Patient and Provider Perspectives of Self-Management of Ulcers in SCI/D

Dawn Ehde, PhD
Marylou Guihan, PhD
Disclaimer

This study was funded the Department of Veterans Affairs, Office of Research and Development, Health Services Research and Development Service (IIR 06-203).

The views expressed in this presentation are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the US government.
Disclosure

• This study received Department of Veterans Affairs’ Funding and Staff Support.
• This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with the Paralyzed Veterans of America. Neither PESG nor PVA nor any accrediting organization supports or endorses any product or service mentioned in this activity.
• PESG Staff and the Program Planning Committee have no financial interest to disclose.
• Commercial Support was not received for this activity.
Overview

• Study Rationale
  • Pressure ulcers (PrUs) as a chronic condition
  • Chronic Care Model, which emphasizes self-management

• Study of patient & providers perspectives on self-management of PrUs

• Discussion of steps for integrating self-management into the care of PrUs
Why focus on PrUs in SCI?

- PrUs are the most common secondary complication after SCI. In FY 2012, there were 4,394 admissions for PrU treatment at VA SCI Centers.
- Only 1.3% of the PrUs treated in SCI units were hospital-acquired.
- Community-acquired pressure ulcers are the main reason for hospitalization of Veterans with SCI/D.
- Virtually all published literature on prevention is based on institutional settings, where the focus is provider behavior.
PrU Prevalence and Recurrence Rates

• PrU prevalence rates in persons with SCI residing in the community range from 17-33%.
• High rates of recurrence (31% to 79%) also have been reported.
• Chen and colleagues found that although PrU risk was relatively stable during the first 10 years following SCI, there was a significant trend toward increased PrU prevalence 10-15 years post-SCI.
• The mean age of Veterans with SCI is 61 (sd=1.1) and the mean time since post-SCI in Veterans with PrUs is 20 years.
PrUs in SCI

• PrU etiology is multi-factorial, encompassing mechanical, metabolic, nutritional and environmental factors, all of which are influenced by a person's behavior.

• In a 2003 survey, VA SCI providers were nearly unanimous in their agreement that patients who comply with treatment recommendations can prevent PrUs.¹

• Despite the strong opinions expressed by providers, the evidence supporting most SCI PrU CPG recommendations is based on expert consensus.
PrU Risk Factors and Prevention

- Modifiable and non-modifiable risk factors (e.g., decreased mobility and lack of sensation, coupled with other physiologic changes), put everyone with SCI at lifelong risk for PrUs.
- PrU prevention typically focuses on patient education (e.g., pressure relief, skin hygiene, adequate nutrition, skin protective behaviors, avoiding substance use, proper equipment use and seeking timely medical attention).
- The role of motivation and self-efficacy in the self-management of other chronic conditions (e.g., diabetes) is seen as critical to long term outcomes.
Pressure ulcers = chronic condition

- Why do we believe that PrUs in SCI should be re-conceptualized as a complex chronic condition?

- PrU prevention & management requires substantial and sustained changes in patient behavior & system support.
PrUs are a non-communicable condition characterized by:

- Duration
- Prognosis
- Pattern
- Sequelae
Chronic Care Model (CCM)

• Why the Chronic Care Model?
• Because it has led to improved health care outcomes in other complex chronic health conditions, focusing on:
  • Improving patient activation via education, improved motivation and self-management (SM) skill-building;
  • Redesigning the healthcare system to provide more proactive patient support and productive patient-provider team interactions;
  • Providing decision support to healthcare providers to maximize adherence to evidence-based guidelines; and
  • Creating clinical information systems that provide timely data about patients and populations.
Medical Versus Self-Management

= Health care providers

= Individual with pain

< 0.5%
What is Self-Management?

“...what people do on a day to day basis to feel better and pursue the life they desire.”
Teresa Brady, PhD, Centers for Disease Control and Prevention, 2010
What is Self-Management?

- The tasks that the individual must do to live well with one or more chronic conditions.

• Tasks include having the confidence to deal with:
  • Medical management
  • Role management
  • Emotional management of their condition

(IOM, 2004; Brady, 2011)
What is Self-Management Support?

