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TITLE OF THE STUDY:

Development and Validation of a Medical Home Model
for Persons with Spinal Cord Injuries in an
Acute Rehabilitation Outpatient Specialty Center

Submitted to the Faculty
Yale University School of Nursing

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Nursing Practice

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Doctor of Nursing Practice.



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March 21, 2018

Development and Validation of a Medical Home Model for Persons with Spinal Cord Injuries in

an Acute Rehabilitation Outpatient Specialty Center

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Abstract

Background:

Primary care is difficult for patients with spinal cord injuries to find. As such, these patients typically turn to rehabilitation centers and clinics that do not provide primary care services.

Purpose:

The purpose of this project was to develop a model of care that integrates primary care into specialty care clinics for patients with spinal cord injuries.

Design:

A review of the literature on the healthcare needs of patients with spinal cord injuries was completed. The Donabedian framework was used to guide the development of the Spinal Cord Injury Medical Home Model (Donabedian, 1966).

Methods: An expert panel rating tool was developed based on a comprehensive literature review on the primary care needs of patients with spinal cord injuries. The rating tool was completed by subject matter experts in the field of spinal cord injury care management.

Findings:

Key components of the structure, process, and outcomes of the model were evaluated for importance and relevance, and validated by a panel of experts.

Conclusion:

This model has the potential to improve overall access to care, care coordination, and outcomes for this population. The next step is to implement and evaluate the model.

Clinical Relevance: The experts' high level of agreement on the components was remarkable and underscores the importance of the need for the integration of primary care and specialty care.

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Keywords: *Spinal cord injuries, medical home model, primary care, specialty care clinics*

Key Practice Points:

- Accessible scales, height-adjustable exam tables, and portable floor lifts were all ranked at 100 percent importance for clinic equipment
- Essential referral management included access to urological services, vocational rehabilitation and seating/cushion services
- Access to a care manager during a primary care visit was identified as important for care coordination needs
- Expert panel members identified a co-management approach as important to support the primary care's provider's aptitude to properly manage the SCI population.

Introduction

Access to primary care is vital for any patient. For those with disabilities, particularly for those with spinal cord injuries, primary care is difficult to find. Most providers do not have physically accessible clinics, nor do they have extensive knowledge on spinal cord injury care (Stillman, Frost, Smalley, Bertocci, & Williams, 2014). In addition, the resources needed to provide primary care to patients in this population tend to be quite high, often more than most primary care clinics have (McColl et al., 2015).

With little-to-no access to a primary care provider, most individuals with spinal cord injuries typically turn to rehabilitation centers and clinics for their healthcare needs (Stillman & Williams, 2014). These clinics are generally equipped to handle the specialty care needs of these individuals, such as bowel and bladder care, neuropathic pain, spasticity, and other physical related issues. However, these centers typically do not provide primary care services; the focus is strictly on the specialty care needs of this population.

The purpose of this project was to develop a model of care that integrates primary care into specialty care clinics for patients with spinal cord injuries, specifically at Rancho Los Amigos National Rehabilitation Center's Outpatient Center.

Background

Primary care is the cornerstone of medical care for most individuals in the United States (Starfield, Shi, & Macinko, 2005). Despite this, those most likely to be without primary care are marginalized and disadvantaged subsets of the population, including people with disabilities. The more severe the disability, the less likely individuals are to receive comprehensive care (McColl, Aiken, & Schaub, 2015). In Canada, persons with disabilities represent 6 percent of the primary care caseload; however, they consume 33 percent of primary care resources (McColl et al.,

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2015). In 2006 alone, disability-associated healthcare expenditures accounted for 26.7 percent of all healthcare expenditures for adults, totaling \$397.8 billion in the United States (Anderson, Armour, Finkelstein, & Wiener, 2010).

These individuals are often seen as difficult to treat and manage due to the intense resource utilization they require. Since our healthcare system is volume driven, it tends to create a reimbursement process that based on a per visit bill. Such a reimbursement structure tends to navigate providers to maximize their clinic time and work with clients that can be easily seen within a 15-minute clinic visit model. Unfortunately, individuals with disabilities are seen as economic liabilities: they generally do not fall into a 15-minute clinic visit model and, thus, are seen as unattractive to a prospective provider (McColl et al., 2015). In turn, the very patients who are most likely to benefit from primary care are the least likely to be welcomed into a primary care practice (Kasperski, 2005).

