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Health-Related Quality of Life in Caregivers of Individuals with Traumatic Brain Injury: Development of a Conceptual Model

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Abstract

Objective—To identify aspects of health-related quality of life (HRQOL) that are relevant to caregivers of individuals with traumatic brain injury (TBI) and propose an integrated conceptual framework based on this information.

Design—Nine focus groups with caregivers of individuals with moderate-to-severe TBI were qualitatively analyzed to ascertain the effect that caring for an individual with a TBI has on caregiver HRQOL.

Setting—Focus groups were conducted at three rehabilitation centers across the United States (Michigan, New Jersey, and Texas).

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Participants—55 caregivers of individuals with moderate-to-severe TBI

Interventions—Not Applicable.

Main Outcome Measures—Not Applicable.

Results—Qualitative analysis indicated that caregivers were most concerned about their social health (42% of comments); other important issues were emotional health (34%), physical health (11%), cognitive health (3%), and feelings of loss (9%; feelings of loss related to changes in the future/potential of the care recipient or related to the caregiver). Areas of concern that were discussed that were specific to the caregiver and not fully evaluated by existing patient-reported outcomes (PROs) included feelings of loss, anxiety related to the caregiver role (reinjury concerns, worry about leaving the person alone, etc.), and caregiver strain (burden, stress, feeling overwhelmed, etc.).

Conclusion—Although existing PROs capture relevant aspects of HRQOL for caregivers, there are HRQOL domains that are not addressed. A validated and sensitive HRQOL tool for caregivers of individuals with TBI will facilitate initiatives to improve outcomes in this underserved group.

Keywords

Caregiver; Outcome Assessment (Health Care); Traumatic Brain Injury; Health-Related Quality of Life; Underserved Populations

The incidence rate of civilian-TBI is estimated to be 1.4 million per year,⁶ with approximately 90,000 individuals experiencing long-term impairments and disabilities.^{7,8} Approximately 17% of individuals with TBI have moderate-to-severe disability,⁹ with persisting, devastating deficits in everyday functioning. These deficits can lead to changes in the family system, with family members having to assume the role of “caregiver” and bear primary responsibility for assisting the person with TBI with physical, cognitive, financial, and leisure activities.² Significant levels of emotional distress have been documented in caregivers.¹⁰⁻²⁰ The majority of caregivers of individuals with TBI report unhealthy family functioning,^{18,21-23} which is related to negative outcomes for the caregiver (e.g., increased depression and higher levels of perceived burden).^{11,21-26} There is also evidence that family members of persons with TBI experience increased social isolation.^{14,21,27-32} Furthermore, caregiver burden and stress is also associated with negative outcomes in individuals with TBI including poorer functional ability, poorer cognition, decreased psychosocial well-being, less social integration, poorer work productivity, and poorer adjustment.^{24,33-39}

Although it is clear that caregivers are affected by providing care for an individual with TBI, the specific aspects of the caregiving role that contribute to decreased health-related quality of life (HRQOL; a multidimensional construct that reflects how mental, physical, or social health influence overall health status),³ are less clear. Many studies investigating the impact of TBI on caregivers have used general measures of emotional distress (e.g., Brief Symptom Inventory;⁴⁰ General Health Questionnaire⁴¹) that do not capture distress that is specific to the caregiving role. Furthermore, existing caregiver-specific measures are borrowed from other caregiver populations, such as dementia (Zarit Burden Interview⁵) or multiple sclerosis (Caregiver Burden Scale⁴²). These measures do not capture the unique aspects of caring for

an individual with a traumatic injury, have unknown validity in caregivers of those with TBI,⁴³ and do not capture the multidimensional nature of HRQOL. These measures have also been criticized for limited psychometric data to support reliability and validity, and the absence of a clear conceptual framework.⁴

