Thriving vs. Surviving: Learning to Direct Care After Spinal Cord Injury

Jeanne M. Zanca, PhD, MPT; John Morris, PhD; Carol Gibson-Gill, MD; Marcel P. Dijkers, PhD; Joyce Williams, MSW; Tomicka McMillion, RN

1Kessler Foundation, West Orange, New Jersey
2Shepherd Center, Atlanta, Georgia
3VA New Jersey Health Care System (VANJHCS), East Orange, New Jersey
4Icahn School of Medicine at Mount Sinai, New York, New York
5Wayne State University, Detroit, Michigan
Presenters have the following interest to disclose:

- Grant support from
  - The Department of the Army/Department of Defense
  - Department of Veterans Affairs
  - National Institute on Disability, Independent Living, and Rehabilitation Research
  - Craig H. Neilsen Foundation
  - New Jersey Commission on Spinal Cord Research
  - Patient-Centered Outcomes Research Institute

PESG staff, PVA staff, and planning/review committee members have no financial or non-financial interest to disclose.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with Paralyzed Veterans of America. PESG, PVA, and all accrediting organization do not support or endorse any product or service mentioned in this activity.
Learning Outcomes

At the conclusion of this activity, the participant will be able to:

1. Identify challenges faced by veterans and civilians with tetraplegia as they learn to direct their own care.

2. Identify factors that veterans and civilians with tetraplegia feel were helpful to them as they became skilled directors of their own care in the community.

3. Discuss ways in which patient/caregiver training may be augmented to foster effective development of direction-of-care skills.
CE/CME Credit

If you would like to receive continuing education credit for this activity, please visit:

https://pva.cds.pesgce.com
This research was supported by the Department of Defense Spinal Cord Injury Research Program under award number W81XWH-12-1-0553.

Views and opinions of, and endorsements by the presenter do not reflect those of the US Army or the Department of Defense.
Background

- People with tetraplegia due to SCI with significant loss of physical function require assistance from others for most activities

- Average hours of care/day reported to range from 7 to 19, depending on the level of injury (Robinson-Whelen and Rintala 2003; Prince et al, 1995)

- Care may be provided by “informal” caregivers (spouse, other family, friends, etc.), paid caregivers, or a combination of both (Walker et al, 2015; Boschen et al 2005; Lucke et al 2004; Robinson-Whelen and Rintala 2003; Weitzenkamp et al 2002; Unalan et al 2001)

- Appropriate personal assistance is critical to maintain health and hygiene, prevent secondary complications, avoid institutionalization, participate in family and community roles, and maximize quality of life
Background

• The ability to instruct others in how to provide assistance (known as “direction of care”) is important to:
  – Empower people with SCI to take an active role in their own care
  – Maximize autonomy and personal choice
  – Ensure that needs are met to prevent complications
  – Facilitate participation in activities considered important to the person receiving assistance
Background

• Teaching people with SCI to be able to direct their care is an important goal of inpatient rehabilitation

• No studies to date have focused on the experiences of people with SCI as they learned to direct their care

• Data presented here were collected in the context of a larger study to create an assessment tool for direction of care skills (of people with SCI) and caregiving skills (of formal or informal caregivers)

• Analyses presented here focus on themes related to barriers and facilitators of learning to direct one’s own care
Methodology

• Focus groups were conducted with civilians and veterans with tetraplegia due to SCI (n = 26) who met the following inclusion criteria:
  – Traumatic or non-traumatic SCI of a non-progressive nature
  – SCI for at least 1 year
  – At least six months experience directing caregivers on a regular basis

• Most participants were nominated by professional colleagues (clinicians or researchers)
Methodology

- Focus groups took place at Kessler, Shepherd Center, and the VA New Jersey Health Care System (VANJHCS)

- Discussion questions developed with input from investigative team

- Two hour discussions were facilitated by lead investigator (JZ)

