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Starting a new conversation: Engaging Veterans with spinal cord injury in discussions of what function means to them, the barriers/facilitators they encounter, and the adaptations they use to optimize function

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Abstract

Background: Assessments of function in persons with spinal cord injury (SCI) often utilize pre-defined constructs and measures without consideration of patient context, including how patients define function and what matters to them.

Objectives/hypothesis: We utilized photovoice to understand how individuals define function, facilitators and barriers to function, and adaptations to support functioning.

Methods: Veterans with SCI were provided with cameras and guidelines to take photographs of things that: (1) help with functioning, (2) are barriers to function, and (3) represent adaptations used to support functioning. Interviews to discuss photographs followed and were audio-recorded, transcribed, and analyzed using grounded-thematic coding. Nvivo 8 was used to store and organize data.

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Results: Participants ($n = 9$) were male (89%), Caucasian (67%), had paraplegia (75%), averaged 64 years of age, and were injured, on average, for 22 years. Function was described in several ways: the concept of ‘normalcy,’ aspects of daily living, and ability to be independent. Facilitators included: helpful tools, physical therapy/therapists, transportation, and caregivers. Barriers included: wheelchair-related issues and interior/exterior barriers both in the community and in the hospital. Examples of adaptations included: traditional examples like ramps, and also creative examples like the use of rubber bands on a can to help with grip.

Conclusion(s): Patient-perspectives elicited in-depth information that expanded the common definition of function by highlighting the concept of “normality,” facilitators and barriers to function, and adaptations to optimize function. These insights emphasize function within a patient-context, emphasizing a holistic definition of function that can be used to develop personalized, patient-driven care plans. Published by Elsevier Inc.

Keywords

Spinal cord injury; Function; Photovoice

Background

Sustaining a spinal cord injury (SCI) can have a major impact on physical, cognitive, and emotional function.¹ Corresponding adjustments to lifestyle are typically described as moderate to extremely severe.¹ Persons with SCI, their families/caregivers, and their health care providers are concerned about impacts on function and challenges that might be encountered due to poor or reduced functioning.² A study of individuals with both new and existing injuries found significant decreases in perceived physical and cognitive function, which sustained over time in those with existing injury.¹

Rehabilitation medicine is focused on optimizing function and health in individuals with disabilities.³ Commonly used measures to assess function in the clinical setting include the Functional Independence Measure (FIM) and the Spinal Cord Independence Measure (SCIM).^{4,5} The FIM has been found to be a valid and reliable tool for persons with SCI and includes assessment of physical and cognitive abilities.^{6,7} The SCIM (and newer SCIM II), a functional independence scale, focuses on areas of functional importance for persons with SCI and is weighted according to clinical relevance with respect to overall function.⁸ Recent literature, however, suggests that SCI research would benefit from comprehensive, precise, and sensitive functional measures⁹ and from utilizing approaches to defining function that complement the existing ‘static’ measures which contain pre-selected items defining function in a narrow range.¹⁰

A key concern of using existing measures (e.g., FIM) as the only source for characterizing function is the lack of involvement of persons with SCI in defining aspects of function.¹¹ These outcomes are insufficient when considered alone because they do not capture the perspectives and values of individuals with SCI in an open-ended way^{12,13} and highlight a gap in current definitions of function. Andres and colleagues (2003) took steps to address this gap by defining activity and selecting measures of activity from the patient viewpoint.¹⁴ This resulted in the creation of the Activity Measure for Post-acute Care (AM-PAC)¹⁴ which

is administered in a structured interview format and designed to define functional activity from the patient perspective in three domains: (1) physical and movement, (2) personal and instrumental, and (3) applied cognition.

In more recent efforts, studies have utilized patient-reported outcomes resulting in recommendations to expand traditional definitions and assessments of domains that individuals perceive as important to their function.^{9,10} Inclusion of these individual perspectives in the development of a holistic definition of function that accounts for areas that are important to them is critical to SCI care and research. A potentially promising way to do this is use of participatory research methods. Photovoice is a participatory research method that has been used in a variety of ways in the health care setting, including in the area of disability and rehabilitation, to gather insights of persons with disabilities and promote engagement in research.^{15,16} Ripat and Woodgate (2012) utilized photovoice in a study of persons with SCI to understand how assistive technologies contributed to self-perceived participation and to refine existing definitions of assistive technology (AT), which resulted in an expanded definition of AT.¹⁷ In another study, photovoice was used to explore barriers and facilitators that impact community participation in persons with SCI.¹⁸ The insights offered by these studies may serve as important components for refining the way in which some aspects of functioning are defined.