Researchers and clinicians have come to recognize that HRQOL represents important variables that determine long-term satisfaction. As a result, several large-scale research efforts have sought to maximize the efficiency and sensitivity of existing patient reported outcomes (PROs) systems with the goal of capturing HRQOL using state-of-the-art measurement technology. For example, the Patient Reported Outcomes Measurement Information System (PROMIS)^{45,46} provides dynamic assessment of PROs that measure key health symptoms/concepts for both the general population and several chronic conditions. PROMIS instruments assess “physical,” “mental,” and “social” health (see Table 1). PROMIS allows for items to be administered as a full set, a computer adaptive test, or a calibrated “short form” (preselected set of items).⁴⁷ While PROMIS instruments may be applicable to caregivers, none were developed or tested with caregivers of individuals with any illness/injury, much less in caregivers of individuals with TBI. Development of caregiver-specific instruments would be beneficial in allowing for comparison across caregiver studies and evaluation of treatments targeted toward improving HRQOL for caregivers.

To summarize, there is a need for a HRQOL measure that is targeted for caregivers of individuals with TBI.⁴ Although PROMIS offers a logical and sophisticated state-of-the-art measurement solution to HRQOL assessment in these caregivers, more work is needed to support the content validity of PROMIS in this population. Furthermore, more work is needed to extend PROMIS to include additional content that can capture caregiver-specific concerns. Thus, the purpose of this paper is to lay the groundwork for a new measurement system that is appropriate for use in caregivers of individuals with TBI. Such a system requires a well-developed conceptual framework, the generation and refinement of items, psychometric testing and analysis, and guidelines for score interpretation.^{48,49} Below, we describe the development of the conceptual framework that will provide the basis for a new PRO measure that extends the PROMIS measurement system for use in caregivers of individuals with TBI—the TBI-CareQOL. In addition, we examine the PROMIS framework to identify HRQOL concept areas that may warrant future measurement development.

Methods

Participants

We conducted caregiver focus groups to identify HRQOL domains that are specific to caregivers of individuals with moderate-to-severe TBI. Nine focus groups were conducted with 55 caregivers across three locations (Michigan, New Jersey, and Texas). Caregivers were at least 18 years old, were able to read and understand English, and were caring for an individual with a medically documented moderate-to-severe TBI (i.e., the individual with the TBI was required to be ≥ 1 year post-injury and meet TBIMS inclusion criteria for a moderate or severe TBI⁵⁰). Since individuals with mild TBI typically do not require a caregiver, this was an exclusion criterion. All data were collected in accordance with the

local institutional review boards, and participants provided informed consent prior to participation.

Participants were contacted through existing registries, by referrals from TBI patients, and through local support programs. Among caregivers, the average age was 57.7 years ($SD = 9.7$), 78% were female, 78% were Caucasian, and 15% were Hispanic/Latino. The majority of caregivers were parents (58%), followed by spouses (36%). Caregivers were in the caregiver role for an average of 6.5 years ($SD=4.8$; range 1-26). The causes of TBI for the care recipients were motor vehicle accidents (75%), falls (9%), gunshots/other assault (5%), sports related TBI (4%), and other accidents (7%; bicycling accident, tree falling, etc.). Self-reported household income was <\$20,000 for 11% of participants, \$20,000 - \$39,999 (20% of participants), \$40,000-\$74,999 (24%), \$75,000-\$99,999 (16%), \$100,000 (27%), and unknown (2%).

Data Collection and Analysis

Focus group sessions began with broad, open-ended questions, which allowed participants to express what the term “HRQOL” meant to them, and to discuss what they perceived to be the most important aspects of their HRQOL (See Appendix 1 for the Focus Group Interview Guide). All focus groups were ~90 minutes in duration and led by two PhD-level clinical psychologists (NC and AK). Groups were recorded, transcribed verbatim, and de-identified. Transcripts were analyzed systematically⁵¹⁻⁵³ using a deductive and inductive approach that replicates the methodology used in PROMIS and other PRO initiatives.⁵⁴⁻⁵⁷ This coding blueprint⁵⁶ is designed to inform new PRO measurement development; it expands upon more traditionally based grounded theory approaches of qualitative analysis^{58,59} and utilizes the development of a domain framework (i.e. conceptual model), open and axial coding, selective coding, and descriptive analysis. For each domain, the two co-facilitators collaboratively identified major content areas and developed a list of subdomains through thorough transcript review (“open coding”). This information was used to develop the initial structure for a codebook for each domain (i.e., a hierarchical taxonomy). Seven Ph.D. and 2 master’s level investigators were involved in the iterative process of review and revision of each draft codebook through a large, in-person meeting and two teleconferences. Codebook structures were refined and expanded to reflect the emerging themes until group consensus was reached regarding a final codebook scheme.