- Discussion topics included:
  - Process of learning to direct and provide care
  - Characteristics of good direction of care and caregiving
  - Suggested topics for training
  - Other experiences related to direction of care and working with caregivers

- Discussions were recorded and transcribed
Methodology

• Transcripts were reviewed by two or more investigators
• Initial list of primary themes and subthemes identified by lead investigator, then reviewed by co-investigators who suggested additions and revisions
• Final list of themes determined by consensus
## Participant Characteristics

### People with Tetraplegia

<table>
<thead>
<tr>
<th></th>
<th>Kessler</th>
<th>Shepherd</th>
<th>VANJHCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>9</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Age in Years [Median (Range)]</td>
<td>44 (29–67)</td>
<td>45 (30-61)</td>
<td>59 (43-81)</td>
</tr>
<tr>
<td>Sex [% Male]</td>
<td>67</td>
<td>57</td>
<td>100</td>
</tr>
<tr>
<td>Ethnicity [% Hispanic]</td>
<td>11</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Race [% Caucasian]</td>
<td>56</td>
<td>57</td>
<td>33</td>
</tr>
<tr>
<td>Years Post-Injury [Median (Range)]</td>
<td>16 (2-50)</td>
<td>20 (1-44)</td>
<td>21 (2-38)</td>
</tr>
<tr>
<td>Paid Hours of Care Received Per Week [Median (Range)]</td>
<td>37 (6-56)</td>
<td>35 (9-72)</td>
<td>36 (0-140)</td>
</tr>
<tr>
<td>Unpaid Hours of Care Received Per Week [Median (Range)]</td>
<td>10 (2-12)</td>
<td>12 (0-24)</td>
<td>24 (2-168)</td>
</tr>
<tr>
<td></td>
<td>Kessler</td>
<td>Shepherd</td>
<td>VANJHCS</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>n</td>
<td>9</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Age in Years [Median (Range)]</td>
<td>44 (29–67)</td>
<td>45 (30-61)</td>
<td>59 (43-81)</td>
</tr>
<tr>
<td>Sex [% Male]</td>
<td>67</td>
<td>57</td>
<td>100</td>
</tr>
<tr>
<td>Ethnicity [% Hispanic]</td>
<td>11</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Race [% Caucasian]</td>
<td>56</td>
<td>57</td>
<td>33</td>
</tr>
<tr>
<td>Years Post-Injury [Median (Range)]</td>
<td>16 (2-50)</td>
<td>20 (1-44)</td>
<td>21 (2-38)</td>
</tr>
<tr>
<td>Paid Hours of Care Received Per Week [Median (Range)]</td>
<td>37 (6-56)</td>
<td>35 (9-72)</td>
<td>36 (0-140)</td>
</tr>
<tr>
<td>Unpaid Hours of Care Received Per Week [Median (Range)]</td>
<td>10 (2-12)</td>
<td>12 (0-24)</td>
<td>24 (2-168)</td>
</tr>
</tbody>
</table>
Challenges Encountered When Learning to Direct Care
Challenges

1. Not yet knowing one’s post-SCI body.
2. Lack of capable or willing assistants.
3. Hesitance to criticize caregivers.
4. Embarrassment about personal care needs.
5. Difficulty engaging in inpatient direction-of-care training due to denial of one’s long-term needs.
7. Differences between the hospital and “the real world.”
Challenges

1. Not yet knowing one’s post-SCI body.
2. Lack of capable or willing assistants.
3. Hesitance to criticize caregivers.
4. Embarrassment about personal care needs.
5. Difficulty engaging in inpatient direction-of-care training due to denial of one’s long-term needs.
7. Differences between the hospital and “the real world.”

Expressed by both civilians and veterans
Challenges

1. Not yet knowing one’s post-SCI body.
2. Lack of capable or willing assistants.
3. Hesitance to criticize caregivers.
4. Embarrassment about personal care needs.
5. Difficulty engaging in inpatient direction-of-care training due to denial of one’s long-term needs.
7. Differences between the hospital and “the real world.”