Specialty facilities that focus on patients with disabilities offer the appropriate resources, staff, and expert knowledge to provide the appropriate care to this population (Stillman & Williams, 2014). Although most spinal injury patients turn to physiatrists for primary care, physiatrists feel unqualified to provide these services (Johnston, Diab, Chu, & Kirshblum, 2005). However, developing a model that builds on the expertise of the acute rehabilitation specialist and incorporates primary care knowledge could have a significant impact on the quality of care for these individuals.

Etiology

It is estimated that the prevalence rate for Spinal Cord Injury (SCI) is 40 cases per million people, or approximately 12,000 new cases each year in the United States, excluding deaths. Currently it is estimated that 236,000 to 327,000 people in the US are living with a SCI (“Spinal

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Cord Injury Facts”, 2012). According to the National Spinal Cord Injury Statistical Center (2012), the etiologies of SCIs are as follows:

- Motor vehicle accidents: 39 percent
- Falls: 28 percent
- Violence: 15 percent
- Sports-related injuries: 8 percent
- Other: 10 percent

While SCIs mostly affect men, with more than 80 percent of patients’ being male, there is greater diversity in race and ethnicity of SCI patients. Nearly two-thirds of patients are Caucasian and just over one-quarter are African-American; Hispanics and Asians make up a smaller fraction: 10 percent and 2 percent, respectively (“Spinal Cord Injury Facts”, 2012).

Almost all SCI patients are discharged to a non-institutional setting (89 percent), typically their own home, with potential access to post-acute care depending on the patient. The lifetime cost for a SCI patient varies, depending on myriad factors (education, severity of injury, pre- and post-injury employment); however, the average cost is approximately \$69,000 per year per patient. This does not include indirect costs such as wages, benefits, and lost productivity, which can substantially increase the cost (“Spinal Cord Injury Facts”, 2012).

Individuals living with a SCI face serious health issues, in addition to concerns about access to and quality of care. The most frequent reported issues for these individuals are pain, spasticity, pressure sores, mobility impairment, and bladder management (Cox, Amsters, & Pershouse, 2001). In addition, obesity is a common issue in the SCI population due to inactivity, as well as osteoporosis and fractures due to the loss in bone density (Groah, Steins, Gittler, Kirskhblum, & McKinley, 2002). Addressing these issues is important to improving the quality

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of life for these individuals, yet access to services to meet these needs are limited in primary care.

Patient-Centered Medical Home

The Agency for Healthcare Research and Quality (AHRQ) defines a medical home as a model of the organization of primary care that delivers critical aspects of primary care (“Defining the PCMH”). This is achieved through five functions:

- 1) Comprehensive care, which includes both physical and mental health needs, through the use of an interdisciplinary team of healthcare providers, including physicians, advanced practice providers (nurse practitioners), social workers and case managers.
- 2) Patient-centered care that is focused on the whole person. This includes patients’ unique cultural values and preferences. The medical team and patient are partners in establishing and prioritizing health needs.
- 3) Coordinated care through the medical home. The medical home coordinates care through all aspects of the healthcare system including acute, post-acute, and community services.
- 4) Accessible services, which includes timely access to routine and urgent care. It also ensures patients can access a provider electronically or by telephone around the clock (e.g. a nurse advice line).
- 5) Quality and safety is accomplished by using evidence-based practice and quality improvement tools, and measuring the effectiveness of care delivery through patient experience, population health management, and quality of life indicators (“Defining the PCMH”).

According to the National Committee for Quality Assurance (NCQA), the patient-centered medical home (PCMH) improves quality while reducing cost. In a Medicaid PCMH study,

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patient access improved, while inpatient admissions decreased by 21 percent and per-member, per-month cost decreased by 22 percent from baseline (Takach, 2011). In a northeastern Pennsylvania Chronic Care Initiative, with approximately 27 NCQA PCMH practices, NCQA PCMHs improved care related to diabetes management, including HBA1c testing, LDL-C testing, nephropathy monitoring, and eye exams. These improvements lead to reduced emergency room visits and decreased utilization of specialty services (Friedberg, Rosenthal, Volpp, & Schneider, 2015).