Two independent raters and a third expert completed an inter-rater reliability exercise designed to ensure the consistent interpretation of each code (raters were required to achieve 80% agreement). Once inter-rater reliability was established, the two coders coded each transcript according to these thematic codebooks for each domain; raters reconciled all instances of disagreement. Raters were either bachelor’s or master’s level research assistants that were supervised by a PhD-level psychologist (AK) who reconciled any disagreement between coders.⁵⁶ Finally, all comments were compiled and summarized in frequency tables denoting the number of times each response was made.

To develop the conceptual model, specific themes were grouped under broad domains of functioning based on common content.

Results

Data saturation, or the point at which no new nodes were developed, was achieved by the 4th focus group, after which the codebook did not require additional revisions. Additional groups were conducted beyond saturation to maximize the robustness of the overall frequency counts. Percentages that are reported below are based on the number of times that a topic was coded relative to the total number of codes, which is indicative of the relative importance of each of the topic areas that was discussed. A summary of the themes that were discussed during the focus groups included social health (42%), emotional health (34%), physical health (11%), cognitive health (3%), and feelings of loss (9%).

SOCIAL HEALTH (see Table 2)

The most frequently identified HRQOL area of functioning was social health (42% of the discussion). Discussion included community life/recreation, role changes (including loss of independence), stigma, companionship/support, social isolation, abuse, vocation, and finances. While several of these domains overlap with the content covered by PROMIS Social Health subdomains (i.e., community life/recreation, stigma, companionship/support, social isolation, and vocation), some of them are not fully captured within this framework (i.e., role changes, abuse and finances).

EMOTIONAL HEALTH (see Table 2)

The second most frequent topic of discussion was emotional health (34% of the discussion). Specifically, participants frequently discussed positive emotions, depression, anger, general anxiety/concern, all of which are constructs that overlap with existing PROMIS measures. Concepts that were discussed less frequently included guilt, emotional roadblocks and spirituality/religion, which are concepts that are not currently evaluated by PROMIS.

Other caregiver-specific issues raised that are also not currently captured by PROMIS included caregiver-specific anxiety/concerns, caregiver strain, and feelings of being trapped. Caregiver-specific anxiety/concerns were characterized by feelings of anxiety that were directly related to the caregiver role. Caregiver strain encompassed feelings of being overwhelmed, stressed, and self-defeated. Feelings of being trapped were expressed with regard to caregivers feeling like they were unable to leave the person that they provide care for.

PHYSICAL/MEDICAL HEALTH (see Table 2)

Physical health issues were the third most commonly identified HRQOL domain (11% of the discussion). The most frequently discussed physical health complaints were health behaviors, which included lifestyle choices such as exercise and medication. Participants discussed difficulties keeping up with their own medical care. Caregivers discussed sleep difficulties and fatigue. To a lesser extent there was discussion of sexual functioning, weight gain/loss, physical pain, and gastrointestinal complaints. While many of these concepts are captured within PROMIS (i.e., pain, sleep difficulties, fatigue, sexual functioning), others are not (i.e., health behaviors, medical care/medication, weight gain/loss, gastrointestinal complaints).