Expressed in civilian groups only
1. Not Yet Knowing One’s Post-SCI Body

- SCI creates profound changes
- Participants reported having to learn about:
  - Their functional capabilities
  - What sensations (spasms, pain, etc.) are “normal” or not for them
  - What techniques work best for transfers, dressing, etc.
  - How caregivers should use equipment of various kinds (catheters, wheelchair, mechanical lift, etc.)
  - What complications are possible and how to prevent them
- Difficulty seeing the body areas where important activities are done (such as bowel and bladder care) created challenges in being able to understand their needs
1. Not Yet Knowing One’s Post-SCI Body

“When you come out of here [inpatient rehab] you're so raw, you have no idea. I think I only stayed here for two months, and it was such a shock, I was 24 years old, independent, just starting my life, and I had no idea…Then when you go home, how are you going to teach somebody if you don’t know yourself?”

- Civilian participant
1. Not Yet Knowing One’s Post-SCI Body

“So you can have a mirror to see your back, your butt, your feet and all that... If you don’t know what you’re talking about, how are you going to teach them?”

- Veteran participant
2. Lack of Capable and Willing Assistants

• Most assistants are not familiar with SCI
  – How SCI affects functioning
  – Nature and extent of care needs
  – How to use technology (mechanical lifts, power chairs, etc.)

• Assistants are sometimes unwilling to do things in the manner requested by the client with tetraplegia

• Lack of professionalism among assistants is an issue (lateness, excessive cell phone use, etc.)

• Challenging to work with caregivers who are not fluent in English
2. Lack of Capable and Willing Assistants

“Everybody thinks that they know how to move you, and not knowing your injury and not knowing what parts of your body are sensitive and not sensitive to different types of pain, they could grab you a certain way, which would not be a problem for anybody else, but for me it was a problem.”

- Veteran participant
“A lot of the aides had no idea. They just thought that you had a broken bone or something like that. So, they didn't understand some of the neurological things that if you had an accident or you had spasms or something like that--they thought that it was something that they were doing or they would kind of be hesitant trying to move you.”

- Civilian participant
2. Lack of Capable and Willing Assistants

“There are a lot of people who are aides who want to be aides, and there are people who are aides with their 3rd job and 4th job and they are just there to collect a paycheck…I hate to say, a lot of them will try to work you, and they have got every sob story in the book.”

- Veteran participant
2. Lack of Capable and Willing Assistants

“You tell them to do one thing and they do what they want to do...Most of them want to do it on their pace, when they need it done instead of when you want it done. Some of them are non-chalant and they don’t care. They half do it.”

- Civilian participant
3. Hesitance to Criticize Caregivers

• Early on post-injury, some felt as if their needs were inconveniencing others

• Some perceived themselves to be in a vulnerable position, unable to even get out of bed without help

• Some expressed fear of being retaliated against or losing a caregiver if they criticized their performance

• While mentioned by both civilians and veterans, these concerns were more prominent in the civilian group
3. Hesitance to Criticize Caregivers

“How do you lie in bed in need of certain services, certain care, direct your employee? Now, how do you reprimand them and give them direction without worrying about retaliation, passive aggressive stuff? It's so tough.”

- Civilian participant
3. Hesitance to Criticize Caregivers

“You picked your battles because you didn’t want them to leave before you had their replacement.”

- Veteran participant
4. Embarrassment

• Discussed feeling embarrassed about certain care needs, particularly bowel care
4. Embarrassment

“There are certain situations where you really don’t want to speak up, whether it be you’re embarrassed or you don’t want to make the other person uncomfortable. But due to your situation, if you don’t speak up upfront to prevent a situation from occurring…you may cause a bigger issue in the long run.”

- Civilian participant
4. Embarrassment

“You get over the embarrassment of things that you have to [get help with]. If you are embarrassed, you can lose so many things. There are so many things that they have to do for you that you cannot do for yourself. You got to give it up.”