The Joint Commission also promotes the development of a PCMH and provides national certification for primary care. The Joint Commission uses the same definition of a PCMH as AHRQ, and uses that definition to develop standards that drive patient-centeredness and expands comprehensive care to include chronic care, behavioral health, oral health, and addressing phases of a patient's lifespan. Coordinated care under the Joint Commission includes robust health information technology, population-based care and tracking treatment towards goals. In addition, an emphasis on superb access to care is required, including 24/7 access to appointment availability/scheduling and urgent care needs.

The PCMH design is not yet standardized; there are opportunities to develop meaningful PCMH models using standardized criteria and quantitative analysis, according to NCQA. If the Patient-Centered Medical Home (PCMH) Model could be developed for the SCI population, it may meet both the primary care needs and specialty care needs of this population. If systems of care, including the PCMH, address prevention and promote a philosophy of functional independence and wellness, they could capitalize on the strength of that population while reducing the economic burden on healthcare (Cruise & Lee, 2005). Unfortunately, as most primary care settings do not adopt this philosophy in the post-acute care arena, the SCI

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population is still receiving its post-acute care in a fragmented environment (Jesus & Hoenig, 2015).

Although patients with spinal cord injuries suffer access issues pertaining to their primary care needs, most patients are followed by specialty clinics for their disability needs. Currently, most acute rehabilitation centers provide inpatient care, outpatient specialty care, and outpatient therapy needs for this population. They generally do not offer primary care services to the clients served.

However, post-acute care (PAC) and rehabilitation care is fragmented. In the US, PAC and rehabilitation services can be provided in diverse settings. Acute rehabilitation, long-term care, skilled nursing, and home health agencies all provide such care, with each setting run under its own regulations, data sets, and reimbursement mechanisms. This fragmentation hinders the identification of optimal trajectories of recovery, smooth transitions of care, and the ability to monitor or compare quality of care across the rehabilitation continuum (Jesus & Hoenig, 2015). This inability to identify optimal trajectories of recovery can lead to rehospitalization. Current rehospitalization rates of 7.6 percent have been associated with spasticity and pressure sores (Paker, Soy, Kesiktas, et al., 2006). Causes of death for SCI have also changed in the past, from renal failure due to urologic complications generally managed in specialty clinics to pneumonia and septicemia, which can be identified in primary care clinics (“Spinal Cord Injury Facts”, 2012). Therefore, an integrated model of care that incorporates the primary care needs and post-acute specialty care needs of this population would have a positive impact on recovery, reduce complications and increase life expectancy.