Self-management support may be viewed in two ways, as:

• A portfolio of techniques and tools that help patients choose healthy behaviors; and

• A fundamental transformation of the patient-caregiver relationship into a collaborative partnership.

“The purpose of self-management support is to aid and inspire patients to become informed about their conditions and take an active role in their treatment.”¹
Institute of Medicine:
Systematic support is necessary to increase patients’ skills and confidence in managing their chronic conditions, including:

- Regular assessment of progress & problems
- Goal setting
- Problem-solving support
- Relapse prevention
Reims’ Model to Promote ‘High Leverage Changes’ to Improve SM at the System Level

1. Emphasizing the patient’s central role
2. Assessing patient self-management knowledge, behaviors, confidence, and barriers
3. Providing effective behavior change interventions & ongoing support with peers or professionals
4. Using culturally competent, linguistically appropriate approaches in interactions and
5. Assuring collaborative care-planning and problem solving by the team.
Gaps in Self-Management Support in SCI?

• Little is known about what people with SCI think about self-management.

• Little is known about what SCI care providers think about self-management support.
Patient Viewpoint

Patients vary in the roles and degree of control that they are willing or able to assume in self-management, including decisions about their own medical treatment.

Many variables likely impact patients’ engagement in self-management and health care, including:

• Health literacy and numeracy
• Sex, age, education, cultural differences
• Severity of illness
• Perception that they lack knowledge
• Perception that providers may not respect their preferences
• Lack of self-efficacy
One study found that even relatively affluent and well-educated patients felt compelled to conform to socially sanctioned roles and thus deferred to physicians during clinical consultations.

Fear of being labeled as “difficult” prevented many patients from participating more fully in their own health care.
Provider Viewpoint

To effectively support SM, providers need to view patients as being the expert or central manager of their health care and decision-making.

Shared decision making requires attitudes and skills that many providers may not possess or be familiar with.

Partnering with a patient may require providers to counsel patients about lifestyle issues or attend to the patient’s emotional distress.
Provider Viewpoint

Providers may also need to negotiate their own professional biases and emotions.

Studies have shown that when faced with a patient they view as difficult, providers sometimes respond in problematic ways, (e.g., avoidance, anger, and stereotypes as a form of distancing).

Incorporating tools for reflective self-awareness and strategies for how to address them into routine clinical practices may help providers to improve their skills.
Provider Viewpoint

Providers cannot assume that “one size fits all” in promoting shared decision making/self management, with everyone starting off with common meanings and application across different individuals or cultural groups.

Providers need to be aware of cultural assumptions underlying the process and be sensitive to the needs and preferences of patients in diverse cultural groups.
Current Study: Aims

To examine how SCI healthcare providers and Veterans with SCI view pressure ulcer self-management and self-management support
Design

• Conducted concurrently with a large multi-site (4 VA SCI Centers) randomized controlled trial comparing 2 interventions for increasing skin protective behaviors.

• Primary Veteran inclusion criteria: Could not be participating in RCT; did not matter if 0 vs. 1+ PrUs.
Methods, Participants

• Convenience sample participated in focus groups at each site
• n = 8 focus groups
  • 1 for Veterans at each site
  • 1 for providers at each site
• Veterans with SCI/D (n=35)
• SCI/D providers (n=39)
<table>
<thead>
<tr>
<th>Veteran Demographics</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>33</td>
<td>94.3</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36-49</td>
<td>9</td>
<td>25.7</td>
</tr>
<tr>
<td>50 +</td>
<td>26</td>
<td>74.3</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
<td>32.4</td>
</tr>
<tr>
<td>Married</td>
<td>12</td>
<td>35.3</td>
</tr>
<tr>
<td>Divorced</td>
<td>11</td>
<td>32.4</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>5</td>
<td>14.7</td>
</tr>
<tr>
<td>Unemployed</td>
<td>7</td>
<td>20.6</td>
</tr>
<tr>
<td>Disabled/Retired</td>
<td>32</td>
<td>54.7</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High School</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>High School</td>
<td>10</td>
<td>28.6</td>
</tr>
<tr>
<td>College/trade school</td>
<td>13</td>
<td>37.1</td>
</tr>
<tr>
<td>Bachelors’ Degree</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>2</td>
<td>5.7</td>
</tr>
</tbody>
</table>
## Veteran Demographics