COGNITIVE FUNCTION (see Table 2)

Cognitive function was the least frequently discussed area of HRQOL (3% of the discussion). This discussion was generally initiated by specific queries by the moderators; it was rarely discussed spontaneously. HRQOL cognitive concerns included memory, attention, and lack of mental clarity. Less frequently the discussion focused on executive functioning changes and language/comprehension. All of these cognitive concerns are represented by the PROMIS cognition instruments.

FEELINGS OF LOSS (see Table 2)

The other area of functioning that consistently arose in all of our focus groups, and was unique to this population (i.e., not covered by PROMIS), were feelings of loss related to changing social roles (9% of the discussion). This discussion centered around two different themes. The first theme was related to the person with the TBI and the individual's loss of potential, loss of a future, or a normal life. The second theme was related to the loss/change of the life that the caregiver had prior to assuming the caregiver role, and included a loss of relationships, loss of a "previous" life and a loss of future plans.

CONCEPTUAL MODEL (see Figure 1)

The thematic content that comprised the final codebook is represented by a unified conceptual model (Figure 1) that represents the TBI-CareQOL framework. Themes with content that seemed to span across domains (i.e. feelings of loss, spirituality/religion) were depicted in the model as existing between two broad domains. This conceptual model expands upon the PROMIS conceptual framework (which was originally based on the conceptual framework from the World Health Organization⁶¹) and will serve as a summation of the thematic content that was identified through the frequency analysis that is detailed above.

Discussion

This study provides evidence for the diverse array of HRQOL concerns that are present among caregivers of individuals with moderate-to-severe TBI. Results from caregiver focus groups identified interrelated factors which informed the conceptual model reflecting the relationship and interconnections among HRQOL concerns in this population. This conceptual model (see Figure 1) will guide item development for the TBI-CareQOL, a caregiver-specific PRO instrument. The methodology employed was conducted in accordance with the PROMIS system^{62,63} and standards,⁶⁴ which will allow for seamless merging of these tools. Study findings suggest the content validity of several existing PROMIS item banks, providing support for the relevance of these measures in caregivers of individuals with TBI.

Several item banks from PROMIS appear to be relevant for caregivers of individuals with TBI. As such, future validation work should target the HRQOL subdomains that were identified most frequently. Social health concerns were the most frequent topics of discussion and it will be useful to conduct validation work with the PROMIS Social Health item banks (Ability to Participate in Social Roles and Activities, Satisfaction with Social

Roles and Activities, Companionship, Emotional Support, Informational Support, Instrumental Support, and Social Isolation)⁶⁰ to evaluate how well they capture caregiver concerns. Emotional health concerns were frequently discussed so validation work on PROMIS Depression, Anxiety, and Anger is also warranted. Finally, the most frequently identified Physical health concerns were fatigue and sleep difficulties; therefore, future work should target validation of the PROMIS Fatigue, Sleep Disturbance and Sleep-Related Impairment item banks.

There were also caregiver-specific issues that were not fully captured by PROMIS' conceptual framework. Therefore, content validity of PROMIS would be enhanced by expanding the content coverage of items through additional items or item banks. In particular, issues of Caregiver-Specific Feeling of Loss, Caregiver Strain, Caregiver-Specific Anxiety, and Feeling Trapped are not sufficiently reflected in the current PROMIS banks. Additional item content in these areas would enhance relevance for caregivers of individuals with TBI. Furthermore, while some of this caregiver-specific content is captured by existing caregiver measures (e.g., the concept of caregiver strain overlaps with caregiver burden which is captured in measures such as the Zarit Burden Interview⁵ and the Caregiver Burden Scale⁴²), the development of additional measures that can be administered as computer adaptive tests will be a valuable contribution to the field. These measures can be used to help improve clinical care and ultimately HRQOL for this underserved population, and should also improve the HRQOL for the individual with the TBI.