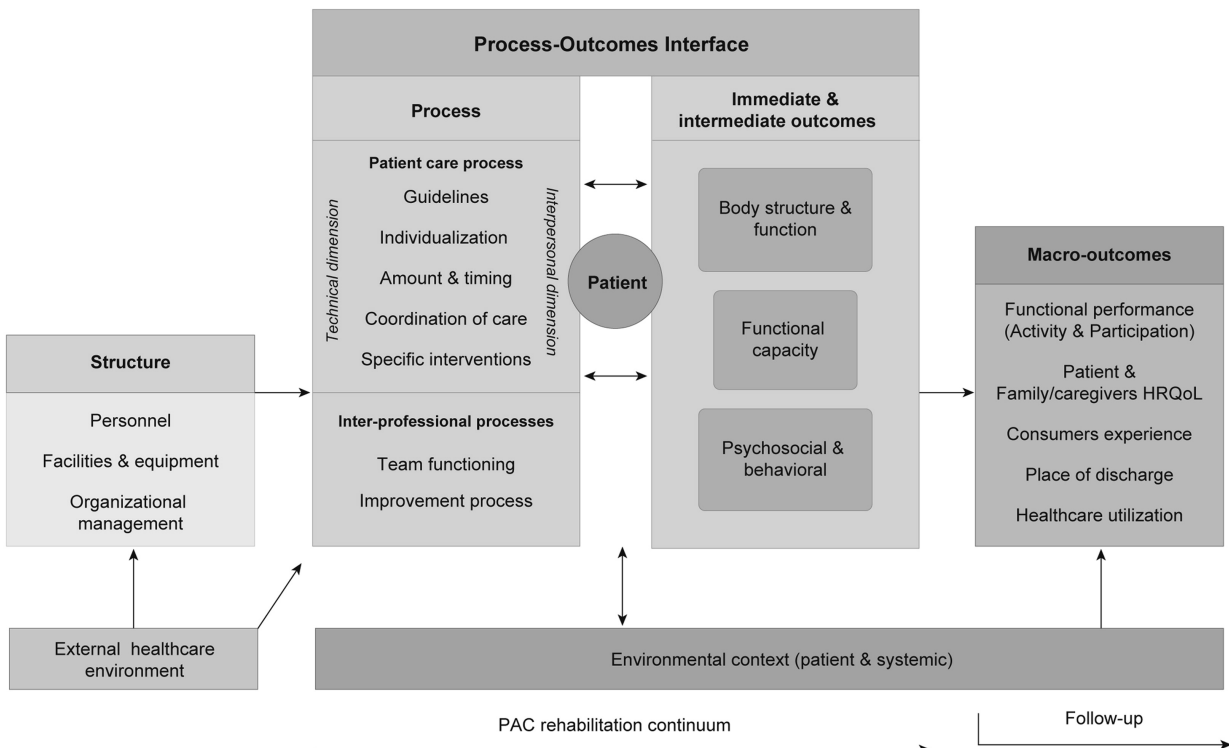
Conceptual Framework

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The conceptual framework for this medical home model of care combines the PAC-Rehabilitation quality framework (Tiago & Hoenig, 2015) and the Donabedian Quality of Care framework. The PAC-Rehabilitation framework utilizes the core components of the Donabedian framework for organizing, operationalizing, and evaluating the medical home model (Figure 1).

The Donabedian framework is comprised of three components: structure-process-outcomes (Donabedian, 1966). The framework was originally introduced as a method for evaluating quality in medical care; it has since become an established framework for evaluating healthcare services and the quality of healthcare provided (Donabedian, 1988). The Donabedian framework relies on the relationship and impact each component has on the subsequent component. Hence, the structure impacts the process, which impacts the outcomes.

Structure includes the context in which care is delivered, setting, staff, finance, and equipment. Process is the interactions between the patient and provider through the delivery system. Outcomes are the effects of the structure and process on health outcomes of the patients.



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Figure 1. Application of the Post-Acute Care Rehabilitation Quality Framework with the Donabedian Quality of Care Framework utilized to form the Medical Home Model

The PAC-rehabilitation framework incorporates the International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) to frame the functional outcome measures. ICF provides a standard language and conceptual basis for the definition and measurement of disability. It integrates the major models of disability - the medical model and the social model - as a “bio-psycho-social synthesis” (ICF Manual, 2013).

Methods

The model of care delivery was completed through a systemic review of literature relating to spinal cord injury population health needs and models of care delivery for this population in the outpatient setting. The development of the model of care was completed through the review of the literature and evidence matrix, using relevant elements under specific categories using the Donabedian (1986) criteria and standards of structure, process, and outcomes. Using the Donabedian Model, an expert panel rating tool was developed with key components under the categories of structure, process, and outcomes. This tool incorporated the PAC-Rehabilitation framework.

Each component of the model was evaluated independently for relevance and importance by the panel of experts. The model of care was based on the percent of agreement by the expert panel, as indication of validity.

Using the expert panel rating tool, five experts provided input on the relevance (yes or no) and importance (low importance or important) of each component. The scoring and decision criteria for the model of care were based on 78 percent agreement with the identified component for relevance and 78 percent agreement for importance. Components at 78 percent agreement for

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relevance and importance were considered validated by the expert panel. Components that did not achieve this level of agreement were considered not validated (Polit, Beck, & Owen, 2007).

The experts were selected based on their professional expertise on spinal cord injuries, primary care, and care coordination. Professional backgrounds of experts included physical medicine and rehabilitation physician, internal medicine physician, primary care providers, occupational therapist, and certified rehabilitation registered nurse.

The experts were given two weeks to complete their ratings of the components of the model. All experts were given instructions on the rating tool, how to rate the content, and due dates. The components of the model and the experts' ratings of the relevance and importance are shown in Table 1. Components in grey cells were not validated at 78 percent relevance.

