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# Health Care Self-Advocacy Strategies for Negotiating Health Care Environments: Analysis of Recommendations by Satisfied Consumers with SCI and SCI Practitioners

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Individuals with spinal cord injury (SCI) often experience complex health problems that, if untreated, can be costly and debilitating.<sup>1,2</sup> In turn, they are high users of primary care.<sup>3</sup> One study found that, during primary care visits, approximately 80% of the problems mentioned by patients with SCI were related to secondary conditions, such as urinary tract infections, pain, and skin problems.<sup>3</sup> In a study of SCI patients in the Netherlands, over half (52%) of the contact with a primary care doctor was related to secondary conditions, with 34% considered to be preventable.<sup>3,4</sup>

Despite the necessity for quality health care, individuals with SCI face structural and environmental barriers, such as problems with transportation<sup>5,6</sup> and inaccessible provider offices and equipment<sup>5,7,8</sup>; studies have consistently found that these barriers hinder patients with disabilities from receiving needed care,<sup>7-11</sup> including preventive screenings.<sup>2</sup> Process barriers, such as physician's lack of SCI knowledge, are also an ongoing problem. One study reported that emergency department (ED) residents displayed appropriate knowledge of 6 serious complications for SCI patients in the ED only 47% of the time.<sup>12</sup> Other studies reported that SCI patients have difficulty

finding knowledgeable doctors and feel the need to educate them about their disability.<sup>6,13-15</sup> While potentially dangerous, limited provider knowledge can also pose a substantial hurdle for SCI patients in accessing primary health care. Lack of funding and service fragmentation are also cited as major process barriers.<sup>16</sup>

In navigating the numerous barriers within the health care system, individuals with SCI often struggle to get their health care needs met. When surveyed, 33% of patients with SCI expressed an unmet primary care need, with greater unmet needs related to lower income and poorer health status.<sup>3,17</sup> A study of ED use by individuals with traumatic SCI classified half of ED visits as potentially preventable or of low urgency.<sup>18</sup>

Every consumer must navigate a complex interplay of socioeconomic, environmental, and physical factors unique to their situation as they try to access quality primary care. While many studies have documented barriers to care and health disparities, as well as recommended systems-level changes,<sup>3,15,19</sup> few have focused on the navigation strategies utilized by consumers to effectively get their needs met.<sup>7,20</sup> A fuller understanding of consumer-level strategies could facilitate the development of effective interventions – which

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are sorely lacking<sup>2,3,21</sup> – to empower individuals with SCI in decreasing health care disparities. The purpose of this study is to articulate the strategies for self-advocacy and navigating the health care system as perceived by community advocates with SCI who report high satisfaction with their primary care in comparison to SCI practitioners.

## Methods

We conducted a retrospective analysis of recordings of semi-structured in-depth individual interviews with consumers with SCI. These interviews had originally been conducted in the individuals' homes to develop consumer vignette clips for a research intervention rather than as a prospective research study. Ten of 10 consumers invited agreed to be interviewed. These 10 were chosen to represent a range of background characteristics from a larger list generated by the research team based on an individual's local community involvement in an advocacy role. Upon invitation, each participant reported high satisfaction with their primary care. Three of the 10 were not interviewed – 2 because of scheduling issues and 1 due to unexpected health problems. Two independent reviewers analyzed transcriptions of the 5 men and 2 women with diverse injury levels, ages, and backgrounds who participated (see **Table 1**).

Practitioner data came from interviewer notes of 4 invited SCI practitioners, all of whom agreed to be interviewed (see **Appendix A**). All were invited based on their 10+ years of experience supporting individuals with SCI locally and nationally in self-advocacy efforts, including 1 man and 3 women with varying professional backgrounds and roles (see **Table 1**). Three of the 4 were members of a content expert panel to guide the aforementioned study intervention's development.

The SCI consumer interview guide consisted of 18 open-ended questions, such as “How did you go about finding your current primary care doctor?” The overall focus was on the consumers' experiences, advocacy strategies, and recommendations related to primary care, durable medical equipment, overall health care navigation, and personal barriers to advocacy (see **Appendix B**). Each question included optional probes, such as “Did someone recommend a doctor?” and “Did someone help you?” The interviewer asked the questions if they were not covered in the natural course of discussion. Interviews lasted from about 20 to 60 minutes (average, ~41 minutes). At the time of retrospective analysis, all consumer interviews had been professionally transcribed.

