question “<i>In general, would you say your health is ...</i>”, more than half of all participants (N_{UK}=7; N_{US}=4) said their health was linked to their injury, especially as they aged with the injury. In the US group, participants said their SCI and their health were connected. When they thought about their overall health, nearly half said they considered physical and mental health to be equally important. There was no mention of social functioning. Physical health was more important than mental health for seven US and three UK interviewees. More than half of all interviewees (N_{UK}=7, N_{US}=8) said they interpreted the questions about limitations of activities literally, while a quarter (N_{UK}=3, N_{US}=2) said they adapted the questions to suit their context: they replaced “running” and “walking” with “wheeling”</p> <p>Five participants (N_{UK}=4, N_{US}=1) considered skipping items (3a through 3i) that cover daily activities such as running, lifting heavy objects, climbing several flights of stairs, bending, kneeling, stooping, walking more than a mile. They felt these didn’t consider the level of danger, duration, and intensity of activity, type of surface for wheeling, weights of objects to be lifted, and the broader context of living with SCI (having the right adaptations and wheelchair, having assistance, etc). Two respondents took offense to the items regarding climbing stairs.</p> <p>Regarding questions inviting comparisons with other people, two participants mentioned they could compare themselves to either able-bodied people or other persons with SCI</p> <p>Some measurement error was revealed when participants explained the rationale for answers. For instance, those who said that they were “limited a lot” in lifting and carrying things, did so out of an awareness of the danger of the activity, fear of bags breaking in someone’s lap, or awareness that extra weight increases pressure on already vulnerable soft tissue. Their answer was not necessarily an indication that they couldn’t complete the activity.</p>	<p>“<i>In terms of treatment or diagnosis, they tend to be separate, but my general state of health is very connected to my spinal cord injury. The older I get it is very connected</i>” (UK-M4).</p> <p>“<i>I would say that majority of my life is about mental health, obviously because physically I can’t do things. To be mentally sound and to be in a good place, it’s so, so important</i>” (UK-M8).</p> <p>“<i>Walking and wheeling are the same to me</i>” (US-M1).</p> <p>“<i>I could do it. But I’d then have to weigh up the danger in doing that. Because if I can’t see my feet, it’s gonna sound stupid this, but when you’re sitting in a wheelchair, especially power chair, if you can’t see your feet, and you can’t feel your feet, you don’t know whether you’re catching them on something</i>” (UK-M1).</p> <p>“<i>What a bloody stupid question. It’s insulting in a way. I’m C4-5</i>” (UK-M5)</p> <p>“<i>It’s stupid, why are you going to ask me if I can walk when I can’t? I kind of was offended</i>” (US-M5).</p> <p>“<i>If you put me up against spinal cord injured people, I’d say I have very good health. But if you put me up against the general population then I’m going to say fair to good</i>” (UK-M6)</p> <p>“<i>To turn around in the kitchen, if I can’t see my feet where they’re up against the bottom of the cupboard, as the chair is turning, and I have a bulky load sitting on my knees, like clothes ready for the dryer, and I do like a complete U-turn in the kitchen, there’s a possibility that I actually break my foot on the bottom of the cupboard</i>” (UK-M1).</p>
Hedonic Well-Being 12	<p>Those who recognized this survey as important talked about its potential contribution to holistic care, but added that it should be administered frequently to bring up a pattern. Others described it as too abstract, context-dependent, and too broad.</p>	<p>“<i>To me, this survey doesn’t really tell you anything about the person or the circumstances. It doesn’t reveal anything meaningful</i>” (US-F4).</p>
Satisfaction with life scale	<p>Several commented that the survey was too vague, confusing and broad to be helpful.</p> <p>Half of British respondents thought the survey would inform their medical provider about their psychological well-being in a comprehensive and nuanced manner.</p>	<p>“<i>Does conditions of my life refer to my health or life separate from health</i>” (US-F1).</p> <p>“<i>Important in the general mental health assessment, make sure you’re not feeling down about your life</i>” (UK-M2).</p> <p>“<i>This deals with a very specialist area of psychological well-being, which is important to know, and I think should be important for health consultants to know</i> (UK-M3).</p>