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of Injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>15</td>
<td>48.4</td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>16</td>
<td>51.6</td>
</tr>
<tr>
<td><strong>Service-Connected</strong></td>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td><strong>Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>11</td>
<td>35.5</td>
</tr>
<tr>
<td>1</td>
<td>11</td>
<td>35.5</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>12.9</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>16.2</td>
</tr>
<tr>
<td><strong>Number of previous</strong></td>
<td>&lt; 25</td>
<td>2</td>
</tr>
<tr>
<td>/current PrUs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26-50</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>51-75</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>76-99</td>
<td>9</td>
<td>26.5</td>
</tr>
<tr>
<td>100</td>
<td>22</td>
<td>64.7</td>
</tr>
</tbody>
</table>
### Veteran Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Mean (S.D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at injury (years)</td>
<td>39.6 (15.2)</td>
</tr>
<tr>
<td>Duration of SCI (years)</td>
<td>20.9 (12.4)</td>
</tr>
<tr>
<td>Provider Demographic characteristics</td>
<td>N (%)</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>Gender:</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (23.1)</td>
</tr>
<tr>
<td>Female</td>
<td>30 (76.9)</td>
</tr>
<tr>
<td><strong>Age:</strong></td>
<td></td>
</tr>
<tr>
<td>22-35</td>
<td>6 (15.4)</td>
</tr>
<tr>
<td>36-49</td>
<td>20 (51.3)</td>
</tr>
<tr>
<td>50 +</td>
<td>13 (33.3)</td>
</tr>
<tr>
<td><strong>Discipline:</strong></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>9 (23.1)</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>2 (5.1)</td>
</tr>
<tr>
<td>Nurse</td>
<td>8 (20.5)</td>
</tr>
<tr>
<td>Therapist</td>
<td>15 (38.5)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (13.0)</td>
</tr>
<tr>
<td><strong>Trained in another area of specialization:</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15 (40.5)</td>
</tr>
<tr>
<td>No</td>
<td>22 (59.5)</td>
</tr>
<tr>
<td>Provider Background</td>
<td>N (%)</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Percent time spent in:</td>
<td></td>
</tr>
<tr>
<td>Administration</td>
<td>31.1 (28.2)</td>
</tr>
<tr>
<td>Direct Patient Care</td>
<td>75.3 (26)</td>
</tr>
<tr>
<td>Other</td>
<td>30.2 (36.2)</td>
</tr>
<tr>
<td>Patient care setting(s):</td>
<td></td>
</tr>
<tr>
<td>Inpatient</td>
<td>60 (29.2)</td>
</tr>
<tr>
<td>Outpatient</td>
<td>42 (30.9)</td>
</tr>
<tr>
<td>Home Care</td>
<td>6 (8.4)</td>
</tr>
<tr>
<td>Type of care provided:</td>
<td></td>
</tr>
<tr>
<td>Initial rehabilitation</td>
<td>30.1 (26.1)</td>
</tr>
<tr>
<td>Chronic SCI care</td>
<td>81.9 (80.4)</td>
</tr>
<tr>
<td>Provider background</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Total years working in SCI:</td>
<td>11.9 (8.4)</td>
</tr>
<tr>
<td>- VA SCI center</td>
<td>10.1 (7.7)</td>
</tr>
<tr>
<td>- Model Systems facility</td>
<td>3 (4.5)</td>
</tr>
<tr>
<td>- Non-Model Systems facility</td>
<td>3.7 (5.5)</td>
</tr>
</tbody>
</table>
Focus Groups

- Use focus group guides which consisted of open-ended questions, including asking them to:
  - to define “self management” and “skin management;”
  - to describe their skin management activities;
  - to discuss barriers to and supports for skin management
  - their views on patient-provider conversations about skin management.
- Also asked other questions/background info
Procedures

• Conducted in 2010-2011 by an experienced focus group facilitator
• Veteran groups: 90 minutes
• Provider groups: 60 minutes
• Veterans received a small honorarium; providers did not.
Data Analysis

- Audio recordings transcribed verbatim
- Constant comparative techniques
- NVivo 8 used for analysis
- Reims’ conceptual framework was used to organize findings
- Sample quotes from Veterans and providers to illustrate findings
Results: Veteran’s Central Role in Skin Management

• Veterans recognized their responsibility in managing their own skin:
  • “That responsibility is yours and you have to take control of yourself.”
  • “I have to take care of myself.”

