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Authors

Palimaru, Alina

Cunningham, William E

Dillistone, Marcus

et al.

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A comparison of perceptions of quality of life among adults with spinal cord injury in the United States versus the United Kingdom

Alina Palimaru¹ · William E. Cunningham^{1,2} · Marcus Dillistone³ · Arturo Vargas-Bustamante¹ · Honghu Liu⁴ · Ron D. Hays^{1,2}

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Abstract

Purpose To identify which aspects of life are most important to adults with spinal cord injury (SCI) and compare perspectives in the United States and the United Kingdom.

Methods We conducted 20 in-depth interviews with adults with SCI (ten in the US and ten in the UK). Verbatim transcriptions were independently analyzed line-by-line by two coders using an inductive approach. Codes were grouped into themes about factors that constitute and affect quality of life (QOL).

Results Five overarching themes emerged: describing QOL in the context of SCI; functional adjustment; medical care; financial resources; and socio-political issues. Twenty subthemes emerged on factors that affect QOL. Participants in both samples identified medical care as a key influence on QOL. The US group talked about a predominantly negative influence (e.g., fragmented primary and specialist care, insurance constraints, bureaucracy), whereas UK interviewees mentioned a predominantly positive influence (e.g., universal provision, including free

and continuous care, free wheelchairs and home care, and length of rehabilitation commensurate with level of injury). Functional adjustment, such as physical and mental adjustment post-discharge and aging with SCI, was another important contributor to QOL, and varied by country. Most US interviewees reported poor knowledge about self-care post-discharge and poor quality of home adaptations compared to the UK group.

Conclusions For adults living with SCI, good QOL is essential for successful rehabilitation. Differences between interviewees from the two countries in perceived medical care and functional adjustment suggest that factors affecting QOL may relate to broader health system characteristics.

Keywords Quality of life · Health-related quality of life · Spinal cord injury · Rehabilitation · Outcomes

Introduction

Spinal cord injury (SCI) is a dramatic change in a person's life. There are approximately 300,000 (out of about 319 million) individuals living with spinal cord injury in the United States [1]. A majority of these cases (91%) were acquired through trauma (vehicular 38%, falls 30%, violence 14%, sports and recreational activities 9%) while the rest were caused by diseases or surgical complications (5%) or other causes (4%) [1]. In the United Kingdom, there are approximately 40,000 cases of SCI (out of about 64 million), and about 90% of these are caused by trauma [2, 3]. The impact of SCI on physical, mental, and social function varies by the level and extent of the injury.

Quality of life (QOL) is an all-encompassing concept that refers to a person's physical, psychological, social,

✉ Alina Palimaru
alinapalimaru@ucla.edu

¹ Department of Health Policy and Management, UCLA Fielding School of Public Health, 650 Charles E. Young Dr. S., Los Angeles, CA 90095, USA

² Division of General Internal Medicine & Health Services Research, Department of Medicine, UCLA, Geffen School of Medicine, Los Angeles, CA 90095, USA

³ Royal Society of Medicine, 1 Wimpole Street, Marylebone, London W1G 0AE, UK

⁴ Division of Public Health & Community Dentistry, School of Dentistry, UCLA, Los Angeles, CA 90095, USA

spiritual, and economic well-being [4–8]. Health-related quality of life (HRQOL) is a subset of QOL and refers to physical functioning, role functioning, social functioning, emotional well-being (depressive symptoms, anxiety, anger, positive affect), pain, energy, and general health perceptions [9]. However, conceptualization and measurement of QOL and HRQOL within the context of SCI have been largely atheoretical [10–17]. There is a dearth of information regarding perspectives about life and expectations of adults with SCI [18–20].

This paper examines QOL perspectives of adults in the United States (US) and in the United Kingdom (UK) because the SCI journey may differ in these countries. In the US, access to post-acute care is fragmented, and often hinges on individual insurance coverage or premorbid financial resources [21, 22]. In the UK, services are integrated in the National Health Service, where emergency, post-acute care, rehabilitation, and even wheelchair provision are all free at the point of need. As such, most UK SCI patients benefit from integrated long-term care and rehabilitation [23]. There are also cultural differences that may influence QOL and HRQOL perceptions [24].

Methods

Data collection

Participants were eligible to be interviewed if they were 18 years or older, full-time (round-the-clock) 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 and Alzheimer's disease).

Participants were recruited through (1) print advertisements distributed through patient advocacy organizations in the US (e.g., veterans' support groups) and in the UK (e.g., Spinal Injuries Association); (2) online advertisements distributed 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, although only two of them accepted the offer. This study was approved (Certified Exempt) by the Institutional Review Board of the University of California Los

Angeles (IRB#16-000229), and verbal consent was obtained from all participants.

Analysis

Semi-structured interviews were conducted to capture depth and perspective regarding QOL and HRQOL among adults with SCI. The sample varied by gender, age, etiology of SCI injury (trauma or disease), and type of SCI (paraplegia or quadriplegia).