The purpose of this study was to use photovoice, to examine ‘unrestricted’ perspectives (open-ended, visual and narrative freedom) of persons with SCI including definitions of function and optimal functioning, as well as the facilitators, barriers, and adaptations they utilize to assist with function.

Methods

Study design/setting

A convenience sample of Veterans with SCI was recruited via flyers posted at the Edward Hines Jr. VA Hospital SCI Unit and distributed by SCI providers working on the unit. Recruitment occurred concurrently with data collection over a period of 5 months. This study was approved by the Hines VA Institutional Review Board.

Data collection

Participants attended an informational session at which time they: provided informed consent, completed a short demographic survey, received a digital camera, a memory card, an envelope to return the memory card after photos were taken, and instructions for camera use and study participation. Participants were asked to take 25–30 photographs using the following verbatim prompts: take pictures of (1) things that help you function the way you want to, (2) things that are barriers to you functioning the way that you want to, and (3) the adaptations you make so you can do the things you want to do.

After 4 weeks, those who returned a memory card were invited to participate in a 30–60-min, one-on-one follow-up interview to discuss the photographs from their perspectives. The interviews were audio-recorded and transcribed verbatim for analyses. After completing the

interview, participants were given the digital camera and a new memory card to keep along with ten dollars as a token of appreciation for their time and efforts.

Inductive coding was used on an initial set of transcripts ($n = 5$) by three qualitative researchers (JH, KL, SB) to develop a thematic coding structure which was then applied to the initial set of transcripts as well as the remaining transcripts. To ensure reliability, transcripts were first coded independently, then coders met to compare and achieve consensus on disparate codes.¹⁹ Interview data were entered into Nvivo 8 which was used for storing, organizing, and analyzing the data. Further details on data collection efforts for this study can be found elsewhere.²⁰

The International Classification of Functioning Disability and Health (ICF) provides a framework to classify and describe functioning in disability.³ Recently an ICF was created for SCI, and includes 4 primary components each with a number of related sub-components.²¹ The primary components of the Brief ICF Core Set for SCI include: (1) Body functions (e.g., muscle power function, sensation of pain, mobility of joint functions, emotional functions), (2) Body Structures (e.g., spinal cord and related structures, structure of urinary and respiratory systems), (3) Activities and Participation (e.g., carrying out daily routine, moving using equipment, using transportation, handling stress and other psychological demands), and (4) Environmental Factors (e.g., immediate family, products and technology for personal indoor/outdoor mobility, design/construction/building products and technology buildings for public/private use, health professionals).²¹ We used the primary categories of the ICF to organize our results.

Results

Background data

A total of 18 Veterans with SCI were recruited and 9 (50.0%) completed participation in the study while 9 were lost to follow-up. The majority of participants were male (89%), Caucasian (67%), had paraplegia (75%), were 64 years old and had been injured for 22 years on average. Demographics are shown in Table 1.

Interview data

Major themes that emerged from the discussions of the photographs included: definition of function, facilitators and barriers to function, and adaptations to assist function. These are described below and in Tables 2–4.

Definition of function

All nine participants provided a definition of function. Participants defined function using terms such as ‘normalcy’ which was described as the ability to “*do what I want to*,” as well as definitions tied to independence, and the ability to perform daily activities.

Participants described function in terms of normalcy such as “*having as close to a normal life as possible*” (2) and “*being able to move ... like normal people*” (1) and also described function as their ability to do something they want to do: “*I can’t function like I want to. But that don’t make me disabled where I can’t do what I want to do. I still get involved in*

different things as much as I can do.” (7) Other participants described function as their ability to be independent: “My ability, independence. That’s how I see my function. And I define function as a paraplegic as — my hands are a-okay. There is zero impairment with my hands. I have impairment with my balance, that’s not something you can see very easily.” (8) Finally, others described it in terms of being able to perform daily activities such as taking care of hygiene or washing dishes. Illustrative quotes are shown in Table 2.