In addition to providing a conceptual framework from which we can build a new caregiver-specific PRO system, findings from this study also replicate the existing literature on the impact of TBI on caregivers. Not surprisingly, the stress and strain associated with the caregiver role affects caregiver mental, social and physical health.^{11,21-26} As such, a large portion of the groups were spent discussing emotional health concerns (including anxiety, depression, stress, and anger); findings which are consistent with other studies documenting emotional distress in this population.¹⁰⁻²⁰ Furthermore, many of the social concerns that were discussed including social isolation and concerns with social support are also things that are highlighted in the existing literature.^{14,21,27-32} The current study also highlighted the importance of guilt, role changes (i.e., feeling like a spouse one minute and a parent the next), feeling trapped, and feelings off loss with regard to both the individual with the TBI (and that individual's future) and their own future; these are issues that are not reflected in many of the existing measures used to assess the impact of TBI on caregivers.

While this study contributes to our current understanding of HRQOL issues for caregivers of individuals with moderate-to-severe TBI, it is important to acknowledge study limitations. Most notably, we did not control for interviewer bias in our study. Furthermore, the majority of our caregivers have been in this role for an average of 6 years; while this is an adequate time frame to have adjusted to the caregiver role, it may not fully capture the complexity of the caregiver role during the first several months following an injury, making it difficult to generalize findings during this transitional phase. Although participants were encouraged to discuss their experiences since the date of injury, this may have also affected the thematic content that was captured during the focus groups due to the temporal distance from the injury itself. We also did not collect data on the individuals that were approached to

participate but declined or were unable to participate; thus our sample may be biased toward individuals that were interested in participating in HRQOL research. We also utilized a qualitative approach that was developed specifically for the development of PROs; this approach relies much more heavily on frequency counts to highlight relative importance of topic areas than does more traditional approaches. Thus more traditional qualitative assessment may not yield the same pattern of findings. Furthermore, the focus groups were comprised of a convenience sample, and the majority of caregivers were female and Caucasian, therefore extrapolation to males and those of other races may not be relevant.

Regardless of these limitations, this study offers a unique contribution to the HRQOL literature and presents a more contextualized understanding of HRQOL in caregivers of individuals with moderate-to-severe TBI. Most importantly, the findings from this study highlight the impact that caring for someone with a TBI has on a caregiver. Although PROMIS has made significant advances in HRQOL measurement development, caregiver-specific measures are needed to supplement these initiatives to maximize relevance for interventional trials and clinical practice.

Conclusions

This qualitative study was conducted to develop a conceptual framework that examines HRQOL for caregivers of individuals with TBI. Analyses highlighted several themes and concepts related to HRQOL relevant to social, emotional, cognitive and physical health, and included several caregiver specific HRQOL issues including caregiver-specific feelings of loss, caregiver-specific anxiety, caregiver strain, and feeling trapped. Findings support the need for a clinical measurement tool that can assess the specific issues in these individuals. In conclusion, a better understanding of caregiver HRQOL provides valuable insight in developing and evaluating clinical interventions aimed at improving the HRQOL of caregivers of individuals with moderate-to-severe TBI.

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TBI-CareQOL Focus Group Guide

Opening Statement Example

Thank you for agreeing to participate in this research project. I'm Dr. Noelle Carlozzi and I will be your facilitator for this discussion. This is Dr. Anna Kratz, and she will be the co-facilitator for this discussion. We work in the Department of Physical Medicine and Rehabilitation at the University of Michigan. One of our current projects is to develop a questionnaire about what researchers refer to as the "quality of life" of caregivers of individuals with traumatic brain injury. By "quality of life", we mean the symptoms, problems, and concerns as well as any gains, fulfillment, or joys that caregivers have as a direct or indirect result of caring for their loved one with traumatic brain injury. The best way to develop a questionnaire like this is to talk with the caregivers and learn about their experiences caring for their loved ones with traumatic brain injuries. Once we've developed this questionnaire it will be used to identify caregiver needs and develop appropriate interventions to assess these needs.

We've asked you to meet with us here today in what researchers call a "focus group." A "focus group" is a group of people that researchers get together to talk about some topic, so the researchers can learn what the people think or know about that topic. In a focus group it's really important that you say what you think. There are no right or wrong answers. We want to know what you think. If you would like to add to an idea, or if you have an idea that's different from someone else's, feel free to jump in. You don't need to wait for me to call on you to talk, but only one person should talk at a time. We appreciate that you have taken the time to participate in our group today.