Two people were selected for pilot interviews conducted by phone ($N_{US} = 1$, $N_{UK} = 1$) to test the interview questions. 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), their data were excluded from the final analysis.

The main study included 20 participants ($N_{US} = 10$, $N_{UK} = 10$) interviewed between April and June 2016. 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 ($N_{US} = 8$). Each interview was conducted in a single session, lasting between 80 min and 4 h. All interviews were audio recorded and transcribed verbatim.

The interviews focused on life with SCI including topics such as rehabilitation (Table 1). Interview guides were developed using literature on SCI, patient films, and informal conversations with SCI rehabilitation professionals.

Transcripts were uploaded to Atlas.ti [25] to facilitate management, coding, analysis, and interpretation of the data. Based on grounded theory, i.e., inductive reasoning from the interview content, driven by a constant comparative analysis of themes emerging from the data, a codebook was developed and reconciled (by the first author, AP, and a second trained coder, MD) [26].

The unit of analysis was the line of text (left to right margin on the Atlas.ti display), which allowed for a more detailed analysis than a paragraph approach, and open and in vivo coding were used to establish categories and themes [27–29]. Open coding refers to labeling interview content based on dimensions emerging from it [26]. In-vivo coding means assigning code labels using words or short phrases directly from the text [26]. Coding was performed in two rounds, each consisting of two coders coding

Table 1 Condensed version of interview guide (excluding follow-up questions and 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. What matters to you most with regard to your quality of life?
7. What aspect of your injury makes you most unhappy?
8. Who is your primary source of medical advice when it comes to your injury?
9. Do you think your medical provider is interested in knowing about the aspects of quality of life that matter to you? Why, why not?
10. 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?

independently. Inter-coder reliability was estimated using Cohen’s Kappa [30–33] with software from the University of Pittsburgh’s Coding Analysis Toolkit [34, 35]. The first round of coding was done on a random sample of 5 transcripts. One person (AP) created code definitions and coded the transcripts. A total of 386 instances of coding resulted from the transcripts, using 58 codes. Then, the code list was provided to a second coder (MD) and he independently coded the transcripts. This coder added 18 new codes to the existing list, and provided a total of 400 instances of coding. Agreement between the two coders for the cumulative 786 instances of coding was 86%, with an unweighted kappa of .75. After reconciliation, coding was done on the remaining 15 transcripts, with kappa of .82.

After analyzing all 20 interview transcripts, the codebook contained 108 content-grounded codes, all of which were tagged to at least one transcript (the codebook can be provided upon request). Of these codes, 76 (70%) were identified within the first 5 coded interviews. The rest of the codes were identified in the next 11 transcripts, indicating that saturation of the full range of content-grounded themes occurred within the first 16 interviews.

Results

Table 2 shows participant clinical characteristics, and Table 3 shows their demographic characteristics. The two groups were similar in terms of levels of injury, but the median time since injury in the UK group was 32 years versus 8 in the US sample. Five overarching themes (QOL in the context of SCI; medical care; functional adjustment; financial resources; and socio-political context) and 20 subthemes emerged as factors that affect QOL. Tables 4 and 5 provide a summary of themes, subthemes, and their influence on QOL domains. Below we review themes and subthemes, including illustrative quotes.

QOL in the context of SCI

More than half of interviewees ($N_{US} = 7$, $N_{UK} = 8$) explained how they perceived *their own* QOL. For example:

What matters to me is that, since I don’t have people living with me, that I am able to do things that I absolutely must do (US-F4);

QOL for me as a para, I’d like to be able to do what I can that most people do, that’s still within my ability. That’s QOL (US-M5).

My definition of quality of life revolves around care, almost completely around that most basic need – good quality care (UK-M3);

The following HRQOL dimensions emerged: physical health (including ability to conduct *activities of daily living*, e.g., personal hygiene, dressing, eating, continence, mobility, and *instrumental activities of daily living*, e.g., communication, transportation, managing finances); mental health; social functioning; and intimate relationships (including sexual and reproductive functions). QOL dimensions mentioned were as follows: material well-being (including housing security, acquisition of disability-specific items, services, and technology); rights (civil rights, government support); and religious beliefs. Most of these domains were expressed equally by the US and UK participants, apart from religious beliefs, which were offered exclusively by US participants.

Notably, for some interviewees, the prioritized domains of QOL changed not only immediately after the injury, but also over the course of time with the injury.