Continued

Table 4. Continued

Survey instrument	Summary of reviews	Illustrative quotations
	Some participants in both samples doubted its utility because of prior negative experiences with their medical providers: doctors seen as not caring, concerned with physical health only, and lacking a holistic approach to care. While this negative perception of doctors was seen across the two groups, there was a difference: in the US mistrust was directed at both primary care and specialist doctors; in the UK it was mostly directed at lack of SCI specialist training among primary care and emergency room physicians and nurses. Those who regarded this survey as useful, commented on its potential to trigger further probing about psychological well-being.	<p>"I just had such bad experiences with doctors that don't care about their patients that I can't imagine them caring about the answers to the survey." (US-F2).</p> <p>"I think it would be very important, because most patients and most doctors, are not overly concerned about this information that you are bringing up, and I think they should be" (US-M1).</p> <p>"Pretty important because these may lead to questions that help your doctor understand what you need at home. I do believe it's useful. Most of the satisfaction issue, especially with an injury like mine, is because something isn't accommodating you" (US-M3).</p> <p>"I think it's quite important, it could tell the GP if somebody was depressed or didn't like their life" (UK-M6).</p>
Eudaimonic Well-Being	Half of the respondents in both groups noted its importance as part of holistic care, and its potential to instigate more clinical probing on issues of mental health and lifestyle. When talking about things that were worthwhile to them, both UK and US participants talked about family, work, contributions to society, and pursuit of pleasures and creative interests.	<p>"I think worthwhile to me are things that benefit my family, things that, from a selfish point of view, nourish my intellect" (UK-M3).</p> <p>"I think your primary care physician should know this stuff. I think they should know how you feel about your life. How can they possibly make a diagnosis, or even make any assumptions unless they know what's going on psychologically, physically, emotionally. I just think physicians know so little" (US-F1).</p> <p>"I think this was good. I think it's important to know what a person is capable of doing. Because that factors into the quality of life, the potential for experiencing different problems. This is basically practical, this is basically objective almost, these are the things I can and can't do, versus something more subjective like happiness. I think they need to know that" (US-F1).</p>
Spinal Cord Independence Measure III	Participants were positive about this survey, because they felt it was relevant to their life circumstances and their needs. A few stressed the efficiency with which this survey communicates a lot of important information to their medical provider, thus leaving more time to discuss issues during the visit. Several suggested improvements in the scope of the survey.	<p>"This seems to be differentiating between when you are out of the home, and in the home. I don't think that's a meaningful distinction. I am assuming that they are asking it that way, because in the home you have control over what devices you have. Out of the home, you don't necessarily. I want my doctor to understand what I need to function, particularly as it relates to the wheelchair, whether I am at home or not. They are not asking any questions about how long you sit in the wheelchair, do you need to move to a different space to get pressure relief? I need to be some place where I can move to a seat I can actually sit on for a bit, to get different pressure than what's in my wheelchair. That's an important distinction to make" (US-F4).</p> <p>"It's important and I wouldn't have even thought to bring it up" (US-F2)</p>
Fatigue Severity Scale	Most respondents described fatigue as something exacerbated by aging, but also as a symptom of more serious problems such as bowel cancer, thus highlighting the potential of the survey to trigger more probing. About half of interviewees noted that it was unclear if the survey referred to mental or physical fatigue, or both. Regarding question 2 about exercise, about half also noted that the answer it elicited was not informative, because exercise means different things to different people.	<p>"Regarding exercise, there are two sides. If I have to wheel myself to the village that will tire me out. But if I do a work out, let's say, just on my arms, it might make my wrists a bit sore, but I actually come out of that and I feel boosted and stronger, because I have pumped my arms. But some people call exercise just sitting up unaided" (UK-M4).</p>

