Provider Perspectives on the Coordination of Care for Spinal Cord Injured Veterans

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Abstract

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The Veterans Health administration (VHA) provides comprehensive care to their spinal cord injured and diseased (SCI/D) patients. By interviewing staff and providers serving this population this study aims to fill gaps in our knowledge of care coordination for this population. Purposive sampling was used to select administrators and clinical executives (n=25) representing 13 SCI/D facilities and the VHA Central Office. Semi-structured interviews were conducted and a qualitative description approach with deductive content analysis was used in analysis. Informants revealed that actual care coordination varies from, and extends beyond, that formalized in VHA Directive 1176. Major themes included the role of provider awareness of the SCI/D system in promoting referrals, challenges utilizing contractors and nursing facilities, difficulties maintaining care coordination between hub and spoke facilities, and the value of information technology and community organizations. By studying the experiences of our informants, we identified multiple opportunities for improving care coordination of Veterans with SCI/D.

1 BACKGROUND

1.1 SPINAL CORD INJURY

Spinal cord injuries (SCI) are injuries between the cervical and cauda equina regions of the central nervous system (Branco et al., 2007). These injuries are classified according to the motor or sensory nerve level (e.g. C7) and severity of impairment (e.g. complete) of the injury (Branco et al., 2007). The most common etiology in adults is vehicular accident, followed by falls (Branco et al., 2007; Richards et al., 2017). SCI effects roughly 294,000 people in the US (National SCI Statistical Center, 2019). The incidence rate of acute SCI In the US is estimated at 54 per 1 Million people (95% CI +/- 1) (Jain et al., 2015) with two thirds of cases being male (National SCI Statistical Center, 2019). The average age of injury is 43 and most cases are due to sudden traumatic injury due to vehicular accident (38.6%) or falling (32.2%) (National SCI Statistical Center, 2019).

Leading health concerns within the SCI population are distinct from the general US population. The primary causes of death are respiratory disease (21.4%) and infection (12%) in the SCI population versus heart disease (23%) and cancer (23%) for the general US population (Heron, 2017; National SCI Statistical Center, 2019). Additionally, SCI patients suffer from multiple co-morbidities including pain, pneumonia, sleep apnea, cardiovascular dysfunction, autonomic dysfunction, neurogenic bladder dysfunction, neurogenic bowel dysfunction, and pressure injury (Lavis & Goetz, 2019). These conditions can often present as symptoms that would be mild or benign in the general population, but be life threatening in the SCI population. Proper care thus requires specialized support depending on the level and severity of injury including, but not limited to, psychological support, urological care, language pathology, respiratory care, and rehabilitation care, alongside providers trained to differentiate symptoms within the SCI population (Emerich et al., 2012; Richards et al., 2017). Non-clinical supports common for the SCI population include transportation services, vocational rehab, and education services (Emerich et al., 2012). The provision and coordination of these services requires multi-disciplinary care teams coordinating care through-out the patient's lifetime (Emerich et al., 2012).

1.2 SCI RELATED DISEASES AND DISABILITIES

There are multiple diseases of the spinal cord that may manifest in adulthood and cause significant impairment. Because of the similar care needs, these may also be treated within SCI systems of care and, together, are referred to as SCI/D.

1.2.1 Amyotrophic Lateral Sclerosis

Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative condition resulting in muscle weakness, atrophy, and death (Masrori & Van Damme, 2020). ALS affects 5.2 in 100,000 US citizens and has no known cure (Mehta et al., 2018). Most patients with ALS die within 2-5 years of diagnosis with 20% surviving up to 10. While all people are susceptible, higher rates have been noted among whites, males, non-Hispanics, those over 60, and those with a family history of ALS. Additionally, exposures such as chemical, radiation, smoking, and high degrees of athleticism have been shown to increase risk of developing ALS. Treatment is aimed at slowing the disease and maintaining length and quality of life. Riluzole is the only FDA approved drug treatment for ALS and slows the rate of progression. Non-pharmacological treatments include multidisciplinary care from neurologists, physical therapists, speech pathologists, occupational therapists, respiratory therapists, social workers, and dieticians.