We will be tape recording this session to be sure we don't miss anything you say, but we won't be keeping track of who said what, so anything you say is anonymous. That is, your response will not be linked to your name. Please speak up and talk one at a time so we can hear you clearly when the recording is transcribed. We only have 90 minutes, so it will be my job to keep us moving along. In focus groups we want the discussion to be among you, because it is your thoughts and opinions we want to hear. We want you to talk with each other and express your opinions. My job as facilitator will be to keep the discussion moving along and to keep the discussion focused on topics we want to know about, so please don't be offended if I redirect the discussion. Although I am the facilitator, I would like the interaction to flow among you.

I. Introduction & Ice-Breaker

For example: "Let's go around the room and introduce ourselves. Tell us your first name and why you decided to participate in the focus group."

II. Free List Exercise on Quality of Life

Sample Questions:

1. What do you think of when I say the phrase "quality of life" as it relates to your experiences as a caregiver?

2. What kinds of things/what areas of your life are affected because you are the caregiver of a loved one with a traumatic brain injury?

Probes: Emotions (moods and feelings)? Physical abilities and limitations (sleep difficulties and muscle tension)? Social interactions (relationships with family, friends, peers, coworkers)? Caregiver burden?

If additional questions are needed to elicit responses:

In what ways has your life changed (for better or worse) since you assumed responsibilities as a caregiver for a loved one with traumatic brain injury.

In what way is your life different from others who are not caring for an individual with traumatic brain injury?

Probes: Emotions (moods and feelings)? Physical abilities and limitations (sleep difficulties and muscle tension)? Social interactions (relationships with family, friends, peers, coworkers)? Caregiver burden?

NOTE: Emotional, Physical, and Social Health should be discussed.

The following section is optional: After adequate discussion, the facilitator will show a presentation with pre-written domains and sample items from PROMIS item banks. Participants will be asked to indicate the appropriateness and importance of items, and will be instructed to generate any items they feel are “missing.” Participants will be asked to discuss domains of HRQOL that they feel were not adequately covered in the previous discussion.

III. Closure

“Did these exercises bring to mind any other issues that affect your quality of life?”

“Thinking back to our discussion, is there anything else that you would like to comment on now?”

“Thank you again for your participation. Your input is invaluable because no one else can tell us what issues are most important for traumatic brain injury caregivers. The quality of life questionnaire that we are creating will be very important in improving the quality of life of individuals with traumatic brain injury and their caregivers.”

Figure 1. Conceptual Model of Factors Related to TBI Caregiver HRQOL

Note. This figure is not designed to comprehensively depict complex interrelationships between objects in the figure. Absence of lines between objects should not be interpreted as an indication that the objects are unrelated.

Table 1**Domains of Health and Functioning Covered by PROMIS**

Domain	Item Bank
Physical Health	Physical Function
	Fatigue
	Sleep Disturbance
	Sleep-Related Impairment
	Pain Behavior
	Pain Interference
Mental Health	Depression
	Anxiety
	Anger
	Applied Cognition – Abilities
	Applied Cognition – General Concerns
Social Health	Ability to Participate in Social Roles and Activities
	Satisfaction with Social Roles and Activities
	Companionship
	Emotional Support
	Informational Support
	Instrumental Support
	Social Isolation

Table 2

Health-Related Quality of Life (HRQOL) Themes Generated Among Caregivers of Individuals with a Traumatic Brain Injury (TBI)