Continued

Table 4. Continued

Survey instrument	Summary of reviews	Illustrative quotations
A few respondents offered suggestions to improve the relevance and scope of this survey, including differentiating between physical and mental (emotional) fatigue.		<p>"I think of physical fatigue, but when I do get really physically fatigued, then I am more mentally fatigued as well, I won't be able to concentrate as well, if I am really, really tired physically. What makes you vulnerable to fatigue includes sitting tolerance, and the environment in which a wheelchair is used. If you've got a manual wheelchair and you're pushing it in an area where the surfaces aren't great, that can tire you out. But you also get fatigued just from sitting in your wheelchair. You can get fatigued from pain" (UK-M9).</p> <p>"Physical fatigue is if you can't lift one more thing, or can't push that vacuum one more time. Emotional fatigue means you don't think you can do it, but in fact you can physically do it. These things have to be asked very specifically. Because the emotional affects the physical so much, and in fatigue that is more evident than in other things" (US-F4).</p>

Of the total number of 82 items from the six surveys, only 15 (18%) were rated as vital or important, suggesting that overall these surveys do not capture well what matters to them, or what they think their medical provider should know about them.

The findings in this study highlight differences among adults with SCI in their preferences for HRQOL and SWB measures. The participants who rated surveys as vital were primarily those with incomplete injuries. This may be explained by the fact that the persons with incomplete spinal injuries tended to experience higher levels of pain and fatigue. The participants who rated any of the surveys as important tended to be those with higher level injuries. This may be explained by the fact that higher-level cervical-spine injuries often result in loss of control over more of the body (arms and hands, as well as lower body), and in extreme cases tetraplegia may affect vital functions such as breathing. So the importance of communicating survey results to their medical providers could be driven in part by higher levels of pain and physical impairment.

An unexpected finding was the participants' top rating of the FSS as a vital or important survey for medical providers to know about. They talked about the importance of physical and mental fatigue as a functional impairment, and its implications for self-care, mobility and activities of daily living. Yet both groups reported the absence of fatigue from discussions with their medical providers. This could be explained by the short duration of the appointments, and by the fact that much of the patient-physician communication regarding SCI and life with SCI occurs in an unstructured, inconsistent manner. A key advantage of the FSS seemed to be its potential to instigate a discussion about fatigue and its underlying issues. However, there were suggestions for improvement of survey scope, especially language and content to better address fatigue in the context of SCI. This finding invites further investigation into measurement, management and prevention of fatigue for adults with SCI. A survey that captures causes of fatigue would seem particularly useful.

Another finding was the low rating for the importance of the SF-36 survey. Some of the issues relating to this survey, such as items immaterial to life with SCI, or the offence caused to some respondents, were known from previous studies.³⁹⁻⁴² Another issue is the potential for response error. Andersen *et al.* (1999) used the question about lifting and carrying things to mark individuals as having an upper-body impairment.²² But in this study, those who said that they were "limited a

Table 5. Participants' ratings of instruments and items by importance of sharing information with medical providers.

Instruments* and Items**	Vital	Important	Not important	Don't know
Fatigue Severity Scale	5	10	2	3
9. Fatigue interferes with my work, family, or social life.	5	12	1	2
1. My motivation is lower when I am fatigued.	6	10	1	3
2. Exercise brings on my fatigue.	7	8	2	3
6. My fatigue prevents sustained physical functioning.	4	7	4	5
3. I am easily fatigued.	5	5	6	4
Spinal Cord Independence Measure III	6	7	3	4
6. Bladder management.	8	10	1	1
7. Bowel management.	8	10	1	1
3(b). Dressing your lower body.	5	11	1	3
1. Eating and drinking.	4	8	3	5
Eudaimonic Well-Being	4	7	2	7
Overall, to what extent do you feel that the things you do in your life are worthwhile?	4	7	2	7
Satisfaction with Life Scale	1	8	7	4
<i>No items deemed vital or important</i>				
Hedonic Well Being-12	0	9	4	7
12. Yesterday, did you feel pain?	2	8	5	5
Short Form-36	0	6	11	3
29. Do you feel worn out?	0	12	4	4
1. In general, would you say your health is.	4	7	3	6
21. How much bodily pain have you had during the past 4 weeks?	2	9	2	7
22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	2	9	8	1

*We report overall instrument ratings of importance of sharing information in each with medical providers, listed in order of perceived importance, from most to least important. These are numbers of respondents who described each instrument as either vital, important, not important, or don't know.