• And for self-advocacy:
  • “You know your body better than anybody else. And you have to know what to tell [your providers].”
Veterans also recognized the need for help from others:

- “You must pay attention to what your therapist tells you...Listen to what they tell you and accept it...”

- “If you don’t listen to what they’re saying [providers], [you’re] the fool.”

- “You have to manage everyone around you, including yourself.”
Providers also emphasized that Veterans have primary responsibility, although less emphatically:

- “I know we’re the train but [the Vet is] the engine. You got to run it and we will give you the help.”
Provider Role

And with less optimism:

• “[Some patients seem more] motivated by whatever else they need to do in their life than to feel empowered enough to go ahead and follow through with instructions [to properly care for SCI or skin problems].”
Veterans reported possessing adequate knowledge about how to manage PrUs & engaging in many skin-protective behaviors:

• “Basically just having a routine [is important]... have a daily inspection, mornings & evenings. If you have a caretaker, they can see things you can’t see & you can ask them...to look.”
Barriers to SM identified by Veterans

• Personal factors:
  • “Depression or self-pity...if you wallow in self-pity...you begin to stop doing things that you should routinely do.”

• External factors (most frequently reported):
  • Lack of available CGs or CG time
  • Lack of financial resources for CG time
Barriers to SM identified by Providers

• Providers recognized the complexity of the lives of their patients with SCI & to some degree, how challenging SM can be even to the most motivated patients.

• But many comments focused on their perceptions of patient behavior & attitudes:
  • “The VA will care for me no matter what.”
  • “...no incentive to change [their] behavior.”
Provision of Behavior Change Interventions & Support: Veteran Perspectives

• Veterans were mixed on the adequacy of the support they get from providers & the system.

• They consistently stressed the impact & importance of non-medical interventions:
  • especially peer modeling & groups as sources of knowledge, friendship, and emotional support that facilitated self-management.
Peer Support: Examples

- “I learned more from a couple guys that I was in rehab with that had been injured for quite a while, learned from then how to do things and how to take care of myself.”

- “Learning from other people, learning from your peers, learning from people who have been there...is the biggest thing that you can accomplish.”
Some providers discussed using proactive methods to facilitate patient self-management, including a flexible approach to elicit behavior change:

“*You have to negotiate with them...Like, okay, what are you willing to do? I had this patient who [wanted to] sit for 12 hours, and I said, well 12 hours is a little too much. How much can you go down, what would be realistic for you? He said, well, 6; okay, we can start with 6.”*
Providers also acknowledged the importance of social interventions in supporting change or self-management:

“We have the peer partner program that...pairs up a guy with a new injury with a guy who’s been living successfully in the community for at least a year...[Sometimes] that’s a good way of kind of getting the education across.”
Veterans were mixed in their assessment of providers’ communication skills.

Several providers described the need for multiple ways to approach and tailor information to individual patients.

“... [I’m always] trying to find a way, whatever connects with that patient [is important] because it’s not going to be the same with every patient. How do you get them to remember and ...what influences them?”
Assure Collaborative Planning & Problem-Solving by Team

• Veterans acknowledged importance of healthcare team but did not discuss the importance or presence of an ongoing collaborative effort.

• Providers stressed importance of collaboration & communication among team members.

• But providers did not describe patients or caregivers as team members.
Limitations

- Sample size
- May not be generalizable to civilians
- Findings need to be confirmed by further qualitative and quantitative research.
- Perspectives and roles of families’ and caregivers’ needs to be considered in future research.
Discussion

• Some, but not all, of Reims’ recommended health care system changes for supporting patient self-management were described by Veterans and providers.
• Veterans placed more emphasis on their own role (or that of peers) in facilitating self-management.
• Self-management support at the system level was not described in any detail.
Discussion

• Like other areas of healthcare, self-management support likely occurs but may not be systematically integrated into the care environment.