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Table 1

Expert Ratings of Medical Home for Persons with Spinal Cord Injury-Rating Tool

	Relevance		Importance		Comments / Suggestions
	Yes	No	Low Importance	Important	
STRUCTURE					
Space:					
1.Accessible Parking Spaces	5 100%			5 100%	
2. Wheelchair ramp/ accessible walkway	5 100%			5 100%	
3. Accessible Entry Doors	5 100%			5 100%	
4. Exam Room space to accommodate turning a wheelchair	5 100%			5 100%	
Equipment:					
5. Height Adjustable Exam Tables	5 100%			5 100%	<ul style="list-style-type: none"> • For better exam and easy on staff and job-related injuries • Appropriate for staff to take care of patient in exam room • To be able to examine patients
6. Access to Portable Floor Lifts	5 100%			5 100%	<ul style="list-style-type: none"> • To assess skin integrity
7.Access to Ceiling Lifts	5 100%		1 20%	4 80%	<ul style="list-style-type: none"> • Good for within the exam room • To assess skin integrity
8. Accessible Scale with platform to fit wheelchair	5 100%			5 100%	
Personnel:					
9. Higher Primary Care Caregiver Staffing for SCI population	5 100%			5 100%	<ul style="list-style-type: none"> • Most patients are non-ambulatory
10. Physical Medicine & Rehabilitation MD as Primary Care Provider	4 80%	1 20%	1 20%	4 80%	<ul style="list-style-type: none"> • PM&R consultant for SCI issues • Internists should be the primary with co-management PMR • Above is 1-sided model. They should work together to provide the best ideal care, total care; use both their expertise.

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11. Nurse Practitioner as Primary Care Provider with rehabilitation nursing background	4 80%	1 20%	1 20%	4 80%	<ul style="list-style-type: none"> Internal medicine background is important
PROCESS					
Coordination					
12. Co-Management Model with PM&R and Internist for Primary Care	5 100%		1 20%	4 80%	<ul style="list-style-type: none"> Best way to manage SCI patients. Optimal/ideal! This should be the model for specialized primary care for disable population.
13. Access to Care Manager for Primary/Specialty Care Needs during primary care visit (care coordination)	5 100%			5 100%	
14. Access to Physical Therapist or Occupational Therapist during primary care visit	4 80%	1 20%	1 20%	4 80%	<ul style="list-style-type: none"> This is an easy process with referral, messaging. They are here during SCI transition clinic in the clinic. One session per week. Need to open slots in seating center to accommodate patients. Patient's OT can be a separate visit if space and workflow doesn't allow for an efficient visit.
15. Pt. Access to 24/7 SCI specific telehealth services	5 100%		1 20%	4 80%	<ul style="list-style-type: none"> This is very important in light of the difficulty in getting transportation.
16. Access to mental health counselor (MSW or Psychologist) during time of visit	5 100%		1 20%	4 80%	<ul style="list-style-type: none"> It is available at this time.
Referral Management					
17. Access to Urological Services	5 100%			5 100%	<ul style="list-style-type: none"> SCI patients have frequent urological problems. Dysreflexia and UTIs are very common
18. Access to Wheelchair (Seating/Cushion)Services	5 100%			5 100%	<ul style="list-style-type: none"> Common problem/issues in SCI patients. To prevent pressure sores
19. Access to Vocational rehabilitation Services	5 100%		1 20%	4 80%	<ul style="list-style-type: none"> Computer skills, mobile sticks use driving, adaptive devices.
Outcomes					

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Patient Outcomes:					
20. Bowel/Bladder Management	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management
21. Skin Care including pressure ulcer management	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management
22. Neuropathic pain management	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management
23. Weight Management	5 100%		2 40%	3 60%	<ul style="list-style-type: none"> All important aspects of SCI management
24. Spasticity Management	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management
25. Functional Capacity	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management
26. Improvement in Self-Management	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management
27. Improvement in Patient Health-related quality of life (HRQOL)	5 100%			5 100%	<ul style="list-style-type: none"> All important aspects of SCI management; identify who is the patient's caregiver.
Healthcare Outcomes:					
28. Improved Access to care	5 100%			5 100%	
29. Reduction in Cost of Care within 3 years of onset	5 100%		1 20%	4 80%	
30. Adherence to Healthy People 2020 Standards	5 100%			5 100%	

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Results

Structure

The expert panel validated the relevance of the structural component of the model for space and equipment. Accessibility to both the facility (through parking spaces, walkways, and entry doors) and a wheelchair-accessible exam room received ratings of 100 percent in terms of importance. While all equipment was found to be at least somewhat important, accessible scales, height-adjustable exam tables, and portable floor lifts were all ranked at 100 percent; only ceiling lifts received a lower rating of importance at 80 percent. In the subset of personnel, the importance of higher primary care caregiver staffing was identified at 100 percent. However, the two components regarding the primary care provider, physical medicine & rehabilitation (PM&R) and nurse practitioner, were scored at only 80 percent in terms of relevance.