**We report items rated as "vital" or "important" by more than half of participants. Some participants who rated a survey overall as "not important" or "don't know" rated some of its individual items as "vital" or "important". Some who rated a survey as "vital" or "important" rated some of its individual items as "not important" or "don't know".

lot" in lifting and carrying things, did so out of an awareness of danger of activity, fear of bags breaking in someone's lap, or awareness of poor pressure support. Their answer was not necessarily an indication that they couldn't complete the activity.

An important insight is gleaned from the use of newer communications technologies such as Skype/FaceTime to conduct in-depth interviews. This addresses one of the traditional shortcomings of in-depth qualitative research, which is limited in geographic scope, by

Table 6. Summary of identified survey problems and suggested improvements.

Survey instrument	Identified problems	Suggested improvements
Short Form 36	<ul style="list-style-type: none"> • Questions irrelevant to life with SCI, especially about ability to walk or run • Offensive phrasing in questions about ability to walk or run 	<ul style="list-style-type: none"> Adapt content to SCI context Re-write questions to consider SCI target population
Hedonic Well-Being 12	<ul style="list-style-type: none"> • Items not informative of true daily experience • Requires frequent administration to provide a picture of quality of life 	Administer just selected items that are relevant to SCI, such as pain
Satisfaction with Life Scale	<ul style="list-style-type: none"> • Items are vague, confusing and too broad 	Re-write items to make them more focused and relevant to SCI
Eudaimonic Well-Being	<ul style="list-style-type: none"> • The item is too broad 	Provide an open-ended option so that respondents can explain what they mean
Spinal Cord Independence Measure III	<ul style="list-style-type: none"> • Items focus on in-home function as opposed to outside the home 	Improve scope by adding more questions on wheelchair use and function outside the home
Fatigue Severity Scale	<ul style="list-style-type: none"> • Several items were too vague, particularly about exercise and disabling symptoms • Scope was unclear, no distinction between physical and mental fatigue 	<ul style="list-style-type: none"> Focus on causes of fatigue based on a broader range of activities Improve scope to include mental fatigue

Note: After completing each survey, participants were asked to discuss the surveys overall in terms of utility to providers, including identifying problems and suggesting improvements. Here we provide a summary of participants' feedback.