Facilitators to function

All nine participants described things that facilitated their function. One Veteran described keeping tools handy at all times: *“All of these tools make my independence possible. And I think that’s important. This is a picture of my backpack. I carry everything in my backpack, I have to have it. I have bathroom supplies ... my multi-tools and allen wrenches, everything I need. I can’t live without my backpack.” (8)* The main themes that emerged as facilitators to function included the importance of helpful tools to accomplish tasks, transportation, and the role(s) of therapy and caregivers to facilitate function. Additional quotes are shown in Table 3.

Helpful tools—Five participants cited “tools” they used to facilitate physical tasks. Participants described using items to help them “reach” and or “grab” things that were out of their grasp: *“I use that backscratcher to get to my channel volume [adjusted] and also I use that on the telephone to dial.” (4)*

Other examples included devices that helped support challenging situations. In one example, a Veteran describes use of a lift, *“This is my lift, which gets me in and out of bed, out of bed and into my chair; and out of my chair into bed.” (18)* In another example, a Veteran shared a picture of a computer stand explaining that, *“This is a computer stand ... but I use it for a book stand and I bought a book light and connected it too. I drop things sometimes, it prevents the book from falling and I can read lying down in bed, sitting on a chair. it is collapsible and adjustable at different heights” (11)*

Transportation—Five participants also described access to transportation as an important facilitator to their function. Participants described three types of transportation available to them, personal, public (vans/buses), and VA-sponsored transportation. Personal transportation was described as a facilitator in terms of it providing them freedom and independence: *“Oh this one is of my van. I’m able to drive ... and to me, that is very important. I can go to the store, I can come up here and go to the doctor. I don’t have to depend on somebody to take me from point A to point B.” (18)*

Those who utilize public transportation described using the local bus system: *“I think the one [facilitator] that stands out most is that my city provides transportation for our seniors and our handicapped people. [It] shows the integrity and the quality of what the city has negotiated as part of the bus program.” (10)* (Fig. 1)

Finally, Veterans also suggested that transportation to and from the hospital provided by the VA was a facilitator to function. A Veteran stated: *“I would say ... the transportation that VA*

provides to assist you in getting here. Because of the transportation, I don't have to worry about driving.” (6)

Therapy—Three to their function, most of whom referred to the weight training they received in therapy. For example, a participant described its benefits to function as: *“If it hadn't been for my therapist I'd probably be stuck in bed or wouldn't even be alive. I am here at least three days a week ... I will do machines at home too ... something to keep me moving around. My mobility is enhanced because of it.” (1)*

Role of informal and formal caregivers—Four participants described the role of their caregivers as facilitators to function. They described family/informal caregivers, formal VA caregivers (paid/staff), and non-VA paid caregivers as playing a part in their function. Functional help from family/informal caregivers was described as assistance with daily activities: *“I live with my wife, she's my caregiver She bathes me, cooks for me, does bowel care.” (7)* Participants also described their team of VA caregivers as an essential part of their functioning: *“This place has helped me more than anywhere. I've seen other people that were rehabbed through other hospitals and came out and didn't even know they could drive or put their own shoes on. They had no idea! I wasn't allowed to leave the doors until I could prove I could do everything that I needed to live on my own.” (8)*

Barriers to function

Six participants also discussed barriers related to their function. The most common barriers cited were related to their wheelchairs, surfaces they had to maneuver in their wheelchairs both in the community and around the hospital (interior and exterior), and respondents also discussed the adaptations they have found or created to overcome barriers that they encounter. Additional barriers identified and supporting quotes are included in Table 4.

