Research Article

Contextualizing the lived experience of quality of life for persons with spinal cord injury: A mixed-methods application of the response shift model

Edward J. Rohn¹, Denise G. Tate¹, Martin Forchheimer¹, Lisa DiPonio^{1,2}

¹Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan, USA,

²Veterans Administration Ann Arbor Healthcare System, Ann Arbor, Michigan, USA

Objective: The objective of this study was to gain greater insight into individuals' quality of life (QOL) definitions, appraisals, and adaptations following spinal cord injury (SCI).

Design: A mixed-methods design, applying the Schwartz and Sprangers response shift (RS) model. RS is a cognitive process wherein, in response to a change in health status, individuals change internal standards, values, or conceptualization of QOL.

Setting: Community-dwelling participants who receive medical treatment at a major Midwestern medical system and nearby Veterans' Affairs hospital.

Participants: A purposive sample of participants with SCI (N = 40) completed semi-structured interviews and accompanying quantitative measures.

Interventions: Not applicable.

Outcome Measures: Qualitative data were analyzed using content analysis to identify themes. Analysis of variance were performed to detect differences based on themes and QOL, well-being, and demographic and injury characteristics.

Results: Four RS themes were identified, capturing the range of participant perceptions of QOL. The themes ranged from complete RS, indicating active engagement in maintaining QOL, to awareness and comparisons redefining QOL, to a relative lack of RS. Average QOL ratings differed as a function of response shift themes. PROMIS Global Health, Anxiety, and Depression also differed as a function of RS themes.

Conclusion: The RS model contextualizes differences in QOL definitions, appraisals, and adaptations in a way standardized QOL measures alone do not.

Keywords: Spinal cord injury, Quality of life, Response shift, Neurogenic bladder and bowel, Patient experiences, Qualitative research, Mixed methods research

Introduction

Spinal cord injury (SCI) alters the ability to function in daily life, which can lead to other health-related consequences. These challenges can negatively impact quality of life (QOL).¹⁻³ In turn, decreases in QOL can negatively influence social and physical well-being and treatment outcomes.⁴⁻⁶ There is considerable research on the impact of SCI on QOL, often focused on supportive strategies for assisting those with SCI to

survive, adapt, and thrive.⁷⁻⁹ However, what is less well understood is how individuals with SCI actively attempt to preserve QOL; what specific strategies, cognitions, and adaptations they utilize.

Recent studies have revealed complicated relationships between demographic and injury characteristics and QOL.^{7,10} In one study, time since injury was shown to impact QOL, as adjustments over time lead to adaptive changes in outlook.¹¹ Another study revealed how QOL decreased for persons with long-standing SCI, due to increased rates of comorbidities.⁹ Another demonstrated how QOL was unaffected by time; rather functional attainment, secondary conditions, and participation were predictive of QOL.⁷

Correspondence to: Edward J. Rohn, Department of Physical Medicine and Rehabilitation, University of Michigan, 325 E. Eisenhower Parkway, Suite 300, Ann Arbor, MI 48108, USA. Email: ejrohn@med.umich.edu

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Neurological level of impairment showed fewer differences in overall QOL between those with paraplegia and tetraplegia,¹² though those with incomplete injuries often experienced more pain, heightened depression, and lowered QOL.¹³ Changes in health status due to secondary complications after SCI (*i.e.* pressure ulcers, bowel incontinence episodes),¹⁴ new comorbidities (*i.e.* diabetes, cancer),⁹ emotional or social challenges (*i.e.* depression, anxiety, divorce)^{13,15} have all been shown to place additional strain on SCI-related coping and adaptation.

Bladder and bowel dysfunction are critical issues for persons with SCI, significantly impacting QOL.^{14,16} In a study of veterans, bowel-related problems were rated second highest in terms of interference with important life activities.¹⁷ Bowel complications are worsened by level of injury (incomplete tetraplegia), medication use, and access to physicians,¹⁸ with one cross-sectional study showing how bowel function worsened over time, leading to decreased QOL.¹⁹ Further, bladder and bowel management decisions are impacted by peer opinions on treatment options, embarrassment over the use of urine bags, or confidence in one's ability to self-catheterize.^{20–22} Clinical evidence also suggests that persons with SCI often have difficulty maintaining social relationships due to fear of bowel and bladder accidents.²³