The SCI practitioner interview guide consisted of 18 open-ended questions, mirroring the structure and topic areas of the consumer interviews. These interviews occurred on the phone and lasted for about 15 to 20 minutes. The interviewer did not

**Table 1.** Consumer and practitioner characteristics ( $N = 11$ )

	Age	Gender	Race	Injury level	Years injured
Participant 1	72	M	White	Paraplegia, complete	9
Participant 2	39	M	Black	Paraplegia, incomplete	10
Participant 3	22	M	Hispanic	Paraplegia, incomplete	20
Participant 4	39	M	White	Tetraplegia, complete	14
Participant 5	47	F	White	Tetraplegia, incomplete	15
Participant 6	63	F	White	Tetraplegia, complete	7
Participant 7	68	M	White	Tetraplegia, incomplete	46
		Profession			Years of experience
Practitioner 1		Physical therapist			19
Practitioner 2		Social worker			21
Practitioner 3		Nurse			16
Practitioner 4		SCI information specialist; consumer			7; 13 years injured

record these sessions but did take notes during the interview. At the time of retrospective analysis, all interview content had been transcribed and organized in a tabular format by the topic areas described above for each interviewee.

Coding was conducted using thematic domain analysis,<sup>22</sup> based on Spradley's ethnographic interview approach,<sup>23</sup> which involved a 4-step process. Two researchers reviewed the data independently. In the first step, each researcher reviewed indexed tables of consumer quotes to identify concrete, practical primary domains. Second, the researchers created subdomains. Third, the researchers organized meaningful content from the interviews under each subdomain. They then developed a relational framework for the primary domains and (where appropriate) subdomains. At each step, the researchers would review and discuss any discordant items until consensus was reached. Due to the preliminary nature of the data, results from the last step are not detailed here.

For practitioner analyses, researchers incorporated professional interview content at step 3 for comparison within the consumer framework.

## Results

Domain analysis of consumer interview transcripts revealed 3 primary domains, with associated subdomains (see **Table 2**), against

which practitioner data were compared. Consumers were asked about their experiences and recommendations for navigating primary care visits and equipment needs and then, based on this, to recommend what they considered the most important self-advocacy skills and navigation strategies overall.

In the following discussion, specific questions are listed under each domain for consumers and for practitioners that elicited the content groupings presented therein. Practitioner comparative results follow the consumer data within each domain/subdomain (see **Table 3** for summary comparison).

### Primary domain 1: Navigating primary care visits

In interviews, consumer advocates were asked open-ended questions about their experiences with finding a primary care physician (PCP), what they liked (or disliked) about their current PCP, most important PCP qualities, and positive and/or challenging experiences in communicating with their PCP. In this domain, consumer content fell under subdomains of choosing a PCP and maintaining quality health care.

Practitioners were asked to offer consumer tips for finding a PCP, coordinating care, overcoming communication challenges, developing effective patient–doctor relationships, and any other related tips.

**Table 2.** Taxonomy

Primary domains	Subdomains	Subdomain categories
1. Navigating primary care visits	Choosing a primary care physician (PCP)	Effective strategies Qualities to consider Trade-offs
	Maintaining quality health care	Building the physician/patient relationship Effective communication strategies Resolving problems
2. Navigating equipment	Key strategies	Picking the right wheelchair Active consumer coordination
	Overcoming barriers	Insurance requests and appeals Engage professionals as advocates
3. Most important recommendations	Self-advocacy recommendations	Recognizing the need to self-advocate Most important self-advocacy skills
	Navigation strategies	Support networks Persistence

**Table 3.** Congruence of domain themes for consumers compared to practitioners

Characteristics	Domains					
	Navigating primary care visits		Navigating equipment		Most important recommendations	
	Choosing a PCP	Maintaining quality health care	Key strategies	Overcoming barriers	Self-advocacy recommendations	Navigation strategies
Consumer 1	x	x	x	x	x	x
Consumer 2	x	x	x	x	x	x
Consumer 3	x	x	x	x	x	x
Consumer 4	x	x	x	x	x	x
Consumer 5	x	x	x		x	x
Consumer 6	x	x	x	x	x	x
Consumer 7	x	x	x		x	x
Practitioner 1		x	x	x	x	
Practitioner 2	x	x	x		x	x
Practitioner 3			x	x	x	x
Practitioner 4	x	x	x	x		

Note: PCP = primary care physician.