Process

The expert panel validated all five components for relevance in the coordination of care subsets, with access to a care manager for primary/specialty care needs during primary care visits receiving 100 percent agreement on importance. Other components received 80 percent agreement on importance, including co-management model with PM&R and internist for primary care; patient access to 24/7 SCI specific telehealth services; and access to a mental health counselor during time of visit. Access to physical therapy or occupational therapy during a primary care visit was the only component to receive 80 percent agreement on relevance. Referral management was validated in terms of relevance at 100 percent agreement for all three components, with access to urological services and access to wheelchair seating services receiving 100 percent agreement on importance. Access to vocational rehabilitation services received 80 percent agreement on importance.

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Outcomes

The experts validated the relevance of all patient outcomes. Bowel/bladder management, skin care (including pressure ulcer management), neuropathic pain management, spasticity management, functional capacity, improvement in self-management, and improvement in patient health-related quality of life each had 100 percent agreement on importance. Under patient outcomes, only weight management received a rating of 60 percent agreement on importance.

The experts validated healthcare outcomes, with improved access to care and adherence to Healthy People 2020 standards at 100 percent agreement on importance. The reduction in cost of care within three years of onset received 80 percent agreement on importance.

Discussion

The expert panel validated each of the 30 components of the spinal cord injury medical home model in its structure, process and outcome measures. In the structure domain, 9 of the 11 components were validated at 100 percent. In the process measures, 7 of the 8 components were validated at 100 percent. In the outcomes measures, all 11 components were validated at 100 percent.

Under the structure domain, the components of the model that require further review focus on the primary care provider's expertise (internist vs PM&R vs NP). Expert panel members identified a co-management approach, or access to a PM&R physician or internist, as important to support the primary care's provider's aptitude to properly manage the SCI population based on their clinical background. A PM&R-trained PCP should have access to an internist, and an internist-trained PCP should have access to a PM&R. This was validated at 80 percent agreement. A co-management approach between a PM&R provider and an internist would be ideal. This understandably begs the question as to who is ultimately responsible for the

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patient; if a co-management approach is not feasible, it is the responsibility of the primary care provider to ensure access to a PM&R provider or internist consultant.

In the process domain, access to physical or occupational therapy during a primary care visit was identified at 80 percent relevance and 60 percent importance by the experts. Comments by experts indicated that access to therapy services through a referral mechanism is needed, but not necessarily during the primary care visit.

In the outcome domain, weight management was identified at 100 percent relevance. However, this measure was identified at only 60 percent importance. The indication is that weight management, while important, is not as important as skin care and bowel and bladder management. Providers should monitor weight and manage as needed based on clinical presentation.

Conclusions

Using key components under the domains of the Donabedian model (structure, process, and outcomes), while incorporating the PAC-Rehabilitation framework, allowed us to identify key elements of the SCI medical home model of care. Validated, evidence-based components to this model of care include improved access to timely care and wheelchair-accessible exam rooms. A few key components of the SCI medical home model include bowel, bladder, skin assessment and management as part of the routine primary care visit. Easy access to a PM&R specialist or internist, as needed by the primary care provider, was another key component identified using the tool. The experts' high level of agreement on the components was remarkable and underscores the importance of the need for the integration of primary care and specialty care.

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The next step of the process, the implementation of this model at Rancho Los Amigos National Rehabilitation Center's outpatient primary care SCI clinic, is underway currently. Initial empanelment will consist of 2,000 SCI clients managed through the SCI primary care clinic. Clinical and healthcare outcomes will be monitored and benchmarked through national databases, such as the SCI Model System sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). While the SCI medical home model is specialized to the spinal cord injury population, a modified version of the model could support other chronic conditions and disability categories that require complex care management and have similarly inadequate access to primary care.

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