Studies of QOL in SCI have often relied on standardized measures,^{6,24} not well-suited for explaining the interplay between complex factors influencing QOL experiences. Qualitative methodologies are better suited for exploring the open-ended ways in which those with SCI respond to their circumstances in the broader contexts of their lives, contextualizing the ways in which they understand and define QOL.^{25,26} A synthesis of qualitative studies on SCI QOL revealed a number of impactful factors, including embarrassment around bodily functions, social relationships, environmental context, and changes in values and perspective.²⁷ These sorts of individualized factors shape QOL beyond injury characteristics. However, factors alone do not demonstrate how each person's physical, psychological and social contexts overlap and change over time. Allowing participants space to freely explain cognitions and experiences allows for a more thorough understanding of active ways persons with SCI approach their QOL.

The purpose of this study was to examine QOL changes in relation to SCI-related challenges, by exploring participants' points of view. The goal was to expand understanding of QOL as it is experienced; to gain greater insight into individuals' QOL definitions,

appraisals, and adaptations following SCI. Qualitative data illuminated the ways in which participants with SCI actively defined and maintained QOL. Triangulating qualitative and quantitative data provided narrative contexts to numerical responses, providing stories behind the numbers.

Methods

Data presented are derived from a mixed methods study on bladder and bowel dysfunction, seeking to understand bladder and bowel management factors and their influence on QOL. Findings here represent substantive outcomes of the larger study.

Theoretical framework

The response shift (RS) model guided analysis, selected due to its ability to richly conceptualize responses of people facing health-related challenges. RS is a cognitive process where, in response to a change in health status, individuals adjust internal standards, values, and/or conceptualization of QOL.²⁸ The model is founded on broader models of change, building on the stress and cognitive appraisal model.²⁹ Its strength lies in its ability to interpret paradoxical findings, where severe chronic illness does not invariably lead to lower QOL scores.¹¹ RS interposes a layer of nuance between the stimulus of severe health conditions and QOL outcomes, one that accounts for individual context and changes over disease trajectory.^{11,30}

The model utilizes three criteria. These include:

‘(a) a change in the respondent's internal standards of measurement (scale recalibration, in psychometric terms); (b) a change in the respondent's values (*i.e.* the importance of component domains constituting the target construct); or (c) a redefinition of the target construct (*i.e.* reconceptualization).’³¹

The model has five major components: (1) a catalyst, (2) antecedents, (3) mechanisms, (4) response shift and (5) perceived QOL. The *catalyst* in the present case is SCI. *Antecedents* refer to individual characteristics (e.g. sex, level of injury, time since injury, resources). *Mechanisms* refer to behavioral, cognitive, or other processes used to accommodate the catalyst (e.g. coping strategies, social comparisons, seeking social support, reframing expectations). *Response shift* is a change in what QOL means, based on the criteria above. *Perceived QOL* is one's current definition of QOL through subjective appraisal; the outcome of responding to the catalyst by employing one's own mechanisms (Fig. 1).^{11,32}

Figure 1 Model of response shift and quality of life (QOL).

An example from the authors of RS may facilitate understanding. Schwartz and Sprangers recount a woman diagnosed with osteosarcoma. She told her surgeon that if her bone tumor prevented her from being able to walk, life would no longer be worth living. When later confined to a wheelchair, she said her life still held value, but if she became incontinent, then life would no longer be worth living. However, when she became incontinent and bedridden, she vehemently held that life still held meaning for her. Her internal standards, values and conceptualization of QOL changed to accommodate her illness.³⁰

Participants

Participants (N = 40) were recruited through a major Midwestern medical system and a nearby VA hospital. Institutional review board approvals were obtained. Participants were consented and all reasonable efforts taken to protect confidentiality. A purposive, representative sample of time since injury (TSI) and neurological level of impairment was sought in order to capture a range of participant experiences. Given the low sample size and the SCI population in the community, other discrete characteristics (e.g. sex, race) were not evenly sampled. Table 1 illustrates sample distributions.

Table 1 Participant demographic and injury characteristics.