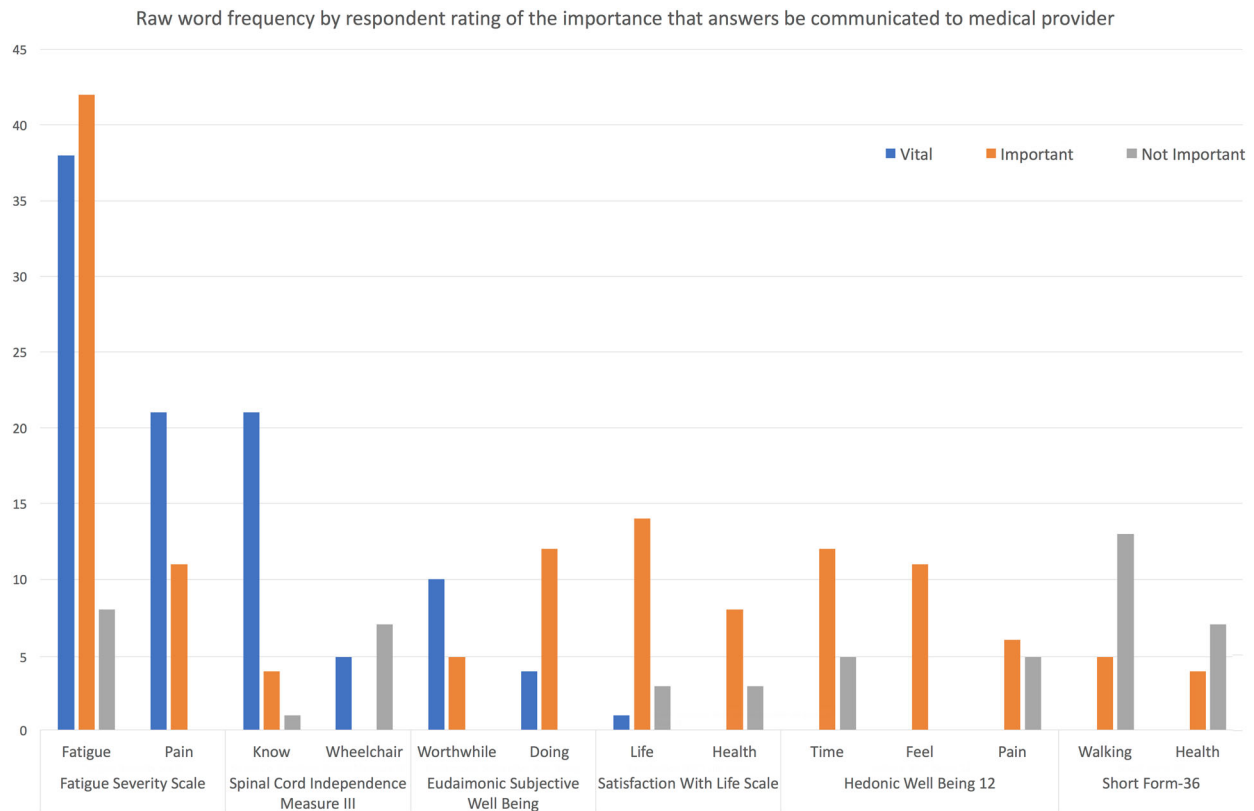


Figure 1. Raw word frequency by respondent rating of the importance that answers be communicated to medical provider. For each of the six instruments, these are the top two most frequently used words when respondents discussed their utility. Word frequency is also displayed by the overall importance rating that answers be communicated to a medical provider: vital, important, not important.

enabling remote data collection. Another advantage is access to participants who otherwise may not consent to having a stranger in their home, either out of fear, discomfort, or embarrassment (particularly because of bladder/bowel accidents). With Skype, they are in control of how much they show of themselves and their surroundings, so they can easily highlight for the interviewer issues with their wheelchair, posture or home adaptations. Although the use of Skype was not primarily driven by participant preference, these advantages were noted by several participants following the interview. This method increased participant comfort, as some accessed Skype from mobile devices, not just a desktop computer, and could change locations during the interview. They could easily discontinue the session if they felt uncomfortable. A disadvantage is that this limits field notes, but considering the access to and wealth of information garnered from individuals who otherwise may not participate, this trade-off is reasonable. Other researchers have outlined the opportunities of harnessing modern communications technology in qualitative research.^{43,44} In the US sample, we did not observe differences in the scope or depth of

information provided by the two in-person interviewees compared to those interviewed via Skype.

Study limitations

A key limitation of the study is small sample size and unknown representativeness, thus, we cannot generalize these findings to SCI in the US or the UK. That there were statistically significant differences between countries on age at injury, time since injury, and post-acute rehabilitation time is another limitation. Being injured when younger, having lived with the injury for longer, and having received inadequately short rehabilitation could affect survey responses as well as views on how these surveys reflect one’s needs. Self-selection and access to a computer or mobile device (tablet/smartphone) may bias the sample against participants who do not or cannot use such technology. We recruited using both print ads and online posts, but only one US participant referenced a print ad when they contacted the interviewer. So adults with SCI who do not use the internet may have been left out. A disadvantage was not using remote interviewing in the UK sample, to provide a basis for comparison for

in-person vs Skype interviewing methods. Finally, the low remuneration offered may have discouraged participation.