- Veteran participant
5. Difficulty Engaging in Direction-of-Care Training

- In the discussions with civilians, some reported that in the early stages of rehabilitation:
  - They were focused on recovering lost function, not learning how to compensate
  - “Denial” of their condition resulted in a lack of interest in direction-of-care training
  - They felt that their impairments would be temporary, therefore they did not need to learn about techniques to compensate (bowel and bladder care, weight shifts, etc.)
5. Difficulty Engaging in Direction-of-Care Training

“...The first two or three months that I was here [in inpatient rehab] I wasn’t trying to hear about, ‘You’re going to have to get a suppository or you have to get cathed,’ or anything like that. I was like ‘I’m going to get better, my spinal cord is going to heal in a couple months, I’m going to go hard in therapy and I’m going to be fine. I’m going to be running around, I’m not going to have to worry about this.’”

- Civilian participant
6. Overwhelming Volume of Information During Inpatient Rehab

- Civilian participants commented on how lengths of stay in rehabilitation have gotten shorter over time
  - Resulted in a large amount of information being presented in a short period of time
  - Reported feelings of being overwhelmed
6. Overwhelming Volume of Information During Inpatient Rehab

“They throw so much at you. It’s a lot to remember. You can't even begin to imagine what life is going to be like when you get home.”

- Civilian participant
Civilian participants also reported that the way they learned to do things in the hospital didn’t always translate well to home.

Differences between home and hospital included:

- Different equipment (manual mechanical lift vs. power lift, different lift slings, etc.)
- Reduced accessibility of physical environment
- Smaller stock of supplies
- Differences in technique used for certain tasks (e.g. sterile technique for bladder care in hospital vs. clean technique at home)
7. Differences Between the Hospital and “The Real World”

“When I came home I was like, ‘oh, how am I supposed to do this’? Because the way I was doing it was on the bed, and then transferring. But then when I got home it just doesn’t quite work that way.”

- Civilian participant
What are your thoughts about these challenges?

- To what extent do you feel that the people with SCI with whom you work experience these same challenges?

- Are there other challenges you have observed that were not brought up in the focus groups?

- Do you perceive differences in the kinds of challenges experienced by civilians vs. veterans? What are they?
Factors that Facilitate Successful Direction of Care
Facilitators

1. The experience that comes with time.
2. Paying attention to your body and to how care is done.
3. Learning to communicate calmly, clearly, and specifically what needs to be done and why.
4. Developing confidence and skill to advocate for your needs.
5. Learning when to let go and when to speak up.
6. Speaking with peers with SCI about their experiences.
1. Experience

• Most participants reported that they learned how to be better directors of care over time, through:
  – Learning about themselves and their condition
  – Encountering problems (and either solving them or learning what leads to them)
  – Gaining experience working with personal care assistants

• Some participants (veterans and civilians) reported that their experience in inpatient rehabilitation was very helpful in preparing them, others attributed their learning more to their experiences after discharge
1. Experience

“I think the only way to do it is time and experience… Unfortunately, your bowels have to touch your urological equipment and you gotta get E. coli and you’ve got to get your urinary tract infection, you’ve got to get your first emergency room visit and stuff like that, and until that really happens you don’t know.”

- Civilian participant
1. Experience

“I learned through therapy, you know, what’s my range of motion, what I could do, what I could not do. They showed me the proper way to tell someone how to do things for me…so when I did get out the initial rehab setting when I got injured, I was able to relate to anybody else what is going on.”