Composition	N	Percent
Sex		
Male	32	80%
Female	8	20%
Race/ethnicity		
Caucasian	33	82.5%
African-American	4	10%
Hispanic	3	7.5%
Level of injury (self-reported)		
Paraplegia	23	57.5%
Tetraplegia	17	42.5%
Time since injury (at time of interview)		
< 1year	10	25%
> 10years	30	75%

Data collection

Semi-structured qualitative interviews were conducted privately with each participant and lasted 60–90 minutes. Interviewers were doctoral-level medical anthropologists, highly-trained in qualitative interviewing techniques and well-versed in psychosocial issues of SCI. Questions were open-ended to allow participants' own thoughts to emerge. A sample of interview questions appears in Appendix A. Interviews were audio recorded and transcribed. Text transcripts were coded using qualitative data analysis software (NVivo10).³³

Standardized measures were administered to each participant, designed to provide context for qualitative data. Measures were administered by an expert in administering SCI-related measures; a nurse with three decades of SCI research experience. Chosen outcomes included general and injury-specific demographic information, bladder and bowel treatment methods (BBTI),³⁴ specific health behaviors (Bladder and Bowel Behavioral Management Questionnaire),³⁵ global health, anxiety, and depression measures (PROMIS),³⁶ and SCI-specific measures of QOL, complications, and social roles (SCI-QOL).⁶ Measures were administered by phone. Data was entered into a secure web-based capture tool (REDCap)³⁷ and analyzed using SPSS v22.³⁸

Analysis

Qualitative data were analyzed using content analysis. First, a closed set of topical codes, derived from the RS model, were applied to the interview transcripts (i.e. catalyst, antecedents, mechanisms, response shift, perceived QOL) by trained coders. The coded text from each code was then extracted. Three investigators (one anthropologist, one psychologist, and one statistician) independently read the coded text, to gain familiarity and begin identification of themes. The readers met to discuss initial thoughts and preliminary themes. The extracted text were then placed into a matrix, a table

organized by columns representing RS codes and rows representing individual study participants. The text in each cell was then paraphrased by the medical anthropologist on the team, rendering the dataset more manageable, while retaining the meaning and intent from each respondent.^{39–41} Paraphrasing involved removing repetitious phrases and extraneous utterances (e.g. “um” and “er”) from the text, followed by careful redaction of extraneous comments, explanations, and long-winded passages. In this way, coded text was reduced to focused statements, capturing the salient topics from each participant.

Themes were identified using pile-sorting.^{39,42,43} Individual participants' rows from the matrix were sorted into piles, based on narrative similarities. Sorting was conducted individually by the first and second authors, who then met to discuss and resolve discrepancies in their respective piles until consensus was reached. When a participant's narrative may have fit into multiple piles, the authors identified the pile into which each narrative most-closely belonged. This process resulted in four piles, representing the dominant themes in the data. Definitions were then crafted to describe each theme, including inclusion and exclusion criteria used for pile-sorting. The resulting four RS themes are discussed below.

Finally, statistical analyses were conducted by the third author, with a background in psychometrics and biostatistics. Analyses assessed relationships of RS themes to assessments of QOL, well-being, demographic and injury-related characteristics, using chi-squared tests and analysis of variance. Results of these analyses are described below.

Results

Four themes illustrate the types of cognitions, emotional appraisals, and behavioral changes within the data. Themes included (1) behavior-driven (*i.e.* taking an active role in responding to SCI), (2) awareness-driven (*i.e.* focusing on sense of self-worth and identity), (3) social comparison (*i.e.* comparing circumstances to those of others), and (4) resignation and despair (*i.e.* being ‘stuck’ or giving up).

Behavior-driven response shift

Narratives indicating behavior-driven RS (N = 9) indicated determination in redefining social roles, often finding and maintaining employment or discovering new ways to contribute. Participants accepted they could no longer do the same daily tasks, but sought new activities, or support for resuming old life activities. They reconceptualized their life roles and found

empowerment despite setbacks. They tended to ‘see the positive’ and demonstrated self-efficacy in decision-making. They rarely mentioned bladder and bowel management complications.

For example, a 56-year-old white male with tetraplegia, commented he could ‘spend time with the boys, teaching them how to cook dinners, to become more responsible’. He defined his QOL and wellbeing by what he could perform as his new ‘job’ – ‘to take care of yourself and continue to be as strong as possible’ so ‘as a family, we are able to do things’. He did lament the loss of spontaneity, and acknowledges ‘I can’t do everything that I once did’ but remained focused on his new role. Table 2 illustrates additional narratives fitting this theme.