What matters to me varied a lot over the last 11 years. Actually, my first one was not being able to get up and do things. But eventually that passed on,

Table 2 Clinical characteristics of the sample

Characteristic	US (<i>N</i> = 10)	UK (<i>N</i> = 10)
Level of injury (%)		
Incomplete paraplegia	4 (40)	3 (30)
Complete paraplegia	2 (20)	3 (30)
Incomplete quadriplegia	2 (20)	–
Complete quadriplegia	2 (20)	4 (40)
Etiology (%)		
RTA (car, motorcycle, pedestrian, off-road)	3 (30)	5 (50)
Disease (e.g., spinal infarct, myelitis)	4 (40)	2 (20)
Leisure (riding all, swimming, diving)	2 (20)	2 (20)
Sport/rugby	0 (0)	1 (10)
Work (fall from height)	1 (10)	–
Rehabilitation (median/range)		
Post-acute SCI rehabilitation (weeks)	14 (2–34)	40 (12–72)

Table 3 Demographic and clinical characteristics of the sample

Characteristic	US (<i>N</i> = 10)	UK (<i>N</i> = 10)
Age (median/range)		
Chronological age	57 (23–69)	51 (31–62)
Age at injury	38 (9–64)	20 (0–49)
Time since injury	8 (2–50)	32 (11–47)
Gender (%)		
Male	6 (60)	9 (90)
Race/ethnicity (%)		
White	8 (80)	9 (90)
Black/African-American	1 (10)	1 (10)
Pacific Islander	1 (10)	0 (0)
Education (%)		
High school or GED	2 (20)	5 (50)
Some college or 2-year degree	2 (20)	1 (10)
Four-year college	3 (30)	3 (30)
More than 4-year college	3 (30)	1 (10)
Employment (%)		
Full-time (30 h/week or more) for pay	2 (20)	5 (50)
Part-time (less than 30 h/week) for pay	1 (10)	1 (10)
Volunteer (no pay)	0 (0)	1 (10)
Disabled (not working)	3 (30)	2 (20)
Retired	4 (40)	1 (10)
Living circumstances (%)		
Alone with no caregiver support	2 (20)	2 (20)
With family live-in caregiver	4 (40)	4 (40)
With non-family live-in caregiver	0 (0)	1 (10)
With someone who is not a caregiver	3 (30)	3 (30)
In a residential home	1 (10)	0 (0)
Living with partner at time of interview (%)		
Yes	6 (60)	6 (60)

and to tell you the truth, if I could only get one thing back without any issues, it would be my bowel care (US-M1).

As I get older, my quality of life and the quality of health are becoming more of an issue. But at the moment it's more about keeping me socially active,

Table 4 Summary of positive themes, subthemes and influence on quality of life domains

Themes and subthemes	Participants US($N = 10$)/UK($N = 10$)	Quality of life domains				
		Physical health	Mental health	Social functioning	Intimacy	Material well-being
Medical care						
Positive rehabilitation	$N_{US} = 6/N_{UK} = 8$	x	x	x	x	
Positive wheelchair provision	$N_{US} = 5/N_{UK} = 8$	x	x	x		x
Positive primary care	$N_{US} = 4/N_{UK} = 6$	x	x			
Caregiving at home	$N_{US} = 5/N_{UK} = 5$	x	x			
Functional adjustment						
Mental adjustment post-discharge	$N_{US} = 0/N_{UK} = 0$					
Impact of SCI on function	$N_{US} = 0/N_{UK} = 0$					
Complications	$N_{US} = 0/N_{UK} = 0$					
Aging with SCI	$N_{US} = 0/N_{UK} = 0$					
Fatigue (physical and mental)	$N_{US} = 0/N_{UK} = 0$					
SCI knowledge	$N_{US} = 0/N_{UK} = 8$	x	x	x		
Home adaptation	$N_{US} = 4/N_{UK} = 7$	x	x	x		
Public infrastructure	$N_{US} = 6/N_{UK} = 6$	x	x	x		x
Financial resources						
Financial resources	$N_{US} = 4/N_{UK} = 9$	x	x			x
Socio-political context						
Family attitudes	$N_{US} = 10/N_{UK} = 10$	x	x	x	x	
Social relationships	$N_{US} = 4/N_{UK} = 8$	x	x	x		
Attitudes towards disability	$N_{US} = 0/N_{UK} = 2$	x	x			x
Government policy	$N_{US} = 2/N_{UK} = 3$	x	x			x

and my relationship with my wife and family, and the quality of life in that respect (UK-M4).

Factors contributing to QOL: medical care

All participants discussed medical care as a key factor affecting their QOL, because “with good quality care you can then build, you have got the foundation blocks to build the rest of your life” (UK-M3). Subthemes of medical care included rehabilitation experience (positive and negative comments), provision of wheelchairs (positive and negative), primary care (positive and negative), and caregiving in the home (positive only).

Rehabilitation experience

Negative rehabilitation experiences were mentioned by participants from both countries ($N_{US} = 10$, $N_{UK} = 9$). In the US group, two participants recalled experiences from the 1960s and 1970s, and eight from 2003 onwards, including one as recent as two years ago. Six UK participants recalled rehabilitation periods that took place in the 1970s and 1980s, two in the 1990s, and two after 2005.

Both groups talked to varying degrees about problems with quality of care during their specialist rehabilitation, particularly rude and impolite behavior by hospital staff; lack of patient education about treatment options, living with an SCI, self-care, sexual education, pressure sore prevention; hospital-acquired complications (e.g., pressure sores: US/UK, *Clostridium difficile* or *C. diff*: US only); lack of resources (range of physiotherapy in the US, and one-on-one specialist-patient time in the UK); lack of an holistic approach to rehabilitation (i.e., physical, mental, social, home environment, lifestyle); and institutional issues, such as privacy and strict routines.