- Veteran participant
2. Paying Attention

• Reported learning what sensations are “normal” for them vs. those that might indicate a problem is present (such as an increase in spasticity)

• Reported that it was important to learn how their care tasks should be done so they could:
  – Train other caregivers when there is turnover of staff or when usual caregivers are not available (e.g. snowstorm)
  – Intervene if a task is not being done properly
2. Paying Attention

“Main thing is to pay attention. If you aren’t paying attention then you can’t relay your information or teach somebody something…I can’t change my catheter, but I could teach a blind man to change my catheter…So if I have a nurse that comes to the house, a different nurse, and my catheter needs to be changed, I tell them exactly how to do it…But if I wasn’t paying attention, then it would be like they would do it their way. It might be wrong, it might not work, I might get an infection…”

- Veteran participant
“Just like I said, know your body…If my feet swell up and my shoes are too tight, my toes will lock off. Time to take my shoes off. Time to put on some flip-flops, you know. Just know your body.”

- Veteran participant
2. Paying Attention

“I know different kind of spasms, what’s causing them. So knowing your body—I know I have different types of spasms. One might be from …not taking my medication. Others might be from some kind of a pain.”

- Civilian participant
2. Paying Attention

“…be aware of yourself, know what’s going on with your body, because you’re the only one who would know whether you need care, you need medication, or you don’t need anything anymore. You just can’t rely on others to do that.”

- Civilian participant
3. Learning to Communicate

• Communication skills were considered critical for successful direction of care

• Important aspects of communication included:
  – Providing sufficient detail about what is needed and how a task should be done
  – Explaining rationale for why a task needs to be done a certain way (to increase likelihood of compliance by caregiver)
  – Communicating in a manner that fosters positive interpersonal dynamics
3. Learning to Communicate

“I explain to them I want the coffee here, not because I'm …a dictator, but why it needs to be here. Because I can reach it, I'm more independent…So explaining to them why you need certain things, when you need them, where you need them, and how you need them.”

- Civilian participant
“I like a sense of humor, too—that helps. You get more flies with honey than with vinegar.”

- Veteran participant
3. Learning to Communicate

“I always thought that when it comes time to discipline, punish, reprimand, etc. it is always better to wait until you have calmed down and not to do it at the time of the incident, because a lot of times you are more emotional at that time, and you can be hurtful and not helpful.”

- Veteran participant
3. Learning to Communicate

“I think learning how to actually communicate with a caregiver is just like any other relationship, whether it be personal or professional. You have to find a diplomatic way to communicate everything.”

- Civilian participant
3. Learning to Communicate

“I also found that people are more willing to help you if you have a pleasant attitude than if you come across as grouchy or if you act as though the world owes you something.”

- Veteran participant
4. Developing Confidence and Skills to Advocate for Oneself

- Participants reported coming to the realization that they had a right to certain care, and became more inclined to communicate their concerns when problems arose.
- Learned the implications of not speaking up (problems with health, being taken advantage of, etc.).
- Developed strategies for providing negative feedback to caregivers when needed.
- Over time, felt more willing to change caregivers if needed.
4. Developing Confidence and Skills to Advocate for Oneself

“...it took a while to learn not to allow the caregiver to bully you, and to know that if you wanted it done a certain way or not at all—that you could get injured or something because the person was doing it the wrong way. It took a while to get used to that because a lot of times in that situation, I felt that I was putting them out by making them do it my way, but then I came to the realization that if I allowed them to do it wrong, and I got hurt, I was the one who was going to suffer.”

- Veteran participant
4. Developing Confidence and Skills to Advocate for Oneself

“There’s a confidence level which has grown over time. Because initially, you feel pretty vulnerable, pretty dependent and helpless…I didn’t feel--almost like--*worthy* [emphasis added], in some cases to make certain demands or complaints or whatever. I was even called picky by one of my caregivers. I’ve learned over time…This is really about me. I deserve a certain level of care and treatment, et cetera. So the hell with being picky, this is how I want it done. And it’s been just very recently that I’ve really come full circle into owning that.”

- Veteran participant
4. Developing Confidence and Skills to Advocate for Oneself

“I ended up having to let her [my assistant] go because of the tension...it’s a relationship. You want to be comfortable with who you’re working with. That was tough for me to do. I was really intimidated about taking that step, but I realized I had to—otherwise, I’m going to get run over.”