### Subdomain 1.1: Choosing a PCP

*Effective strategies in choosing a PCP.* Several consumers reported that they had identified potential PCPs via a list from their insurance company or located them within their hospital(s) of choice. This consumer group commonly interviewed prospective PCPs and followed recommendations<sup>24</sup> to interview 2 or 3 physicians face-to-face. One consumer recorded a phone interview with office staff (rather than the doctor).

*Qualities to consider.* Most consumers suggested a generalist as a PCP, with a physiatrist as a specialist. Two consumers recommended using a physiatrist as the PCP, if possible (though neither did so). Consumers listed accessibility, availability, and responsiveness; experience with SCI and/or other important areas (most notably, aging issues); willingness to listen and learn (caring); and a certain ease in the provider–patient interaction, as being important factors in their choice of a PCP.

*Trade-offs – willingness versus experience.* Consumers consistently spoke of the trade-offs they made in ultimately choosing a PCP to best meet their needs. In practice, the emphasis on the physician's SCI expertise was almost always overridden by other factors. Notably, only 1 of the 7 chose a PCP with particular SCI experience. Most

consumers suggested it was more important that the PCP would readily refer them to a specialist when SCI-related complications arose. Consumers suggested that some PCPs might not feel qualified to treat an individual with SCI. Of the qualities listed above, the PCP's willingness to work with them collaboratively – to listen and learn – was paramount.

Consumers also said they would not compromise on ease of contact (availability) and fast and appropriate triage (responsiveness). They underlined their frequent needs for general checkups, refills of chronic prescriptions, and referrals.

*He is everything that you would want in a doctor. He is thorough. He's smart. He's diligent. He asks a lot of questions. I think he has learned a lot in working with me.... One of the qualities that I like about him is that he is not afraid to work with me. I know that sounds strange, but it's possible for a doctor who is not a physiatrist to be a little skittish about working with people with spinal cord injuries, especially upper, high level quads like myself.*

*Every time I need help, he gets in contact with me within 24 hours, nothing later. And he always makes sure that if I need help he goes up and beyond...*

Several consumers mentioned choosing to trade-off SCI experience for experience in other areas of significance to their life circumstances, such as aging issues or common secondary conditions (eg, pneumonia, urinary tract infections).

*Even though he didn't have experience with spinal cord injuries, he had experience with pneumonia and urinary tract infections, and he was also a good doctor for recommending [me] to other physicians, other specialties.*

### **Subdomain 1.1: Practitioner comparison**

Regarding effective strategies for choosing a PCP, practitioners recommended a variety of sources not mentioned by consumers, including local chapters of United Spinal Association, a physiatrist database from United Spinal's Resource Center, independent living centers, and Web sites. Like consumers, they suggested interviewing multiple doctors and writing down questions before an appointment.

In regard to qualities to consider, they focused almost exclusively on accessibility and experience, notably neglecting other qualities emphasized by consumers. Additionally, one practitioner highlighted transportation as the major access issue. Another practitioner underscored the importance of clinic care coordination (eg, a team model with weekly rounds).

The practice of consumer trade-offs was not mentioned by practitioners.

### **Subdomain 1.2: Maintaining quality health care**

*Building the physician–patient relationship.* Consumers described a high degree of ongoing communication and trust between the physician and patient as being paramount to building a relationship that is conducive to getting health care needs met, starting with the physician's consistent and open communication.

*My doctor will sometimes ask me what I think...I think he knows that I know my own body better than anybody else does, including himself.*

*Every time I go to see him we will catch up to what's new ... He will ask me, "Oh, how did that go, what did you guys discuss about, what's the future goal/plan?"*

Consumers said that honesty about their needs enhanced both communication and trust:

*Find [a PCP] that you're very comfortable with talking to, tell them exactly what's going on, not holding anything back, not feeling like they're going to be judgmental or anything of that nature, build a great relationship with them so that they know everything going on with you so that they can help you appropriately and you can help yourself by allowing them to help you.*

*...sex, having kids, also you know feelings of depression too, you know those are things you've got to be honest with your doctor and communicate those issues.... you should have a comfortable level to where you're able to address those issues.*

*Effective communication strategies for PCP visits.* Consumers recommended strategies to facilitate communication such as:

- Making a list prior to each appointment
- Sharing written notes with the physician
- Bringing a support person (eg, friend, relative, personal care attendant), who is asked to leave when topics are sensitive.