Awareness-driven response shift

Those demonstrating awareness-driven RS (N = 12) did not reference behaviors that would directly improve or maintain QOL, but rather focused on positive emotional and cognitive self-assessments. Their statements showed positive affect, including ‘becoming a better person,’ ‘growing up’ or ‘being in a good place’. They cited strong family support and optimism. Overall, this theme reflected a normalizing of experiences, positive reframing, supportive environments, and ‘blessings’, rather than self-determination or goal-setting. Bladder and bowel management and complications were framed as manageable obstacles.

For example, a 50-year-old white male with paraplegia, commented ‘I suppose like anything else, you just get used to things the longer they go ... my wife would call that my pragmatism’. He mentioned accepting limitations; to ‘not waste my effort on things I don’t have control over’. He cited using energy efficiently, recognizing limitations, and not thinking about how his life could have been otherwise. Instead, ‘I’ve got no real problems ... so I’ve really got nothing to complain about ... I’m just looking at what I’ve got and I’ve got a lot’. Cognitive reappraisals were the chief response by which he reframed and maintained his QOL. Table 2 illustrates additional narratives fitting this theme.

Social comparison

Similarly, those demonstrating social comparison (N = 12) recalibrated their sense of normalcy, finding acceptance through comparing their circumstances with other people or events, either real or imagined. Some talked about ‘learning to live’ with SCI and citing emotional efforts to maintain a clear sense of self. Mentions of both depression and hope for the future were common. Life was framed as neither all good,

Table 2 Response shift narrative examples.

Theme	Participant	Narrative Quote
Behavior-driven	52-year-old white woman with tetraplegia, injured 17 years ago. Now divorced, but unrelated to SCI. Obtained PhD in Rehabilitation Counseling.	I'm totally empowered; I love what I do ... I've achieved everything that I wanted to achieve in my life and more. I've actually exceeded my expectations of what I thought my life would be.
	48-year-old black man with paraplegia, injured 26 years ago. Professional photographer. Married with two children. Served in the military.	I wouldn't change anything. I got two wonderful boys. I've been married over 20 years. My life is perfect ... Once I conquered dealing with the bladder and the bowel ... I never looked back.
Awareness-driven	43-year-old white man with tetraplegia, injured 24 years ago. Unmarried but has supportive family – sister and parents – who act as his caregivers.	... you start looking through a different window. It's not what it was ... and we're going to be in misery for a long time ... Took me two years. I beat my head off shit for two years. Didn't happen overnight.
	45-year-old white man with tetraplegia, injured 20 years ago. Married. Has a military background, though seldom mentioned. Injury inspired him to go to college.	I still write left-handed, I still put pants one leg at a time ... I still like doing the same things I just have to do them differently ... this is what I have to live with and I'm too young to sit here and rot.
Social-comparison	45-year-old white woman with paraplegia, injured less than 1 year prior. Her husband is her caregiver. Both have additional health complications and financial challenges.	I think that kind of made me feel like 'Oh my God, why did this happen to me?' ... but there was people that was worse off than me ... Okay, I should be just thankful that I'm here and I can move ...
	62-year-old black man with paraplegia, injured 28 years ago. Unemployed but with supportive family, including 3 sons. Credits health to the VA for taking good care of him.	... it could be a lot worse ... some guys in wheelchairs they confine themselves away from people ... But I'm not that type ... I still knew who I was in the wheelchair ... not like I'm living in it, I'm just using it.
Resignation and despair	55-year-old white man with paraplegia, injured less than 1 year prior. Married. Able to walk with a cane. Has had considerable financial difficulties since injury.	I used to fear the future even when I had everything in the world going for me ... now I don't even think about it ... to think that I'm going to live the rest of my life like this is not good ...
	72-year-old Hispanic man with tetraplegia, injured 29 years ago. Retired for Ford Motor company. His wife and other paid aids help with his care. Served in the military.	... when I was born, that was the route that was already made for me. And this is the way, I have to stay like this and there was nothing I could change. You either accept it or deny it and then just be miserable ...

nor all bad, but somewhere in the middle. These participants actively compared their circumstances with larger global possibilities or with others they knew. They exhibited a strong sense of identity and personal values as compared to those expressing greater awareness-driven response shift. Some cited bladder and bowel management challenges and complications as a direct negative impact on their QOL.