Wheelchair—Three participants mentioned barriers to function that were related to their wheelchairs including disadvantages of both manual and power wheelchairs. For example, a Veteran with a power chair said: *“I have short arms and I can't reach everything. I have to get close ... because I got that power chair, seems like I can't do as much as I could when I was in a regular manual chair.” (4)*

Barriers around the community—Three participants cited barriers around the community. Many of the examples cited involved sidewalks, walkways, or ramps in community settings that were intended for accessibility, but were not found to be accessible by the participants. For example, a Veteran spoke of the experience of maneuvering his wheelchair in his city, *“I travel through the city in which I reside, and the town is showing its age by degrading walkways. It's broken down. You have to maneuver it. Well [in this photo] you can see the width of the actual breakdown is taking up the whole sidewalk.” (10)*

Barriers around the hospital (exterior and interior)—In addition to mentioning barriers related to surfaces in the community, three participants also mentioned barriers around the hospital that impacted their function. Some examples included accessibility

issues on the exterior of the hospital, while other cited examples of issues within the interior of the hospital.

Frequently mentioned barriers on the exterior of the hospital involved uneven or inaccessible surfaces (e.g., pavement or sidewalks). For example, a participant said: *“Okay this is also by the main gate. You notice the bus stop here? Well, there’s no sidewalk here so you got to come in the street and when you get here, you can’t get into the bus stop because it’s a curb ... there’s no ramp.”* (2) (Fig. 2) In another example, a participant describes an outdoor recreational area for Veterans with SCI: *“We’ve got an area where the garden is at. but the ramp system in the back will only take you so far. Then you have to turn around and go back the way you came. It should have been a ramp down, why put in steps? It didn’t make sense. What was the architect thinking? He’s building a design for people in wheelchairs; anything that’s got a step to it is silly.”* (10)

Examples of barriers on the interior of the hospital varied. For example, one participant described being unable to access a garden area: *“The one with the flowers in there couldn’t access [the garden] because of the doors not being activated in the garden, but you could still observe it through the window.”* (10)

Adaptations to assist function

Five respondents shared descriptions of adaptations they had made to overcome barriers they had encountered. There were many adaptations including those you might expect, such as ramps or lifts in the house, and resourceful adaptations, such as using rubber bands and other items in a creative manner to help them accomplish tasks within their home. For example, a Veteran said: *“Right off the bat, I got ramps everywhere in my house. It helps my function ... helps me get in and out of my house.”* (8) Additional quotes can be found in Table 4.

There were several other examples of creative uses of items to overcome functional barriers experienced by persons with SCI. For example, a participant described a challenge and the adaptation used to assist with function: *“I can’t make sandwiches because my hands shake. but I was in a store and saw in the bath section they had this tray where you could put things on it, I thought that a couple of slices of bread would fit there. So I put two slices of bread on there, I can spread condiments without the bread moving and this has rubber things on the bottom which keeps it from sliding.”* (11)

Limitations

There are limitations to this study. First, this study utilized a small convenience sample which may not represent the larger population of persons with SCI, and the results (including the themes expressed by participants) may not be generalizable or representative of the views of persons with SCI at large. Therefore, the results of this study should be considered preliminary and with additional research is needed to further build upon the findings. In addition, this sample of Veterans is older and has a longer duration of injury than the population of Veterans with SCI at large, so their perspectives may differ from younger Veterans or those with newer injuries. Finally, participants may have had different levels of understanding of the study aim/task and different levels of ability to handle the camera and take pictures.

Discussion

Our study gave persons with SCI the opportunity to capture the meaning of function as it is important and applicable to them through use of photos and narratives. This proved to be an ideal way to gain insight that would not likely be elicited using objective measures or validated surveys with closed-ended, pre-defined response options, and can be used to complement commonly used measures. Using this ‘unrestricted’ method, we empowered persons with SCI to characterize their function in their own words and share facilitators and barriers that support or impede their functioning. This also enabled them to share information on the adaptations they used to function the way they want and to accomplish their goals related to function. Although in many ways, our thematic findings share similarities with those in existing literature and elicited from existing measures, understanding how persons with SCI characterize their function and the things that support and impede their function also provides insights that augment these measures.