I came down with *C. diff*, and I have had off-again on-again episodes for about probably 3 months. In one case, it was just lousy hygiene. The time that I spent sick in bed, they might well have taught me other things (US-M1).

In 1983 they cut my sphincter to my bladder. I hadn't a clue what that meant, so they just did it when I was in hospital, it wasn't explained in terms of what might come further in life, that I might just drain all the time. Looking back on it I would go and slap them for doing that to me (UK-M4).

Table 5 Summary of negative themes, subthemes, and influence on quality of life domains

Themes and subthemes	Participants US($N = 10$)/UK($N = 10$)	Quality of life domains				
		Physical health	Mental health	Social functioning	Intimacy	Material well-being
Medical care						
Negative rehabilitation	$N_{US} = 10/N_{UK} = 9$	x	x		x	
Negative wheelchair provision	$N_{US} = 7/N_{UK} = 5$	x	x	x		x
Negative primary care	$N_{US} = 7/N_{UK} = 4$	x	x			
Caregiving at home	$N_{US} = 0/N_{UK} = 0$					
Functional adjustment						
Mental adjustment post-discharge	$N_{US} = 10/N_{UK} = 10$	x	x	x		
Impact of SCI on function	$N_{US} = 10/N_{UK} = 10$	x	x	x	x	
Complications	$N_{US} = 10/N_{UK} = 10$	x	x	x	x	
Aging with SCI						
Fatigue (physical and mental)	$N_{US} = 6/N_{UK} = 8$	x	x	x		
SCI knowledge	$N_{US} = 9/N_{UK} = 2$	x	x	x		
Home adaptation	$N_{US} = 6/N_{UK} = 3$	x	x	x		
Public infrastructure	$N_{US} = 6/N_{UK} = 6$	x	x	x		x
Financial resources						
Financial resources	$N_{US} = 6/N_{UK} = 1$	x	x			x
Socio-political context						
Family attitudes	$N_{US} = 0/N_{UK} = 0$					
Social relationships	$N_{US} = 5/N_{UK} = 1$	x	x	x		
Attitudes towards disability	$N_{US} = 7/N_{UK} = 4$	x	x			x
Government policy	$N_{US} = 3/N_{UK} = 0$	x	x			x

The US rehabilitation experience showed pronounced fragmentation of care, provision of care contingent on type of insurance and on insurers' judgements about medical necessity, little or no post-discharge follow-up, and insufficient length of rehabilitation.

I was in a hospital for about a month, then I went to a rehabilitation center for three and a half months. Then I came home. The reason why they sent me home is because the insurance stopped paying. All that they care about is money (US-M6, Incomplete Quadriplegia).

Participants in both samples discussed positive rehabilitation experiences ($N_{US} = 6$, $N_{UK} = 8$). Of the six US participants with positive experiences, four obtained rehabilitation through the VA system, while the other two had private insurance. Aspects that both groups mentioned include good specialist care, physiotherapy/occupational therapy resources, regular follow-up post-discharge, and access to on-demand advice/support. In addition, British participants talked about the importance of social activities and peer support received during rehabilitation, and adequate support in transitioning home (coordination with social services).

Wheelchair provision

Both groups ($N_{US} = 7$, $N_{UK} = 5$) experienced negative wheelchair provision; however, the problems differed by country. US participants talked about receiving no assessment (such as pressure mapping, measurements, consideration of home environment, and post-discharge aspirations); no information about the range of wheelchairs, cushions, and accessories available for their level of injury; no wheelchair training; and little wheelchair maintenance. More than half of the US group felt burdened by excessive bureaucracy when seeking wheelchairs and related accessories.

They gave me a wheelchair that was absolutely unusable. I have rheumatoid arthritis, it was too wide and I did damage to my shoulders trying to get around in it. I had no pressure mapping, no evaluation, I did the research myself, it was an absolute nightmare (US-F4).

In the UK sample, there was only one mention of inadequate wheelchair training. Problems related mostly to lack of consideration for caregiver needs (e.g., wheelchair heavy to handle), limited availability of free outdoors/off-

road wheelchairs through the National Wheelchair Service, and perceived exorbitant pricing by private wheelchair providers.

Positive wheelchair provision experiences ($N_{US} = 5$, 3 of whom went to a VA hospital, and $N_{UK} = 8$) also differed by country. In the US, it related to whether they were assessed in-hospital or at a mobility store when the wheelchair was selected, receipt of chair that the participant felt was adequate for their condition and needs, and to having the financial means to purchase the latest desired models. In the UK, it referred to having received assessment, such as pressure mapping (i.e., assessing the distribution of a body's downward pressure on a seating surface to determine the asymmetry of weight distribution and pressure points of concern) at rehabilitation center, at NHS Wheelchair Center, or in a mobility store; having received a free wheelchair through National Wheelchair Service; having received multiple wheelchairs to meet diverse needs (e.g., an outdoor chair, an indoor chair); having a spare wheelchair (in case of mechanical failure); and receiving assistance through the Access to Work scheme (such as chairs, accessories, or adapted cars).