*...if it's a question about depression and you might not want the person with you to know that you're depressed. I mean, I'm sure they're going to know it anyways, but there are some cases where you might want them to actually even leave the room ... where they're in your lives all the time, that might be uncomfortable but it's something that's got to be done.*

*Resolving problems with a PCP.* Consumers shared additional recommendations and experiences for resolving problems with a PCP:

- For recurring accessibility issues, inquire about home visits or call ahead.
- Visit the office in person when faced with a lack of response to a particular need-based inquiry.
- Express global or general concerns to the physician.
- Role-play before the appointment.

*At first we had terrible communication. I really didn't like the doctor... and all of a sudden he started to really get into my case ... after about 4 or 5 months... I would recommend that you say to the doctor that you're unhappy with the way that you are being treated, or the information that the doctor has about your injury... I wish I had done that.*

If problems persist despite repeated attempts to resolve them, consumers unanimously recommended finding a new doctor.

*If all else fails, find a new doctor, because you really need someone who's going to listen to you.*

### **Subdomain 1.2: Practitioner comparison**

In relation to building physician–patient relationship, practitioners did not confirm consumer themes. They emphasized the consumer taking control of the relationship and educating their physician, rather than mutual openness and honesty led by the physician.

Practitioners highlighted similar effective communication strategies as consumers. One practitioner suggested setting up a consultation through the PCP with an SCI specialist to foster ongoing collaboration.

In regard to resolving problems, practitioners offered similar advice as consumers, such as role-playing and finding another doctor. They additionally suggested contacting a case manager or SCI nurse for assistance.

### **Primary domain 2: Navigating equipment needs**

Consumer interviewees were asked about their experiences and recommendations for obtaining a wheelchair and other equipment, including the role of insurance.

Practitioners were asked to describe the ideal process for obtaining a wheelchair, the most common problems, and related resources and strategies and their advice for frustrated consumers and for obtaining other equipment.

A clear theme arose around the description of delayed access to appropriate equipment and needed repairs as common and intractable. All 7 consumers shared their experiences in this regard. Consumers spoke in detail about complications, delay, and their sense of frustration over the process of obtaining the most appropriate wheelchair and other equipment (eg, special mattresses, shower chairs [not covered by insurance]). Consumers offered key strategies based on their experiences, as well as tips to overcome common barriers in this process.

#### **Subdomain 2.1: Key strategies for obtaining equipment**

*Picking the right wheelchair.* To find the right chair, several consumers stressed the importance of involving the wheelchair clinic to be measured for the right fit. The Internet can be very helpful, as can support groups. One consumer reported trying out power chairs through the physical and occupational therapist's office and through wheelchair companies. Another consumer mentioned making trade-offs to avoid potential delay by, for instance, requesting a power chair that would meet their needs sufficiently as opposed to trying to get a state-of-the-art standing chair that would likely be denied.

*Active consumer coordination.* To navigate equipment needs, consumers underlined communication and persistence. Consumers recommended persistence in contacting equipment companies, speaking with appropriate staff (ie, managers, supervisors), and using a positive, assertive, and proactive approach. Consumers stressed the need to monitor the process closely.

*I was checking up to see how the process was going along and the person at [the wheelchair company] told me ... my primary doctor's signature - they never even received it... you could say that I was part of the process, I actually had to be on top of it myself. They're not just going to sit back and do all the work... you've got to follow up on things like that.*

Active involvement was identified as being essential in choosing a new wheelchair.

*If ... they fit you with a chair that they think you are going to like ... it's not like you can turn it back in again. I know people who ... have really been very passive ... and it's just never comfortable for them because they never really took the time to really figure out what they needed.*

#### **Subdomain 2.1: Practitioner comparison**

Practitioners' recommendations largely mirrored those of consumers in regard to key strategies. One practitioner (physical therapist) precisely outlined the "ideal" 3-month process for obtaining a wheelchair; another estimated a year in actuality. They stressed the need to understand insurance coverage up front. Several mentioned the need to consider trade-offs due to insurance coverage limitations, yet encouraged consumers to request the optimal equipment and persist to justify its need with a support team.

#### **Subdomain 2.2: Overcoming barriers**

*Insurance requests and appeals.* Consumers characterized the insurance approval process for obtaining equipment as lengthy, confusing, and extremely challenging. Lack of coordination among multiple providers (eg, PCP physical therapist) was cited as an obstacle that the consumer must address. Consumers offered some key tips:

- Write down the equipment justification before placing the phone call.