In some ways, definitions of function that emerged in this project are consistent with existing measures such as FIM and SCIM (e.g., mobility, self-care) and descriptions of function in published literature (e.g., ability to perform daily activities and having independence).^{4,5,11,13} However, our findings add depth to existing literature about function in SCI by characterizing and defining function through the experiences and perspectives of persons with SCI. Recent recommendations suggest the need for patient perspectives in both defining and identifying salient areas of function^{9–11} and for selecting measures to define function.^{12,13,22} Our study takes early steps to explore the nuances of function as defined by the patient. Further, our study offers distinct advantages over interview-only studies because it documents individual’s experiences in two ways rather than only one, through both their eyes (photographs) and their voice (interviews/narrative). The photos add a layer to the synthesis of the patient perspective and further elucidate individual’s experiences by facilitating conversations that support expression and exploration of elements that are important to them.

This study, though exploratory in nature, suggests that persons with SCI personally define their function largely through factors which are captured by the ICF components of Activities and Participation and Environmental Factors. In this study, environmental factors such as barriers associated with manual and power wheelchairs and challenges with areas designed for accessibility were seen as important factors impeding patient’s optimal functioning. However, Environmental Factors identified as facilitators such as helpful tools and the role of therapy were seen as important factors supporting optimal functioning. Furthermore, our open discussions with participants revealed that adaptations to function were equally important, as demonstrated by the ingenuity and creativity they employed to aid in their functioning.

Interestingly, there were only limited discussions that fell within the ICF component of Body Functions. The concept of ‘normalcy’ in the definition of function was interesting because it emerged not only as something to achieve, but also involved concessions such as not performing at the desired level but still ‘doing what I want’ or functioning ‘as close to normal as possible.’ This suggests that despite sharing ingenuity (which emerged in

discussions of adaptations to assist function) and success in accomplishing functions they ‘want to accomplish,’ perceptions of normalcy in the domain of function remain tied, at least partially, to pre-injury functionality and/or function lost due to injury. This finding suggests the need to consider strategies to help individuals ‘rethink their narrative’ on an ongoing basis. These strategies should include encouraging individuals to (1) focus on their capability and competence rather than their inadequacies or limitations²³ and (2) utilize their experience with SCI to challenge society’s norm and create their new definitions of normal within that context.^{23,24}

Patient-driven discussions within the context of function identified barriers and facilitators that can be incorporated into care plans and goals for maintaining and improving function. For example, a wheelchair is an important mobility device used by persons with SCI and though wheelchairs have been identified as barriers to participation,²⁵ the finding that they are perceived as a barrier to function is compelling. Conversations can also be used to identify facilitators of function, for example, participants in this study noted helpful tools such as tools to help reach and grab and tools to help maneuver challenging situations as facilitators to function. The richness of these conversations that relate to personal context provide insights not captured by traditional clinical assessment tools and can be used to inform clinical interventions^{26,27} while also complementing and augmenting current approaches to defining function to provide a more holistic definition and a clearer picture of factors impacting function.

Finally, these discussions can also be used to uncover the ingenuity and creativity that individuals use to assist them to function the way they want to. Previous studies have suggested that interest in or ability for problem-solving among persons with SCI may be limited^{23,28} and that incorporating active learning strategies or context-based strategies into patient education might be needed, especially for recently injured individuals.²⁸ In this study, participants described utilizing standard adaptations (e.g., ramps and lifts) but also those they created on their own (e.g., use of non-slip bath mats for making sandwiches, strings to help with opening doors, rubber bands for gripping). These adaptations and problem-solving techniques may improve receptivity for individuals that are resistant to acquiring or applying problem-solving skills.

Conclusion

The interest in gathering information from the patient perspective expands beyond its use for defining and measuring function. Patient-centered care efforts are being used to enhance the value of a patient’s health care experience by encouraging involvement of the patient and their family in care planning, enhancing communication between the patient and the care team, and personalizing the care provided by taking into account the factors or context of the patient’s own life.²⁹ The insights gained by use of photovoice might be useful in developing personalized, patient-driven care plans that can be used in goal-setting related to function. Photographs generated by participants with SCI in this study may be used as tools to promote engagement and advocacy for persons with SCI¹⁸ which may facilitate function at home and in the community.

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Fig. 1.
Facilitator to function – transportation: *“I think the one [facilitator] that stands out most is that my city provides transportation for our seniors and our handicapped people. [It] shows the integrity and the quality of what the city has negotiated as part of the bus program.” (10).*

Fig. 2.