Primary care experience

Both groups ($N_{US} = 7$, $N_{UK} = 4$) mentioned negative experiences with primary care provision, describing uncaring physicians, as well as general physician inexperience in dealing with SCI. Differences emerged regarding having no access to primary care because of lack of insurance (US only), perceived ineffective medical care (US only), refusal by a primary care doctor to keep a patient in the doctor's primary care panel after SCI occurred (US only), and difficulties with arranging home visits (UK only).

I made a phone call, told him what had happened, told them that I was now a T10 complete, and asked him if he was OK to treat me, as a guy who was a paraplegic. And he told me No, he wasn't, he would much prefer it if I went and found someone else. So that attitude alone made me look for someone else (US-M1).

I broke my leg once, and rather than go to the hospital here, I drove myself 40 miles down to the spinal injuries unit. I knew they would understand and would be able to treat me better. Whenever I broke my leg up here they insisted that they do a full-leg plaster cast on my leg. I have a huge mistrust of the GPs and the mainstream system (UK-M4).

Interviewees in both groups ($N_{US} = 4$, $N_{UK} = 6$) mentioned positive experiences with similar aspects of primary

care: care coordination, proactive in facilitating access to specialists, follow-up with care and appointments, and involving them in medication management.

Caregiving at home

Half of the participants in both groups ($N_{US} = 5$, $N_{UK} = 5$) remarked on the importance of receiving good quality care at home. Those who receive care from their spouse or other family members talk about the importance of specialist training for their caregivers:

The VA trains your caregiver for things, bowel management programs, they make sure that you're not going home to somewhere that you are not going to be taken care of (US-M3).

K. was very good at learning and asking the staff to teach her the best ways to do this sort of thing, so we have always kept that very much as the top priority. She took a number of caregiving courses while I was in hospital. She was always asking questions about what's best, how best to do this how best to do that. I think the staff were always willing to teach her as well (UK-M2).

Factors contributing to QOL: functional adjustment

All participants mentioned physical and mental function (including perceiving, thinking, memorizing, and reasoning) as factors contributing to their QOL. The subthemes emerging were as follows: mental adjustment post-discharge, impact of SCI on physical and mental function, SCI-related complications, consequences of aging with SCI, fatigue (physical and mental), SCI knowledge post-discharge, home adaptations, and public infrastructure.

Mental adjustment post-discharge

All participants ($N_{US} = 10$, $N_{UK} = 10$) talked about difficulties adjusting mentally to life with SCI immediately after their discharge from rehabilitation. Both samples mentioned feeling shocked, anxious, sorry, helpless, self-conscious, having doubts about self-worth, being in denial, accepting the injury, and expecting to improve.

Both groups also talked about a range of fears: fear of health complications, fear of institutionalization (i.e., going back to hospital, to rehabilitation, to a nursing home), fear of not being able to provide for oneself and the family, and fear of uncertainty (i.e., staying married, having children, housing).

Difficulties in adjustment were ameliorated by family support during transition from rehabilitation to home (e.g., managing logistics, moral support), an individual's pre-injury mindset (e.g., independence, optimism, not dwelling on negatives), and having the right home adaptations (e.g., having correct wheelchair ramps, showering facilities).

Impact of SCI on function (physical and mental)

The impact of the injury on daily function was another issue addressed by all study participants ($N_{US} = 10$, $N_{UK} = 10$). The most cited issues affecting physical and mental function were bladder and bowel (sphincter) management ($N_{US} = 7$, $N_{UK} = 10$), pain ($N_{US} = 7$, $N_{UK} = 5$), mobility ($N_{US} = 6$, $N_{UK} = 4$), spasticity ($N_{US} = 2$, $N_{UK} = 4$), sitting tolerance ($N_{US} = 2$, $N_{UK} = 2$), and lack of sensory ability ($N_{US} = 2$, $N_{UK} = 1$).

Your life revolves around your bowels (US-M5).

I need help with my bowel care and bladder care. That is the absolute essence, that's the only thing that dictates my lifestyle now (UK-M3).

Fatigue (physical and mental)

Interviewees in both countries ($N_{US} = 6$, $N_{UK} = 8$) talked about differentiating between physical and mental fatigue. Physical fatigue was defined as reduced physical function due to wear (joints, shoulder, back), disease, or SCI-related issue (pain, spasticity). Mental fatigue refers to reduced mental function resulting from perceived high-level of stress, worries about the future, perceived need for extensive logistical planning, and perceived bureaucratic burden (e.g., filling out applications to receive health care, social support, disability-specific services, etc.).