- When inquiring about pending claims, ask to speak to managers or supervisors.
- Task the physician with placing the call, to increase the insurance's responsiveness to the request.
- Be persistent and keep "fighting."
- Be represented by an advocate or, if denials continue, by a lawyer.

*Make sure you write down what you do want and your medical needs as to why, try and think what [the insurance company] would want to hear for justification because their bottom line is dollars so you need to give them valid reasons medically why them spending that money on you is important...*

*You also have to be dealing with the right people that are really concerned and that really want to help you out with this. If it seems you're not dealing with the right person, then you need to ask if you could speak with someone else in the company right? Is there someone else I can talk to that you know you might get a different response?*

**Engage professionals as advocates.** While promoting consumer self-management, consumers noted that the system's complexities and idiosyncrasies require engaging an instrumental support network.

*...it's a long drawn out process to get [a new wheelchair]. What I recommend is finding a company that's experienced.... the person that I spoke with at the company was real knowledgeable ... not just working on chairs but also he's involved with the sales - recommending chairs...*

*You need a medical advocate. You can't really get it for yourself. You need someone who can say, "You need this mattress for these reasons." So, that's usually the specialist doctor...*

### **Subdomain 2.2: Practitioner comparison**

In terms of overcoming barriers, practitioners presented a breadth and depth of tips and resources (including funding) not represented in consumers' discussions, confirming the importance of engaging instrumental support in this area. Practitioners identified the 2 major challenges as being the lengthy process from evaluation to obtaining equipment and insurance coverage. They recommended utilizing social workers and independent living centers to navigate appeals and support groups for emotional support.

### **Primary domain 3: Most important recommendations**

Consumers were asked to consider the experiences they had already shared in the interview for navigating primary care and equipment in order to summarize the most important recommendations overall to self-advocate and navigate the system (see **eAppendix A**). Practitioners were asked the same.

#### **Subdomain 3.1: Most important self-advocacy recommendations**

**Recognizing the need to self-advocate.** First and foremost, several consumers pointed out that every individual with SCI needs to recognize the importance of advocating for themselves, in a way no one else can, to get health care needs met.

*So the notion of advocating for myself really comes down to recognizing that I need to advocate for myself, recognizing that I probably know more about myself than anybody else does in terms of my body.*

*Well they're going to have to learn to be that person, to be assertive, there's just no way around it - you have to do that, you know? Because you're going to run into problems and you're going to need to be your own self-advocate or be able to stress to your doctor your needs, what you need.*

**Most important self-advocacy skills.** The most important self-advocacy skills identified included becoming knowledgeable about your injury and health care needs, speaking up and being persistent, practicing communication skills, being organized, engaging with peer mentors and others who teach essential self-management skills, and keeping a positive attitude.

*Not long after I was hurt another doctor that I had again reminded me ... that I was the person who knew the most about my own body ... he said the best thing that I could do was to become as knowledgeable as I possibly could become about all the issues about spinal cord injury that a patient should be aware of ... I think that has probably been the best thing that ever happened to me was this knowledge, because ... then I could more effectively advocate for myself.*

*The best way to advocate for yourself is to just be honest with whoever you're dealing with and letting them know what the problems or issues you're having...*

*I always find that you get a lot more results which sugar than with salt. In other words, don't be so aggressive that you sound angry.*

*Try saying it, try practicing with a friend, whatever you need to in order to be able to find your voice.*

*I think you need to have some skills in trying to talk back to [doctors] and try to push them to do what you want to have done.*

### **Subdomain 3.1: Practitioner comparison**

Practitioners echoed consumers about the need to self-advocate and in listing the most important self-advocacy skills. They offered specific resources not mentioned by consumers and recommended that consumers journal about what they have learned.

### **Subdomain 3.2: Most important navigation strategies**

*Support networks.* Consumers characterized instrumental support as being an absolute necessity for learning how to navigate the complexities of the health care system. They mentioned obtaining emotional support when obstacles begin to feel overwhelming. The sources of support that were mentioned were advocates and advocacy services/organizations, support groups, and SCI professionals (eg, physicians, social workers; wound care nurses, etc).