For example, a 55-year-old white female with paraplegia, commented 'I marveled at the ones that would get up, get dressed and make it to work every morning,' suggesting her comparisons urged her on to overcome her own limitations. As a former police officer, she reflected on how she 'could have gotten shot and killed 20 years ago ... things happen to everybody'. She cited having to deal with her injury, to put herself 'out there' to overcome her limitations. Her comparisons with others and with what 'could have been worse' were the chief mechanisms by which she framed her experiences and retained her sense of self: 'I'm still very confident ... and I've been lucky'. While she could frame her circumstances clearly through comparisons, she demonstrated little active behavioral

change. Table 2 illustrates additional narratives fitting this theme.

Resignation and despair

Those demonstrating the resignation and despair theme (N = 7) presented a clear sense of being 'stuck,' with little or no apparent RS. Many espoused fear or ambivalence for the future. Most focused their comments on loss of mobility and independence, with little or no talk of self-determined actions to improve and maintain QOL. Personal goals and expectations were not redefined except when they had been abandoned. QOL was framed in either a resoundingly negative way or with ambivalence, suggesting resignation: e.g. 'that's just the way it is'. Some suggested they ignored their health-related or social problems, including avoiding social engagements, as a direct result of their injury and/or bladder and bowel management issues.

For example, a 64-year-old white male with paraplegia, commented 'It was pretty devastating but I had no choice and I had to adapt'. This attitude might suggest some RS had occurred, but his adaptation reframed his expectations negatively. He decided to

‘accept it and move on’ and characterized his QOL in a positive light, because ‘I don’t care anymore’. Rather than taking efforts to maintain or reprioritize his QOL, he lowered his expectations and resigned himself to a life without the activities, opportunities, and independence he once had. While remaining happy, and therefore not in despair, there were others who demonstrated worse negative affect regarding their injury. Table 2 illustrates additional narratives fitting this theme.

Triangulation with quantitative data

Average QOL ratings differed as function of response shift themes ($F = 3.479$, $P = .026$); those with behavior-driven themes had the highest QOL (8.28 out of 10) and those with resignation and despair themes having the lowest (5.88). *Post-hoc* comparisons with Bonferroni correction showed these differences were significant ($P = .047$). While statistically significant relationships were not observed between response shift themes and demographic or injury-related attributes, given the small sample, these were not expected. There was a strong trend for awareness driven themes to be more common in those with paraplegia, behavior driven ones being more common in those with tetraplegia. Similarly, while none of those with recent injuries had awareness-driven themes, 40% of those injured for more than ten years reported them. Table 3 provides a breakdown of RS themes by demographic categories.

PROMIS Global Physical Health scores did not differ as a function of response shift themes ($F = 1.597$, $P = .207$). There were differences in PROMIS Global Mental Health ($F = 3.544$, $P = .024$) with those with Resignation and Despair themes having the lowest

scores (45.55), and those espousing the Social Comparison theme having the highest ones (54.29). PROMIS Anxiety and Depression scores also differed significantly as a function of RS themes ($F = 4.527$, $P = .009$ and $F = 5.167$, $P = .005$ respectively), with those demonstrating Resignation and Despair having the highest levels of both anxiety and depression.

Discussion

The purpose of this study was to examine ways in which persons with SCI experience, define, and maintain QOL via the application of the RS model. Findings revealed important lived experiences, demonstrating a range of appraisals, behaviors, and responses that impacted QOL.

Applicability of the response shift model

The RS model contextualized the QOL construct beyond that seen in standardized measures of QOL. That the RS themes closely mirrored self-reported QOL scores, suggests RS data credibly expounds upon QOL scores in a way that better captures participants’ lived experiences. Further, these lived experiences show that not only bladder and bowel management, but a range of other issues both impact and are impacted by cognitions and appraisals towards an evolving and personalized definition of QOL. The literature on QOL shows momentary correlations between various personal attributes and QOL,^{7–10} our data show how the RS model captures changing attributes, cognitions, appraisals, and meaning-making over time, and in individualized ways, for each participant. While Hammell’s²⁷ synthesis of qualitative findings of SCI QOL embraces a nuanced understanding of QOL factors, RS pushes this a step further, integrating the behaviors and cognitions of participants in shaping their QOL experiences in response to influencing factors.