SCI knowledge post-discharge

Nearly all participants ($N_{US} = 9$, $N_{UK} = 10$) talked about how they acquired knowledge about SCI and life post-discharge. Although all study participants talked about learning from their lived experience, there were marked differences in knowledge acquisition. In the US group, nine participants described how they did not receive adequate information about SCI (what it is, levels of injury, types of care), basic self-care (such as managing bladder and bowels, skin management), wheelchair training (such as transferring) and wheelchair provision (understanding their own wheelchair needs), and sexual function and intimacy. Six individuals in this group indicated that they had to resort to the internet and online peer support to find out

about SCI, understand their own needs, and perform certain activities (particularly bowel management, wheelchair transfers, and dressing oneself).

Your family tries to Google everything, but you get three different answers for the same question (US-M3).

I learned to transfer and get my clothes on, through YouTube videos (US-M5).

Seven UK participants mentioned receiving sufficient information about prevention of complications (e.g., skin management), wheelchair training, bladder and bowel management, and diet and nutrition advice. The other three talked about the lack of receiving specific information during rehabilitation.

Home adaptation

Both groups ($N_{US} = 8$, $N_{UK} = 10$) mentioned home adaptation—that is, layout and structural modifications made to a home to facilitate access (e.g., ramps), personal hygiene (e.g., showering, grooming, dressing), and activities such as transferring in/out of bed, using a wheelchair, cooking, and working. In the US group, four participants said their homes were still not adequately adapted for their needs: not having ramps, no access to basements or upper floors, inaccessible bathrooms, narrow doorways, not enough space to maneuver wheelchairs, and not being able to get in and out of bed with ease.

Where I am living now, the bathroom is on the second floor. That means I cannot really have guests in, because I use a potty chair which is in my kitchen, because that is the only way I can empty it, that's the only place to do it, in the kitchen (US-F4, 7 years since injury).

The entire UK group reported that their homes were adequately adapted to their needs, including ramps, wet rooms (bathrooms that facilitate open showering in a wheelchair, with central, sunken drainage, wall and floor tiling), and other assistive technologies. Three British interviewees added, however, that at the time of their injuries (in the 1970s and 1980s) they had to wait between one and five years to have their places adapted.

SCI-related complications

Both groups ($N_{US} = 10$, $N_{UK} = 10$) talked about complications related to their SCI because of poor management of skin care (pressure sores), blood pressure (persistent hypotension), bladder (chronic urinary tract infections), and bowel (bowel obstruction).

My pressure sore was 9 cm long and 7 cm across and 3 1/2 cm deep. And this is on the tailbone, so you can imagine that part of my tail bone was sticking out. So 11 and 1/2 months later I finally pulled the thing off, and a month later it healed (US-M1).

Does low blood pressure bring on fatigue or does fatigue bring on low blood pressure? I don't know but both of them happen simultaneously. It's just wanting to go. I shut myself away a bit and recharge (UK-M3).

Consequences of aging with SCI

Participants in both groups ($N_{US} = 9$, $N_{UK} = 9$) talked about not only consequences of aging with SCI, and how it affects their function in terms of diminishing physical function (deterioration in upper-body strength, range of movement, wear and tear, weight gain), but also fear of loss of (caregiving) family and friends, fear of loss of housing, and fear of institutionalization.

After 50 years of SCI, my arms or my shoulders are not a lot of fun. I literally don't sleep. At the moment I laid down on my arms or shoulders, I'm in a lot of pain. It is bad so I literally will sleep sitting up (US-F1).

My muscle spasms have increased over the years as I got older, they've got worse. Also, getting tired really easily, and after a particularly busy day I do feel particularly tired the next day (UK-M2).

Public infrastructure

More than half of the sample ($N_{US} = 6$, $N_{UK} = 6$) discussed public infrastructure. The US group talked about positive aspects, such as wheelchair accessibility on public transit (bus), and having wheelchair-adapted cars and vans. They also mentioned such negative aspects as inaccessible car parks, cinemas, public transit, and even inaccessible hospital transportation.

I think the environment disables me (US-F1).

I can't get VA transportation here, because the VA system has vehicles for those who can ambulate but not the handicapped, so no lifts for chairs. So I am at a disadvantage (US-M5).

British participants mentioned positive aspects such as support when traveling by train and airplane, having access to wheelchair-adapted cars and vans. They too talked about negative aspects, such as accessibility issues on streets, in supermarkets and smaller shops, primary care facilities, hotel rooms, pubs, and sports facilities.

There's no facilities in the surgery for a paraplegic or somebody who's paralyzed from the chest down to be able to transfer from the chair onto like a consultancy table. It's too dangerous (UK-M1).

Factors contributing to QOL: financial resources

Positive financial status consisted of having enough money to support oneself and/or family (housing, utility bills, including heat), and provide for one's health and rehabilitation needs (wheelchair provision, home adaptation, adapted transportation, and assistive technologies). This was typically associated with being independently wealthy before the injury ($N_{US} = 2$, $N_{UK} = 1$), receiving a settlement after the injury ($N_{US} = 1$, $N_{UK} = 4$), or continuing to work after the injury ($N_{US} = 4$, $N_{UK} = 6$). (There is overlap between these categories, that is, some who received a settlement in the UK continued to work, and some who were independently wealthy in the US continued to work.)