The following quotes illustrate how support facilitates health care navigation:

*Find a case worker or someone at a clinic or hospital that you go to that understands the system a lot more and have them help you ...you're learning as you go along so you don't just have them do everything...but you ask them to do it or help you with it and you find out exactly what it is they're doing so that you can do the same thing for yourself in the future, so that you have a better understanding.*

*More and more I started understanding who to reach out to and when and, as I understood the process, I started doing it bit by bit here and there, and then I understood what was going on a little better so at that point I started doing it.*

*Persistence.* Consumers emphasized the need to persist, to keep fighting in the face of obstacles.

*And definitely just keep fighting ... if they tell you no, just keep on fighting, because we all struggle through everyday life, and a lot of people don't know how difficult it is...with certain disabilities...*

*It's possible for a person with a severe spinal cord injury to really create for themselves a fine lifestyle and quality of life that they probably at the beginning never thought they could ever have... You will be surprised how pleasant it can be.*

### **Subdomain 3.2: Practitioner comparison**

Practitioners recognize that the health care system can be complicated, overwhelming, and ever-changing. They adamantly warn consumers not to attempt system navigation alone. They recommend that at least one other person should know the consumer's entire story as a support, coach, and helper. They spoke of being persistent and staying focused. They also mentioned system change in areas such as transportation, physician training and knowledge, and reducing insurance barriers.

## **Discussion**

Consumers recommended the most effective self-advocacy skills for health care settings, which also tended to be endorsed by SCI rehabilitation practitioners. Overall, it is encouraging to note the congruence between consumers and experienced SCI rehabilitation practitioners. Although this is a small sample, the responses are consistent with other studies of the provider perspective.<sup>25,26</sup> We may have seen less congruency if other types of medical practitioners with less SCI experience had been interviewed.

Several themes overlapped across domains, namely, active consumer participation and seeking out instrumental support (and, as needed, emotional support) to navigate the system. The importance of these 2 strategies, particularly for individuals with SCI, makes sense in light of research into health care system fragmentation for this group. In qualitative interviews, providers recognized that, due to system limitations, they need to engage in different health care and advocacy roles for individuals with SCI and yet multiple obstacles prevent this.<sup>25</sup> A small survey ( $N = 30$ ) found that only 50% of patients with physical disabilities (including SCI) received care coordination.<sup>14</sup> In turn, individuals with SCI take on the role of coordinating their own

care.<sup>20</sup> Given this lack of support in the health care system, it makes sense that finding social support to help address health care needs has been shown to facilitate better health and functioning<sup>27</sup> and greater self-management.<sup>26</sup> The integration of social support in rehabilitation delivery was recommended by consumers and providers in recent qualitative research, including peer mentoring and social learning self-efficacy groups, to help empower consumers to navigate the system.<sup>28</sup>

Another theme was that of making trade-offs, which emerged both in domain 1, navigating primary care visits, and domain 2, navigating equipment needs. Of note, in choosing a PCP, the important provider qualities mentioned by consumers are consistent with the literature.<sup>3,15,29,30</sup> Yet a unique facet of consumer choice arose in our analysis that is not often represented in the discourse on health care access. That is, at least some consumers in practice are finding ways to make trade-offs in PCP choice that allow them to meet their unique health care needs. A theme arose of being highly satisfied with a PCP despite other undesirable factors, such as his/her lack of SCI knowledge.

For the study's consumers, the PCP's eagerness to listen and learn acted as an overarching facilitator that precluded the need for PCPs to have any particular SCI knowledge base. In some cases, consumers also noted that if the PCP had other specific expertise that they valued, SCI-specific knowledge was not requisite. Perhaps a PCP's caring and collaborative demeanor fosters or indicates the presence of other desirable qualities. Provider training that targets caring and collaborative qualities would seem feasible in light of intervention research that demonstrates the efficacy of provider training programs to improve patients' perceptions of provider empathy<sup>31,32</sup> and perceptions of providers' rehabilitation-specific communication skills.<sup>21</sup>

Presumably, trade-offs in PCP choice occur out of necessity due to the lack of providers with SCI expertise<sup>14,29</sup> and/or the lack of data to help locate knowledgeable PCPs.<sup>33</sup> This strategy is particularly relevant for consumers with SCI because of SCI's

relatively low prevalence compared to other conditions with complex health needs.<sup>34</sup> If making trade-offs in the choice of a PCP is indeed a practice of necessity for consumers with complex health needs, it is unclear from the current study data what, if any, consequences may arise as a result. It stands to reason, given that preventable ED visits are disproportionately high for individuals with disabilities,<sup>35</sup> that such health disparities could be affected by the need to forego PCP knowledge of SCI. Alternatively, the consumers in this study, as active self-advocates, may have been able to effectively weigh the qualities of a PCP that are necessary to prevent unnecessary health problems, given that they report high satisfaction with their PCP.<sup>15</sup> Further research would be needed to better understand the impact that trade-offs may have on consumer health outcomes, perhaps using a measure such as the Patient Activation Measure<sup>36</sup> stratified by consumers' level of activation.