Conclusions

In this study, we found that participants in both samples identified the FSS as “vital” in terms of importance of informing medical providers about what it measures. The most frequently used distinctive words to discuss FSS were “fatigue” and “pain.” The FSS was followed by the SCIM III, and a stand-alone EWB question. Knowing what HRQOL and SWB measures are valued by adults living with SCI can help clinicians select informative population-specific instruments, thus helping them to complement and tailor established care and rehabilitation protocols for individual needs. The results reported here need to be examined in further studies, ideally with nationally representative samples in both countries. Future studies should also continue to investigate the potential of new communications technologies in conducting one-on-one interviews, preferably by offering respondents a choice between in-person and Skype interviews. Finally, further research should investigate survey length and respondent burden of surveys for adults with SCI.

Compliance with ethical standards

Conflicts of interest

We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or on any organization with which we are associated AND, if applicable, we certify that all financial and material support for this research (eg, NIH or NHS grants) and work are clearly identified in the title page of the manuscript.

The manuscript submitted does not contain information about medical device(s).

Human and animal rights

All procedures performed in this study involving human participants were in accordance with the ethical standards of the UCLA institutional review board and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study.

Authors' contribution

AIP was involved in conception and design, acquisition and transcription of data, analysis and interpretation of

data; drafted the article; revised the article critically for important intellectual content; involved in final approval.

WEC was involved in conception and design, interpretation of data; revised the article critically for important intellectual content; involved in final approval.

HL was involved in conception and design, interpretation of data; revised the article critically for important intellectual content; involved in final approval.

MD was involved in analysis and interpretation of data; revised the article critically for important intellectual content; involved in final approval.

RDH was involved in conception and design, interpretation of data; revised the article critically for important intellectual content; involved in final approval.

Abbreviations

spinal cord injury (SCI); quality of life (QOL); health-related quality of life (HRQOL); subjective well-being (SWB); eudaimonic well-being (EWB); short form 36 (SF-36); spinal cord independence measure version III (SCIM III); hedonic well-being 12 (HWB-12); fatigue severity scale (FSS); satisfaction with life scale (SWLS); keyword in context (KWIC).

ORCID

Alina Ionela Palimaru  <http://orcid.org/0000-0002-2777-4079>

Funding

Alina Ionela Palimaru was supported by a University of California Los Angeles Graduate Fellowship. Dr. Hays was supported in part by the Resource Centers for Minority Aging Research/Center for Health Improvement of Minority Elderly (RCMAR/CHIME) under National Institutes of Health/National Institute on Aging (NIH/NIA) grant P30-AG021684. Dr. Cunningham was supported by Resource Centers for Minority Aging Research/Center for Health Improvement of Minority Elderly (RCMAR/CHIME) under National Institutes of Health/National Institute on Aging (NIH/NIA) grant P30-AG021684, and NIH/National Institute for Minority Health and Health Disparities (NIMHD) / 2P20MD000182-11 / Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training Center (Drew-UCLA Project EXPORT Center). The funders had no role in the study design, data collection, analysis and interpretation of data, writing of the report, or in the decision to submit the article for publication.