In the US sample, participants emphasized negative financial status, that is, having insufficient money to support oneself and/or family, and provide for one's health and rehabilitation needs. This was typically associated with being disabled and unable to work, being retired, and receiving no settlement ($N_{US} = 5$). Also notable is that outside the VA system, individual health insurance status determines out-of-pocket payment for care and rehabilitation, for receipt of assistive technology, support with housing adaptations, etc.

With universal provision of medical and social care, the UK stands out because health care and rehabilitation are free at the point of need, wheelchair provision is free at the point of need, and in most cases, care coordination between specialist centers and social services ensured a standard level of provision regarding home adaptations and assistive technology. For instance, three UK participants were too disabled to work, two of them received settlements back in the 1980s, as well as continuous government support with care and rehabilitation, so they experienced a positive financial status. In the UK, negative financial comments were related to expensive disability products and services on the private market ($N_{UK} = 2$), and generally financial concerns are on an altogether different level.

Factors contributing to QOL: socio-political context

Study participants talked about socio-political factors: issues regarding society at large were family attitudes to SCI, social relationships, other people's attitudes to disability, and government policy.

Family attitudes

All participants talked positively about family attitudes to SCI post-injury. Family attitudes were positive for both groups and manifested themselves through moral, financial, and logistical support.

When I became spinal cord injured I didn't go to rehab. My father went, and it was full of old people, and he said 'That's going to break her spirit, she cannot go there'. So we did it on our own (US-F1).

My dad's a builder and he actually built me a self-contained sort-of flat that I could move into. So I had a place to go to (UK-M8).

Social relationships

Most participants ($N_{US} = 9$, $N_{UK} = 8$) spoke of the role social relationships played in their lives. While some cited positive social experiences ($N_{US} = 4$, $N_{UK} = 8$), such as friends being inclusive, supportive, and accepting of the situation, participants also recalled negative experiences ($N_{US} = 5$, $N_{UK} = 1$). The most common negative experience was abandonment after injury.

Attitudes towards disability

More than half of the participants ($N_{US} = 7$, $N_{UK} = 4$) mentioned attitudes to disability as a factor affecting QOL, particularly lack of understanding of disability, failure to consider the needs of people with disabilities, infantilizing adults with disabilities, biased media representation of disabled people, disenfranchisement (e.g., being deprived of access to care or public spaces), and predatory behavior by commercial providers.

Not many people know people with SCI, they don't! So it's got to be done on television. And how many times have you read an article where they talk about being wheelchair-bound? I am wheelchair enabled, I am not bound. The stereotypes are so ingrained, so part of the public psyche, that the language is all over the place (US-F1).

I almost feel that a lot of companies prey on the vulnerable, which really frustrates me, with regards to disabled equipment, especially wheelchairs. I'd be able to buy a top of the range BMW with the price that I paid for my wheelchair. Which, for me, I just don't get really, which is why it's very frustrating, just unfair really (UK-M8).

Government policy

A quarter of participants ($N_{US} = 3$, $N_{UK} = 5$) mentioned ways in which government policy affected QOL. In the US, three participants were highly critical of government policy towards people with disabilities.

Anybody who does not fit into the bell curve, those of us on the fringes of society, those of us with a disability, which is a big cauldron of worthlessness, because there's no distinction to it. What I need is not what somebody with autism needs. And the government made that determination. Nobody asked us. So it's gotten so diluted, that nothing gets done. Nothing (US-F1).

In the UK, three participants mentioned universal provision of medical and social care as a positive experience, while two recalled instances of discrimination during the 1980s in education provision and commercial services.

I went to the cinema in my wheelchair and when I was told to get out of my wheelchair I refused, then they called the police and I was thrown out (UK-M3).

Discussion

The findings in this study are supported by previous studies on adults with SCI, especially the lifetime changes in priorities of QOL [36, 37]. Domains of HRQOL (physical, mental, and social functioning) stand out in this study as key contributors to QOL in the context of SCI.

There were differences in the demographic and clinical characteristics of the two groups: 90% of the UK group were male versus 60% of the US group. The US sample had a higher median age at injury (38 years) than the UK sample (20 years), and a more recent time since injury (8 years vs. 32 years). The etiology distribution is also different across groups: 40% of US sample acquired SCI through disease, compared with only 20% of the UK sample. Finally, the UK group did not include anyone with incomplete quadriplegia. Being injured when younger and having lived with the injury for longer could affect views on QOL and adjustment to life with an SCI. But changes in views about what mattered most in relation to QOL were mentioned both by those with relatively short time since injury (e.g., US male, 9 years) and those with longer lived experiences (e.g., UK male, 34 years). We also captured concerns about aging with an SCI, which were mentioned both by younger participants (e.g., US male, 32 years old, injured at 23) and aging participants (e.g., UK female, 60 years old, injured at 49). Half or more participants in each group discussed most themes and subthemes that

emerged in the study, so it does not appear that clinical differences between the groups were a driving factor for differences of opinion or experience.