Barriers to function – surfaces at the hospital: *“Okay this is also by the main gate. You notice the bus stop here? Well, there’s no sidewalk here so you got to come in the street and when you get here, you can’t get into the bus stop because it’s a curb there’s no ramp.” (2)*

Table 1**Demographics**

	<i>n</i> = 9 Frequency (%)
Gender	
Male	8 (88.9)
Female	1 (11.1)
Age (years)	
Mean (range)	64 (36–86)
Race	
Caucasian	6 (67.0)
African American/Black	3 (33.0)
Marital status	
Married	3 (33.3)
Divorced or separated	2 (22.2)
Widowed	2 (22.2)
Never married	2 (22.2)
Health status	
Excellent	1 (11.1)
Very good	2 (22.2)
Good	2 (22.2)
Fair	4 (44.4)
Poor	0 (0)
Education completed	
High school graduate (grade 12 or GED)	2 (22.2)
Some college or technical school	5 (55.6)
College graduate (4 years or more)	2 (22.2)
Level of injury ^a	
Paraplegic	6 (75.0)
Tetraplegic	2 (25.0)
Years since injury	
Mean (range)	21.8 (2–59)
Residential status	
Resides at VA (residential care facility)	2 (22.2)
Resides in community (recruited as inpatient or outpatient)	7 (77.7)

^a Indicates missing value (*n* = 1).

Table 2

Definition of function and perceptions of function

Theme (subtheme)	Quote
ICF component: Activities and Participation, ICF code d230: Carrying out daily activities	
Definition of function (independence)	"It's being able to do what you can for yourself. Try to keep learning, find some way to get it for yourself, do for yourself. You can't always get somebody to do it for ya." (4) "My ability, independence. That's how I see my function. And I define function as a paraplegic as – my hands are a-okay. There is zero impairment with my hands. I have impairment with my balance, that's not something you can see very easily." (8)
Definition of function (aspects of daily living)	"Functioning, to me, is being able to complete an activity, without resistance or compromise. Functionality, to me, is being able to complete normal activities in a timely and efficient manner as well. It branches out of all aspects of daily living." (10) "To me it means your ability to do things and how easy or difficult it maybe to do it and how it may have changed because of something happening. For me, it's specific things like ability to feed yourself, dress yourself, take care of hygiene needs, walking, reading, Daily activities." (11) "Function is the ability to perform certain tasks. That's it to me. It can be washing dishes [for example.]" (6)

Table 3

Facilitators to function.

Theme (subtheme)	Quote
ICF component: Environmental factors, ICF code e115: Products and technology for personal daily use	
Facilitator to function (helpful tools)	"[My foot stop]. I'm short, so it raises me up to a sitting position, I use it to keep me from sliding down in bed. When I put the tray table across me, I can reach." (4) "The computer is important because with the advent of the Internet, I go online and I need some bandages, and I can just look online, type it in, and order it and it comes to me. And with that service, Lumosity, I use it, they claim it helps your brain." (6) "This is a multi-tool and this is an allen wrench, I take them everywhere I go ... they're pocket-friendly. I use them on a daily basis to tighten things up on my wheelchair and shower chair." (8)
Facilitator to function (weight-lifting)	"Here is a weight machine like they have in therapy. I use this at home, sometimes I don't want to come all the way [to the hospital]. At least three days a week I do therapy; on off days I'll do it at home. I do at least 25 min of something, everyday, to keep myself moving around. My mobility is enhanced because of these machines. ... I'm not stiff. (6) "It's helped me a lot. I love to go to therapy. I don't miss it. I go every week. They keep you going. They work you out. I ride the little thing, the bicycle backwards, I lift weights." (7) "These are my hand cycle bikes. They help me with cardiovascular workouts ... I notice if I don't do cardio my resting pulse is like 100 beats per minute ... If I work out for a month or two in a row ... I can bring that resting heart rate down to like 75 or 80." (8)
ICF component: Environmental factors, ICF code e355: Health professionals	
Facilitator to function (therapists)	"She's really helpful to me, she's my physical therapist. If it hadn't been for her, I would probably be stuck in bed. She forced me to walk; I wouldn't be alive today without her." (1)
ICF component: Using transportation, ICF code d470: Using transportation	
Facilitator to function (transportation: personal)	"This is a picture of my ramp in my van. It makes getting in and out possible. The hand control ... right by the steering wheel that operates the gas and the brake ... the adaptive stuff in my van ... that helps." (8)
Facilitator to function (transportation: public)	"When I go to church I take PACE. The PACE [bus] takes me from the house to church and church and back." (7) "I gave up driving. I couldn't go out to eat like I used to ... but now I got me a PACE [bus] card." (4)
ICF component: Environmental factors, ICF code e310: Immediate family	
Facilitator to function (caregiver: family)	"I'm really dependent on my wife. When my twins were born I depended on her for the bathing because, with my balance, I was just nervous ... they are my first babies." (7)
ICF component: Environmental factors, ICF code e355: Health professionals	
Facilitator to function (caregiver: VA health care team)	"My social worker ... she knows more about my business than I know about my own, I couldn't get along without her." (1)
ICF component: Environmental factors, ICF code e340: Personal care providers and personal assistants	
Facilitator to function (caregiver: paid caregivers)	"I couldn't get along without her [my aide]. Well you have laundry, she does it for me. Besides that she helps me straighten up my room, fix my bed, anything else that needs to be done." (1)