The consumer theme of trade-offs in the choice of a PCP did not emerge in practitioner interviews. Given its prominence for consumers, it would seem prudent for practitioners to consider this dynamic of decision-making when providing services and support. Practitioners could play a mitigating role to help educate consumers on health disparities, supporting them to weigh trade-offs to make the best decision for their health care needs.

There are some clear limitations that limit the generalizability of study findings. First, the interviews on which this retrospective analysis is based specifically targeted consumer advocates highly satisfied with their primary care to understand their effective strategies. Our results may not translate to SCI consumers who are less activated as health care self-advocates. Indeed, at lower levels of activation as evaluated on the Patient Activation Measure, consumers needed much more social support with education and confidence building.<sup>36</sup> Second, interviews likely had more of a structure and focus when they were designed to generate targeted vignettes than if they had been conducted for research purposes. As such, derived domains for this analysis are not necessarily comprehensive. Also, practitioner interview analyses were based on interviewer

notes; without direct quotes, practitioner data did not allow for as precise comparative analysis as would have been possible if transcripts had existed. Of note, while the focus of analysis was mostly the consumer's relationship with the PCP, the perspective of the PCPs is lacking in the data.

## Conclusion

In this analysis, we lay out primary domains and related subdomains of satisfied SCI consumers' effective self-advocacy strategies in getting their primary care needs met compared with experienced practitioners' responses. Many studies report on the multidimensional factors that create barriers and facilitators to health care access for consumers with disabilities.<sup>3</sup> Yet, we believe this analysis represents a unique contribution to the discussion in the literature by examining strategies of highly satisfied consumers. Most notably, we examined how consumers consider and weigh presenting factors collectively in making a particular choice about how to address their health care needs in the real world – the “trade-offs” they must make. A more frank discussion in the public domain may prove important, given that these trade-offs must be considered in the reality of daily living for each consumer – particularly for individuals with SCI who represent a small patient group that must navigate complex health care needs.<sup>3</sup>

Generally speaking, it could be extremely valuable to focus more on the consumer decision-making processes in qualitative research, programs,

and policy discourse to inform the development of particular interventions to help consumers navigate the health care system and ultimately to reduce health disparities.<sup>30</sup> Further research is needed to understand the ramifications of necessary trade-offs on health disparities, as well as effective applications of this strategy by consumers. In the meantime, discussion of necessary trade-offs in navigating the system becomes particularly relevant in light of the expanding role of patient navigators through the Patient Protection and Affordable Care Act (signed into law in 2011)<sup>30,37</sup> and the interventions focused on improving the provider–patient relationship.<sup>21,31,32</sup> With this focus in mind, our research team applied the current domain analysis to guide the development of a peer-led phone intervention currently being tested, to empower consumers with chronic SCI in getting their primary health care needs met.

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## APPENDIX A

### Practitioner Interview Questions

#### Primary Care Physician (PCP)

- What tips do you have for finding a local PCP for people with spinal cord injury (SCI)?
- What are the most common problems with access to primary care that you've seen your clients face?
- Can you provide any tips on coordinating care between multiple clinicians (PCP, SCI specialist, therapists, mental health provider)?
- Depending on the particular providers, some PCPs, physiatrists/physical medicine and rehabilitation docs, and related SCI specialists may overlap in some areas (eg, prescribing medications, wheelchairs and other durable medical equipment, etc). What advice would you give to patients to make sure they're asking the right care provider for help without getting passed around or falling through the cracks?
- If a person is having difficulty communicating their needs with their provider, what might you suggest?
- What advice would you give to a person with SCI on how to have successful, respectful, and effective patient-provider interactions?
  - What if they are having difficulty expressing their SCI-specific needs?
  - What if they feel like their provider is not listening to them?
- What else should consumers know about to get the care they want/need from their primary care and other rehab providers?
- Any resources to suggest?