Instances where RS themes and QOL seemed to contradict one another adds value to a more-nuanced understanding of QOL. The participant discussed under Behavior-driven RS theme above rated his QOL as a 5.5 (out of 10). All other participants demonstrating this theme rated their QOL 7.5 or higher. He had not recalibrated his standards or expectations of himself, though he shifted his efforts from one job to another; from paid labor to parenting. This suggests expectations representing one’s own internal frame of references may play a major role in adjustment and perceptions of QOL. At the other end, the participant discussed under Resignation and Despair rated QOL as 9. In this case, his resignation, response, and QOL all stem

Table 3 Response shift themes by demographic and injury characteristics.

Composition	BD	AD	SC	RD	Total
Sex					
Male	6	10	10	6	32
Female	3	2	2	1	8
Race/ethnicity					
Caucasian	6	11	11	5	33
African-American	3	0	1	0	4
Hispanic	0	1	0	2	3
Level of injury (self-reported)					
Paraplegia	3	9	7	4	23
Tetraplegia	6	3	5	3	17
Time since injury (at time of interview)					
< 1 year	1	0	7	2	10
> 10 years	8	12	5	5	30
Total in each RS theme	9	12	12	7	40

BD, Behavior-driven; AD, Awareness-driven; SC, Social comparison; RD, Resignation & Despair.

from the same basic idea, 'I don't care anymore'. He recalibrated his standards such that his QOL score improved based on his lowered expectations. In other words, as he expected less, he avoided disappointment.

These contradictions demonstrate the benefit of narrative analyses, confirming the findings from Schwartz's work in understanding inconsistencies in patient-reported outcomes.¹¹ That someone can actively struggle to improve their lives and still have a medial QOL, or do little to maintain their QOL and accept their circumstances, thus experiencing a subjectively higher QOL, points to the challenge of measuring the QOL construct outside broader contexts. QOL is a dynamic process that does not always lend itself to standardized measurement.

Implications for clinical practice

Contradictions between RS and QOL illustrate the need for clinicians to understand the complex ways in which QOL and factors contributing to it are understood, experienced, and acted upon. RS provides a framework that enable clinicians to explore individual patient perspectives more systematically, beyond the standardized assessment of QOL. Exploring RS domains with patients may open up the possibility of more-tailored interventions based on patient readiness. Recognizing common characteristics observed within each of these four themes could serve to better explore and begin treatment for broader psychosocial issues impacting QOL.

Spending the time to identify patients' RS category may help guide clinicians' approaches to patients in a more individualized way, providing richer, more-personalized data for decision-making than standardized assessments alone. Exploring patients' perspectives on their own definitions of QOL could help providers focus on patients' current state of mind and contextualize decision-making rationales more-reflective of patients' own values and perspective; to be able to speak and understand a patient's perspective through that patient's own words. Future research will further explore these themes towards development of a RS assessment tool.

Limitations

There are limitations in this study. First, there is the possibility of bias in the selection of representative quotes. Working in teams towards consensus, while a well-accepted qualitative analysis credibility check, is still open to group bias in sampling a large set of narratives. Second, using RS as both guiding coding scheme and interpretative frame may have produced self-evident findings. Though we are confident that the model guided our examination towards salient

participant-derived meaning, reflecting the key concepts of the RS model, alternate analysis with other theoretical models may have produced different results. Third, our sample size, while typical of qualitative studies, is small for statistical analyses. Future work will endeavor to increase the scope of our investigation with a larger sample.

Conclusion

Persons with SCI experience individual paths in their experiences post-injury, directly influencing how they respond to their injury. These experiences and responses result in differing and evolving definitions of the QOL construct. Applying the RS model highlighted important personal and social contexts and behaviors, and helped identify confounding issues impeding and facilitating adjustment.

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Appendix A: Sample of semi-structured interview questions

Please tell me a little bit about yourself and the circumstances surrounding your injury.

Please tell me your story of living with the loss of bladder and bowel function.

What kind of complications have you had related to your bladder? To your bowel?

How do you feel about your relationship/experience with your caregiver?

In general, to what extent has the loss of bladder and bowel control impacted the relationships with people around you?

Can you tell me how bladder and bowel dysfunction impacts your ability to have intimate and sexual relationships?

To what extent has loss of bladder and bowel control impacted relationships with family or household members? Professional relationships? Community involvement?

In terms of your future goals, what do you hope to be doing, give years down the road?

What areas of your life do you find most satisfying? Least satisfying?

What areas pertaining to quality of life are most important to you right now?