HRQOL Domain and Subdomains	Example Quotation	Overall Thematic Breakdown	Overlap with PROMIS Content
<u>SOCIAL HEALTH</u>			
Companionship/Support	"You don't want to do anything with that person, because you just feel like they hate you"	31	Yes
Role Changes	"you're taking care of somebody that basically cannot take care of themselves, so you tend to lose – it's not your life anymore"	31	No
Finances	"Financially for us it's been absolutely devastating. I'm – I'm a lawyer, but I'm a sole practitioner, and I was out of my office basically for a year and a half"	9	No
Community Life/Recreation	"This weekend my husband and I we went to a marriage conference that's the first time we've done anything in almost seven years now"	7	Yes
Vocation	"I had a business. And I went from making an extremely good income to not working at all, to taking care of her"	7	Yes
Social Isolation	"The patient is actually isolated but then you become isolated too"	6	Yes
Stigma	"Even people around you, they don't understand what it takes"	5	Yes
Abuse	"You see my son, he gets angry with himself because one time, only one time but that's when he was real bad, you know, he beat me"	3	No
<u>EMOTIONAL HEALTH</u>			
Caregiver Strain	"...you get to this point where you don't want to think about anymore because the situation just seems impossible"	22	No
Caregiver-specific Anxiety	"You're scared for them, because they don't know how to decipher good from bad anymore"	19	No
Anger	"And the frustration – the basic frustration is what can I, we as the care providers, what can we do?"	10	Yes
Feeling Trapped	"something I'm learning to cope with is knowing I just cannot get in the car and takeoff"	9	No
Positive Emotions	"It's made me much more empathetic for other people and what they're going through"	7	Yes
Depression	"to see him the way he is now, it's like – it breaks your heart and it puts you more into a depressive stage"	6	Yes
Emotional Roadblocks	"And you think you're going crazy. Really, I think sometimes, am I going crazy? Is it me?"	6	No
Guilt	"..how do you deal with the fact that you don't like them"	5	No
General Anxiety	"I feel like I'm always nervous"	5	Yes
Spirituality/Religion	"but then I start praying, and, you know, thinking God, help me to keep	3	No

HRQOL Domain and Subdomains	Example Quotation	Overall Thematic Breakdown	Overlap with PROMIS Content
<u>PHYSICAL HEALTH</u>	going. Don't let me down. Don't let me down. And that's how I keep moving on"	(11%)	
Health Behaviors	"I went back to smoking, after not smoking for five years"	27	No
Medical Care/Medication	"I have carpal tunnel on both hands. I'm supposed to get surgery, because you see this hand, I really can't even open it that well. And I can't even do that, because who's going to take care of my son?"	20	No
Sleep Difficulties	"I don't sleep. If I sleep three hours a night, that's a lot"	10	Yes
Fatigue	"I feel like more tired, like every day"	8	Yes
Sexual Functioning	"you don't want to have sex"	6	Yes
Weight Gain/Loss	"I've gained like 100 pounds"	6	No
Pain	"I hurt my shoulder because I was trying to help him so that he could move his arm and the whole thing"	5	Yes
GI Complaints	"Yeah. I've kind of developed like IBS because of the stress"	3	No
<u>COGNITIVE HEALTH</u>		(3%)	
Memory	"But in terms of my memory, no, I don't remember like I used to"	30	Yes
Attention	"I just start losing my concentration. I really feel it. I can't function as well"	19	Yes
Mental Clarity	"But yeah, the thought – and very foggy. Very foggy. I'd forget appointments. I'd forget where I was"	12	Yes
Executive Functioning	"The higher the stress level, the less your ability to reason through and figure out a solution"	8	Yes
Language/Comprehension	"And I used to be very, very sharp, very quick, very articulate. Used to have a great memory. And it's like all gone"	2	Yes
<u>FEELINGS OF LOSS</u>		(9%)	
...related to the person with the injury	"I have a hard time seeing my son the way he is, because I know what he used to be"		No
...related to changes due to the caregiver role	"Well, you have to put your life on hold. You don't want to. You just do what you have to do, step up to the plate."		No

Note. Percentages for Domains reflect the total percentage of comments related to this specific domain (Domain percentages should sum to 100 with rounding); percentages within each Subdomains reflect the percentage of comments within each Domain (should sum to ~100).