References

- 1 National Spinal Cord Injury Stastical Center. Spinal Cord Injury Facts and Figures at a Glance [document on the internet]. 2016 [updated 2016, cited 2016 June 30th]. Available from <https://www.nscisc.uab.edu/Public/Facts%202016.pdf>
- 2 Werndle MC, Zoumprouli A, Sedgwick P, Papadopoulos MC. Variability in the Treatment of Acute Spinal Cord Injury in the United Kingdom: Results of a National Survey. *J Neurotrauma* 2012;29(5):880–8.
- 3 Aung TS, El Masry WS. Audit of a British Centre for spinal injury. *Spinal Cord* 1997;35(3):147–50.
- 4 Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. 2001. Washington, D.C.: Author.
- 5 Fung C, Hays RD. Prospects and challenges in using patient-reported outcomes in clinical practice. *Qual Life Res* 2008;17(10):1297–302.
- 6 Martin Ginis KA, Jetha A, Mack DE, Hetz S. Physical activity and subjective well-being among people with spinal cord injury: a meta-analysis. *Spinal Cord* 2010;48(1):65–72.
- 7 Felce D, Perry J. (1995). Quality of life: its definition and measurement. *Res Dev Disabil* 1995;16(1):51–74.
- 8 Naess S. Subjective approach to quality of life. *Fem Econ* 1999;2(2):115–8.
- 9 Kahn RL, Juster FT. Well-being: Concepts and measures. *J Soc Issues* 2002;58(4):627–44.
- 10 Christoph B, Noll H-H. Subjective well-being in the European Union during the 90s. *Soc Indic Res* 2003;64:521–46.
- 11 Dolan P, Layard R, Metcalfe R. Measuring Subjective Well Being for Public Policy: Recommendations on Measures. London: Centre for Economic Performance, London School of Economics. 2011.
- 12 Ravens-Sieberer U, Devine J, Bevans K, Riley AW, Moon J, Salsman JM, Forrest CB. Subjective Well-Being (SWB) measures for children were developed within the PROMIS® project: presentation of first results. *J Clin Epidemiol* 2014;67(2):207–18.
- 13 Ware JE, Sherbourne CD. The MOS 36-Item Short Form Health Survey (SF-36): I. Conceptual Framework and Item Selection. *Medical Care* 1992;30(6):473–83.
- 14 Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The Fatigue Severity Scale: Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol* 1989;46(10):1121–3.
- 15 Diener E, Emmons RA, Larsen RJ, Griffin S. The satisfaction with life scale. *J Pers Assess* 1985;49(1):71–5.
- 16 Kapteyn A, Jinkook L, Tassot C, Vonkova H, Zamarro G. Dimensions of subjective well-being. *Soc Indic Res* 2015;123(3):625–60.
- 17 Fekete C, Eriks-Hoogland I, Baumberger M, Catz A, Itzkovich M, Lüthi H, et al. Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). *Spinal Cord* 2013;51(1):40–7.
- 18 Palimaru A, Cunningham W E, Dillistone M, Vargas-Bustamante A, Liu H, Hays R D. A comparison of perceptions of quality of life among adults with spinal cord injury in the United States versus the United Kingdom. *Qual Life Res* 2017;26(11):3143–55.
- 19 Whitehurst DG, Suryaprakash N, Engel L, Mittmann N, Noonan VK, Dvorak MF, Bryan S. Perceptions of individuals living with spinal cord injury toward preference-based quality of life instruments: a qualitative exploration. *Health Qual Life Outcomes* 2014;12(1):646–54.
- 20 Perreault WJ. Controlling order-effect bias. *Public Opin Q* 1975;39(4):544–51.
- 21 Kreuter M, Siosteen A, Erkkholm B, Bystrom U, Brown DJ. Health and quality of life of persons with spinal cord lesion in Australia and Sweden. *Spinal Cord* 2005;43(2):123–9.
- 22 Andersen EM, Fouts BS, Romeis JC, Brownson CA. Performance of health-related quality-of-life instruments in a spinal cord injured population. *Arch Phys Med Rehabil* 1999;80(8):877–84.