• How much of this is due to terminology, a lack of understanding about SM support, insufficient SM support resources, or other factors is unknown.
What Can We Do to Better integrate Self-Management Support into SCI Care?

- Battersby et al. (2010) recommendations
- Examples of self-management integration into SCI care
## Integrating Self-Management Support into Clinical Practice

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Enhanced Visit Preparation</th>
<th>Focused Visit</th>
<th>Expand Options at Post-visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Brief targeted assessment to guide SMS</td>
<td>●</td>
<td>●</td>
<td>—</td>
</tr>
<tr>
<td>2. Evidence-based information to guide shared decision making</td>
<td>—</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>3. Clinicians use a nonjudgmental approach</td>
<td>●</td>
<td>●</td>
<td>—</td>
</tr>
<tr>
<td>4. Collaborative priority and goal setting</td>
<td>●</td>
<td>●</td>
<td>—</td>
</tr>
<tr>
<td>5. Collaborative problem-solving</td>
<td>●</td>
<td>●</td>
<td>—</td>
</tr>
<tr>
<td>6. Diverse providers can offer SMS</td>
<td>—</td>
<td>—</td>
<td>●</td>
</tr>
<tr>
<td>7. Individual-, group-, telephone-, and self-instruction formats can be employed</td>
<td>—</td>
<td>—</td>
<td>●</td>
</tr>
<tr>
<td>8. Enhance patient self-efficacy</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>9. Ensure active follow-up</td>
<td>—</td>
<td>—</td>
<td>●</td>
</tr>
<tr>
<td>10. Guideline-based case management for selected patients</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>11. Link patient to evidence-based community-based self-management programs</td>
<td>—</td>
<td>—</td>
<td>●</td>
</tr>
<tr>
<td>12. Multifaceted interventions are more effective</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
</tbody>
</table>

Battersby et al. (2010) Evidence-Based Recommendations for Self-Management Support
Collaborative Care for Depression: An example

- **Physician**
- **Psychologist**
- **Psychiatrist**
- **Patient**
- **Care Manager**

- **Feedback**
- **Decision support**
- **Care coordination**

- **Motivate adherence**
- **Monitor response to Tx**
- **Manualized therapy**
  - CBT
  - Problem-solving
  - Physical activity

- **Weekly case supervision**
- **Treatment adjustment**
- **Manage treat-to-target**

- **Care coordination**
High Impact Changes for Self-Management

Before, During, and After the Visit

- Help patients understand their central role in managing their conditions and that the entire health care team is there to help.

Before the Visit

- Ask patients to bring questions and concerns and health monitoring information.
During the Visit

- Collaboratively develop a visit agenda with the patient and family, handling as many concerns as possible, and plan return visits as appropriate.
  
  - Engage the entire team in supporting patients, use “warm handoff” introductions, and explain team member roles to patients.

- Ask patient about their goals to improve their health and help them make action plans that build confidence in their ability to reach these goals.
During the Visit

• Prepare a written care plan or visit summary that includes goals and action plans to ensure patients and families know what to do when they leave the visit.

• Use group medical appointments, peer-led support groups, or patient education classes to provide opportunities for patients to share experiences and support.
After the Visit

- Organize follow-up support to help patients sustain healthy behaviors between visits.

- **Extend care into the community by linking patients to community programs.**
Build a Team

- Designate and train a lead coach for self-management support, who will also support ongoing staff development of skills.
  - **Assign responsibility for self-management tasks to all team members.**

- Identify team strategies to review patient charts, anticipate care needs, and enhance the flow of care.
Self-management support is the care and encouragement provided to people with chronic conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviors.
Summary

• System-level changes are an area for further development & research in SCI PrU care.

• Future research should address questions of how to support self-management at the patient, caregiver, provider, & system level to improve PrU outcomes.

• The Chronic Care Model literature may serve as a useful model for such research and changes.