#### Durable Medical Equipment

- Can you describe an ideal process for an SCI consumer to obtain a custom wheelchair (eg, getting a script, finding an equipment clinic/vendor, getting insurance coverage, timely receipt of equipment)?
- What are the most common problems you've seen people encounter in this area?
- What strategies/resources have you utilized successfully when the ideal process has not occurred?
- What advice would you give to a patient who is frustrated and angry because he or she can't seem to get an appropriate response or resolution to a problem (any type of problem), especially when they *have* advocated for themselves appropriately?
- What is your advice for helping an SCI consumer obtain other equipment such as home safety equipment, accessible bathroom equipment, and bracing?
  - Any resources to suggest?

#### Overall – Self-Advocacy and Health Care Navigation

- What are your most important recommendations for people with SCI to advocate for themselves?
- What are your most important recommendations for people with SCI to best navigate the health care system?
- What are some of the most challenging health care access issues you have helped consumers through successfully?
- Are there areas that you believe need to be addressed more at a systemic level?
- Anything else (eg, other resources, other important areas to consider, etc)?

## APPENDIX B

### Consumer Interview Questions

#### Primary Care Physician (PCP)

- Do you have a primary care doctor (PCP)?
  - If yes, is this doctor a physiatrist?
    - If so, why did you choose physiatrist versus PCP?
- How did you go about finding your current primary care doctor?
  - Did someone recommend a clinician?
  - Did someone help you?
  - Did you interview multiple doctors?
  - Are there specific questions you asked during the process of finding your primary care doctor?
  - Did you go through multiple clinicians prior to finding your current doctor?
- What are some of the reasons you have kept this doctor?
- Can you describe your overall feelings about your current doctor (positive and/or negative)?
  - Knowledgeable, caring, respectful?
- What would you say is the MOST important aspect to getting successful, quality care from your doctor? In other words, what matters the most to you about your doctor, so much that you might deal with other things like waiting room time, appointment wait time, etc?
  - Examples: Knowledgeable about SCI, comfort level, time spent with you, good listener, treats you like a member of the team, etc.
- Can you describe a positive experience where you felt you were able to communicate effectively with your primary care doctor?
- Can you describe a challenging experience where you had difficulty communicating with your primary care doctor? (If not, skip to next question)
  - How did you overcome this challenge?
  - What might you recommend to others with SCI if they are having difficulty getting their needs met by their current PCP?
- Have you experienced accessibility issues at any medical appointments (eg, problems with wheelchair access, difficulty getting onto exam table, etc)?
  - If so, how did you deal with it?
  - What would you recommend to other people with SCI if they encounter difficulties with physical accessibility?
- Please refer to the “During Your Office Visit” handout (eAppendix B) that goes over routine screenings, tests, and topics to discuss with your doctor.
  - Have you had success in discussing each of these topics with your doctor?
  - Can you describe any of the topics that you have had difficulty communicating with your doctor about and how you have dealt with this?
- Have any personal concerns ever come up about self-advocating?

**Examples:**

- Education/lack of knowledge of resources in community
- Support services/social support
- Mental status/depression
  - Motivation/confidence (may be self-identified personality that isn't into being assertive)

**Durable Medical Equipment**

- Can you describe the process you went through to obtain your custom wheelchair?
  - What did you find challenging?
  - Who/what helped you to navigate the process?
- Was the process the same for obtaining bathroom and home safety equipment (eg, shower chairs, ramps, etc)?
- How did you find out whether insurance would cover your equipment needs and how much it would cover?
- Have you ever had to “fight” with your insurance company about coverage for equipment, appointments, etc? (If no, skip to next question)
  - How did you advocate for yourself?
  - Did anyone help you with the process?
  - What might you do differently?

**Overall Self-Advocacy and Health Care Navigation**

- Considering the topics we just discussed, what are your most important recommendations for people with SCI to advocate for themselves and to best navigate the health care system?
- Do you have any specific providers or facilities that you would recommend to others with SCI?

**Personal Barriers Navigation**

- Was there ever a time when you felt unsure of how to advocate for yourself?
  - In what way?
  - How did you work through this?
  - Did you have help with this?
- Have any personal concerns ever come up about self-advocating?

**Examples:**

- Education/lack of knowledge of resources in community
- Support services/social support
- Mental status/depression
- Motivation/confidence (may be self-identified personality that isn't into being assertive)