In both groups, the individuals who appeared to find it more difficult to adapt to SCI were those with very physically and socially active life-styles pre-injury. This suggests that perceived QOL and adjustment to life with SCI may rest in part on individual capacity and disposition to disregard the impact of the SCI on physical health and functional activities.

Factors affecting QOL also resemble to a degree those found in other studies, but this study is different because the findings emphasize the centrality of medical care as an influence on QOL to a much greater extent, both in the US (predominantly negative influence) and in the UK (predominantly positive influence). In the US sample, the negative influence appears to be linked to fragmented primary and specialist care, rehabilitation and wheelchair provision contingent on insurance, and an overwhelming bureaucratic burden on each person to secure basic care, rehabilitation, goods (such as wheelchairs), and services (e.g., home care). In the UK sample, the influence is predominantly positive, because of the advantages and benefits of universal provision, including free and continuous care, free provision of goods (wheelchairs) and services (home care), and length of rehabilitation in relation to level of injury.

This study produced several unexpected findings. First, it was surprising to see how commonly problems with patient–physician communication regarding SCI and life with SCI were reported. UK patients appeared to be better informed upon discharge than their U.S. counterparts. The latter were poorly informed regarding SCI (what it is, levels of injury, types of care), basic self-care (such as managing bladder and bowels, skin management), wheelchair training and wheelchair provision (understanding their own wheelchair needs). Lack of knowledge was consequential for daily functioning, particularly how to manage bladder and bowel, how to safely transfer to and from wheelchairs, and how to approach intimate relationships.

Second, the findings reiterate the importance of physical and mental fatigue as a functional impairment, and the absence of fatigue from discussions between medical providers and patients. This aligns with findings from previous studies, but further investigation into how to measure and manage fatigue is needed [38–40]. Third, the findings hint at the importance of home adaptations for QOL. The differences between the two groups point to the role of individual financial resources in the US to secure provision for basic adaptive needs such as ramps.

Furthermore, US participants' narratives about medical care that is constrained by insurance provision, the practice of discharging insufficiently rehabilitated persons to

inaccessible homes, and insufficient knowledge and training about daily life with SCI, raise serious ethical and policy implications. However, given the small and likely unrepresentative sample in this study, more research on a national scale is needed to ascertain the extent of these issues in this population.

An important insight is gleaned from the use of newer communications technologies such as Skype/FaceTime to conduct in-depth interviews. This approach addresses one of the traditional shortcomings of in-depth qualitative research, which is limited in geographic scope, by enabling remote data collection and broadening the pool from which participants are recruited. Another advantage of remote interviewing is gaining access to participants who otherwise may not consent to having a stranger in their home, either out of fear, or embarrassment (particularly because of bladder/bowel accidents), or discomfort (e.g., having to transfer out of bed several times to accommodate the interviewer). Skype/FaceTime limits the content of field notes regarding an interviewee's home environment, but still enables eye contact and interpretation of upper-body language (attacks of spasticity, upper-body strength and dexterity). Moreover, many video cameras are mobile, and several interviewees repositioned them to show issues with wheelchair cushions, or narrow doorframes for example. In the US sample, two participants were interviewed face-to-face and eight via Skype. We did not identify differences in the scope or depth of information provided by the two in-person interviewees versus those interviewed remotely. A disadvantage of not using remote interviewing in the UK is that we do not have a similar basis of comparison for the two interviewing methods in that sample. Considering the access to and wealth of information gained from individuals who may be otherwise difficult to reach, this trade-off is acceptable. Given the research questions and aims of the study, limited field notes about some participants' home environments do not undermine the validity of the findings. Other researchers have outlined the opportunities of harnessing modern communications technology, such as Skype, in conducting qualitative research [41, 42].

A key limitation of the study is sample representativeness. Although use of newer communication technologies has broadened the scope of participant recruitment, the extent to which these participants represent those with SCI in their respective countries is unknown. Self-selection and access to a computer bias the sample against participants who do not have access to such technology. Another limitation is the low remuneration offered, which may have discouraged participation. Hence, the results reported here need to be examined further in future studies. Strengths of this study include the broad range of injury levels (especially two adults on ventilators), complete and incomplete injuries, the broad geographic scope (two countries, with broad geographic

representation in each), and the diverse professional backgrounds of the participants: professionals with post-graduate degrees, musicians, athletes, artists, blue-collar workers, veterans, unemployed, and retired individuals.

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Authors' contributions AP 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. RDH was involved in conception and design, interpretation of data; revised the article critically for important intellectual content; involved in final approval. WJC was involved in conception and design, interpretation of data; revised the article critically for important intellectual content; involved in final approval. AVB 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.

Compliance with ethical standards

Conflict of interest The authors have no conflicts of interest to report.

Research involving 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.

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