- 23 Dijkers MP. Correlates of Life Satisfaction Among Persons with Spinal Cord Injury. *Arch Phys Med Rehabil* 1999;80(8):867–76.
- 24 Ravenek KE, Ravenek MJ, Hitzig SL, Wolfe DL. Assessing quality of life in relation to physical activity participation in persons with spinal cord injury: A systematic review. *Disabil Health J* 2012;5(4):213–23.
- 25 Office of National Statistics. First annual ONS experimental subjective well-being results. London: Office for National Statistics. 2012 [updated 2012, cited 2016 June 30th]. Available from http://www.ons.gov.uk/ons/dcp171766_272294.pdf
- 26 Catz A, Itzkovich M, Steinberg F, Philo O, Ring H, Ronen J, et al. Disability Assessment by a single rater or a team: a comparative study with the Catz-Itzkovich Spinal Cord Independence Measure. *J Rehabil Med* 2002;34:226–30.
- 27 Anton HA, Miller WC, Townson AF. Measuring Fatigue in Persons with Spinal Cord Injury. *Arch Phys Med Rehabil* 2008;89(3):538–42.
- 28 Garratt AM, Ruta DA, Abdalla MI, Buckingham JK, Russell IT. The SF-36 health survey questionnaire: an outcome measure suitable for routine use within the NHS? *BMJ* 1993;306(6890):1440–4.
- 29 Bradburn NM, Carstensen LL, Diener EF, Dolan PH, Graham CL, Hertz VJ, et al. Subjective well-being: measuring happiness, suffering, and other dimensions of experience. (A A Stone, C Mackie, Eds). 2013. Washington, D.C.: The National Academies Press.
- 30 Atlas.ti. Version 7.5.12 [Computer software]. 1999. Berlin, Scientific Software Development.
- 31 Cohen J. A coefficient of agreement for nominal scales. *Educ Psychol Meas* 1960;20:37–46.
- 32 Cohen J. Weighted kappa: nominal scale agreement with provision for scaled disagreement or partial credit. *Psychol Bull* 1968;70(4):213–20.
- 33 Benner H, Kliebsch U. Dependence of Weighted Kappa Coefficients on the Number of Categories. *Epidemiol* 1996;7(2):199–202.
- 34 McHugh ML. Interrater reliability: the kappa statistic. *Biochimica Medica* 2012;22(3):276–82.
- 35 Shulman SW. Measure Inter-Rater Reliability and Adjudicate Coder Choices for Measures of Accuracy. 2011 [updated 2011, cited 2016 June 30th]. Available from <http://cat.uncsur.pitt.edu>
- 36 Hruschka DJ, Schwartz D, Cobb St. John D, Picone-Decaro E, Jenkins RA, Carey JW. Reliability in Coding Open-Ended Data: Lessons Learned from HIV Behavioral Research. *Field Methods* 2004;16(3):307–31.
- 37 StataCorp. Stata Statistical Software. [Computer software]. 2014. Release 14. College Station, TX: StataCorp LLC
- 38 Sinclair S. Voyant Tools: See through your texts. Available at <http://voyant-tools.org/>
- 39 Mallinson, S. Listening to respondents: a qualitative assessment of the Short-Form 36 Health Status Questionnaire. *Soc Sci Med* 2002;54:11–21.
- 40 Andersen, E. M., & Meyers, A. R. Health-related quality of life outcomes measures. *Arch Phys Med Rehabil* 2000;81(12 Suppl 2):S30–45.
- 41 Mattson-Prince, J. A rational approach to long-term care: comparing the independent living model with agency-based care for persons with high spinal cord injuries. *Spinal Cord* 1997;35:326–31.
- 42 Hays RD, Hahn H, Marshall G. Use of the SF-36 and other health-related quality of life measures to assess persons with disabilities. *Arch Phys Med Rehabil* 2002;83(12 Suppl 2):S4–9.
- 43 Sullivan JR. Skype: An Appropriate Method of Data Collection for Qualitative Interviews? *The Hilltop Review* 2012;6(1):54–60.
- 44 Saumure K, Given LM. Using Skype as a Research Tool: Lessons Learned from Qualitative Interviews with Distance Students in a Teacher-Librarianship Program. 2015. Retrieved from http://lrsv.umd.edu/abstracts/Saumure_Given.pdf