- Civilian participant
4. Developing Confidence and Skills to Advocate for Oneself

“If a caregiver called me picky, that would be an issue. I would then remind her that everybody has personal habits. When you [the caregiver] get up in the morning you have a routine. You have a very specific way of doing things. You’re just not aware of it because you don’t need help doing it. So, the word picky is irrelevant, it’s such a negative kind of connotation. I think it’s important to say that ‘I have a specific way of doing things. There is no right or wrong way of doing it—it’s just the way that I do it. It’s how I prefer to go about my routine and I need your assistance in doing it that way.’”

- Civilian participant
4. Developing Confidence and Skills to Advocate for Oneself

“There’s other times where they didn’t want to do something, and I would wait until after the shift is over, and I would explain to them that this is part of your job, you know. I need you, but you need me too because this is your job, you know. And if you can’t do it my way--I am not trying to be crass--but if you can’t do it my way, because it’s my body, then you have to step out.”

- Veteran participant
5. Learning when to let go and when to speak up

- Reported that there are often times when an assistant may do something in a way that differs from what the person with SCI prefers.
- Participants expressed that too much criticism can damage the relationship.
- Discussed the importance of speaking up for things that can adversely affect you but letting less important things go.
“I try my best not to complain as much, because then when you do complain then they take it a little more serious…So don't complain so much, but when it's serious, complain, when need be. Try to bite your tongue a little bit, but at the end of the day I try to do what I can to make myself happy and go on with my life.”

- Civilian participant
5. Learning when to let go and when to speak up

“Just learning to have patience with other people. That’s a big thing.”

- Veteran participant
6. Speaking With Peers

- Participants reported that peers were a good source of information about living with SCI, which could help support their ability to take an active role in their care.
6. Speaking With Peers

“You see other quads, you talk about your problems, and you learn ‘he’s doing that, I’ll try that’…We’d all talk about similar issues, similar things that are going on with us…When I see other people, you can share information and you gain knowledge that way too.”

- Civilian participant
6. Speaking With Peers

“If you see something on somebody else’s chair, when they are getting in and out of their cars, ask them. If you don’t know what it is, ask them what it is. Because even [though] OTs and PTs are wonderful, they don’t know everything.”

- Veteran participant
What are your thoughts about these facilitators?

• To what extent do you feel these facilitators are relevant to your patients with SCI?

• Are there other facilitators you have observed that were not brought up in the focus groups?

• Do your programs include activities or education that is relevant to these facilitators?

• Are there gaps in service provision that you feel should be filled to better promote direction-of-care skills? What are they? What do you suggest be done to fill those gaps?
Limitations

• Potential for selection bias
  – Skilled communicators and proactive consumers tended to be nominated for participation

• Participants focused on their experiences with paid caregivers
  – Questions asked about caregivers in general
  – Other themes might have emerged if specific questions had been asked about formal vs. informal caregiver interactions
Limitations

- Civilians have greater representation in the overall sample
- Cannot say with certainty whether differences in themes found in the civilian vs. veteran discussions reflect true differences in their experiences
  - Analyses were done after discussions were completed
  - Did not have opportunity to ask follow-up questions in focus group to clarify if experiences reported by one group were also experienced by the other
  - Differences in culture or access to care (such as length of stay in rehabilitation) may account for some differences, such as feelings of being overwhelmed
Conclusion

• The ability to direct one’s care is a complex skill that is developed over time, and requires:
  – In-depth knowledge of one’s body and one’s care needs
  – Awareness of self
  – Good observation skills (to assess caregivers’ performance and interpersonal dynamics)
  – Assertiveness
  – Patience
  – Strong communication skills
Conclusion

• Efforts to prepare people with new SCI to direct care effectively should:
  – Cultivate awareness of one’s body and care needs
  – Address “soft skills” such as communication and self-advocacy
  – Provide opportunities for practice in settings as close to the “real world” as possible
  – Encourage interaction with peers