Table 4

Barriers to function & adaptations to berries

Theme (subtheme)	Quote
ICF component: Environmental factors, ICF code e120: Products and technology for personal indoor and outdoor mobility and transportation	
Barrier to function (wheelchair)	“With this wheelchair here, I need someone to push me everywhere I go. My wife is 63 years old, she’s getting tired. So that’s why I am trying to get a mobile chair so I can take care of myself.” (7)
ICF component: Environmental factors, ICF code e150: Design, construction, and building products and technology of buildings for public use	
Barriers to function (around the community)	“As I travel through the city in which I reside, that age of the town I showing ... by degrading of walkways ... it’s broken down, you have to maneuver it. The actual breakdown is taking up the whole sidewalk. It’s detrimental for someone who is in a [wheel]chair because the ride is not smooth.” (2)
Barriers to function (around the hospital)	Exterior: “Well this picture at the hospital is like cracks in the sidewalk ... when you’re rolling some areas are uneven you’re constantly going hump-bump-bump ... then here ... it’s steep and curved at the same time, so your chair gets hung up.” (2) Exterior: This one is related to that handicapped ramp they just installed. The ramp is a good ramp, unfortunately they’ve got a deceptive curve that is a two inch drop at the end. It’s a trip hazard ... it’s not just people in wheelchairs coming to the SCI unit, it’s also people who are walking, caregivers.” (10) Interior: “The sink right now they got two hampers underneath. And when I go in between them I hit the darn bowl underneath and smash my knees. Maybe they ought to make those counters a little higher.” (2) Interior: “It’s difficult to use my bed control. I can’t tilt my whole body up and down. I have to have somebody else hit the button for me to tilt me back after I slide down in bed.” (5)
ICF component: Environmental factors, ICF code e120: Products and technology for personal indoor and outdoor mobility and transportation	
Adaptations to barriers (ramps)	“I’ve got a mechanical lift that takes me from street level to the first floor and down to the basement. I tied a piece of parachute cord on the door handle, put that in my mouth, and I enter the ramp ... I pull that until I can grab the loop then I am on the lift.” (10) “I took a picture of the side ramp I had built so I can get in and out of my back door with ease.” (6)
ICF component: Activities and Participation, ICF code d465: Moving around using equipment	
Adaptation to barriers (other)	“This picture here, I have a rubber band around the soda can so that gives friction. After pushing around [in the wheelchair] all day, things tend to slip your hands and that prevents it from happening. I’ve heard quads do it because they don’t have superstrength and they don’t have to grip as tight with the rubber band.” (8) “This is a picture of my shower bench. So I don’t have to sit on the floor to get in the bathtub. It makes a bath much, much easier. I bring the one I can collapse down that enables me to go on vacation.” (8)