1.2.2 Multiple Sclerosis

Multiple Sclerosis (MS) is a neurodegenerative disorder affecting approximately 120 in 100,000 Americans (Ghasemi et al., 2016). MS affects the central nervous system and is believed to have a primarily auto-immune component resulting in damage to the protective layer of neurons and a characteristic plaque buildup on parts of the central nervous system (CNS). Any part of the central nervous system may be affected. Symptomology depends on which part of the nervous system is affected and so can be difficult to diagnose. Definitive diagnosis is by observation of characteristics legions in MRI or autopsy. Onset of symptoms varies in frequency and degree of remittance, and rate of progress. There are four subtypes of MS based on these general patterns, relapsing remitting, primary progressive, secondary progressive, and progressive relapsing. Subtypes also vary in which parts of the CNS tend to be affected, and so in symptoms. Pharmacological treatment is aimed at reducing the severity and frequency of relapses and on slowing the progression of disability. Care of slightly disabled individuals may focus primarily on pharmacological interventions (Soelberg Sorensen et al., 2019). Care of moderately and heavily disabled individuals includes multi-specialty care teams including physiotherapist, neuropsychologists, dietitians, speech therapists, social care specialists, pain specialists, continence specialists, and spasticity specialists, occupational therapists, and clinical psychologists.

1.2.3 Transverse Myelitis

Transverse Myelitis (TM) is an inflammatory condition where focal inflammation and the resulting legion cause disability at or below the affected level of the spinal cord (Simone & Emmady, 2021). TM occurs in up to 8 in 1 million people per year. Impairment can be as short as three months or last the remainder of the patient’s lifetime where one third of patients recover completely, one third partially recover, and one third do not recover. Approximately 64% of cases are idiopathic, with no attributed cause. Non-idiopathic cases may be triggered by infection, systemic inflammation, or multifocal CNS disease. Pharmaceutical treatment for the acute legion includes glucocorticoids to reduce inflammation and immunological involvement. For those with incomplete recovery, rehabilitation and adaptive equipment are essential. In addition to physical therapy, bowel and bladder care, occupational therapy, modification of the patient’s living space may be necessary on a short-term or permanent basis.

1.2.4 Syringomyelia

Syringomyelia is formation of a cyst in the spinal cord (Shenoy & Sampath, 2021). Etiology is formation due to T1 Chiari Malformations (CM), tumors, trauma, or infection. Syringomyelia has an incidence of 8 in 100,000 Americans per year and is found in 5% of paraplegics. Most cases present with pain, sensory disturbance, weakness, and atrophy. Other symptoms include spasticity, paraplegia, depression, anxiety, and memory impairment. Untreated, the condition is progressive, as the subarachnoid tissues continue to delaminate due to mechanical stress. Onset and initial progression are rapid and then slows, though left untreated may progress over years. Progress is sporadic, but moments of high intracranial pressure, such as prolonged coughing, can cause rapid progression. Interventions include behavior modification and surgery. Treatment is expected to halt further progress, not reverse current impairment (Leclerc et al., 2020). Long-term care commonly includes pain management, psychiatric therapy, and physiotherapy.

1.3 MILITARY SERVICE AND SCI/D

Service within the armed forces is associated with a roughly ten-fold increased risk for SCI (Schoenfeld et al., 2011). This risk is not spread evenly among service members, and varies by branch of service and demographics, with Junior enlisted status being the highest risk factor, and Marine or Army status being close seconds. Consequently, Veterans are overrepresented within the US SCI population, comprising 43,000 of the estimated 291,000 SCI in the US (14%) while representing only 7% of the US population (Annual Legislative Presentation, 2019; National SCI Statistical Center, 2019; Schaeffer, 2021). This Increased rate of spinal cord injury is associated with elevated exposure to occupational hazards in combat and physical labor, and often accompanied by increased psychological trauma and medical complications when compared with the civilian population (Weaver et al., 2009).

Regarding spinal cord diseases in the SCI population, ALS is overrepresented in military personnel who deploy, while seeming to be unelevated among those who do not (Seals et al., 2015; Weisskopf et al., 2015). Combat related environmental exposures are suspected to be the cause (Haley, 2003). Rates of MS among military personnel are approximately 3.5 times the general world population, with no effect for geography identified (Alonso & Herna´n, 2008; Deussing et al., 2012). Research was not found that identified differences in rates of TM and Syringomyelia among Veterans or Military personnel.

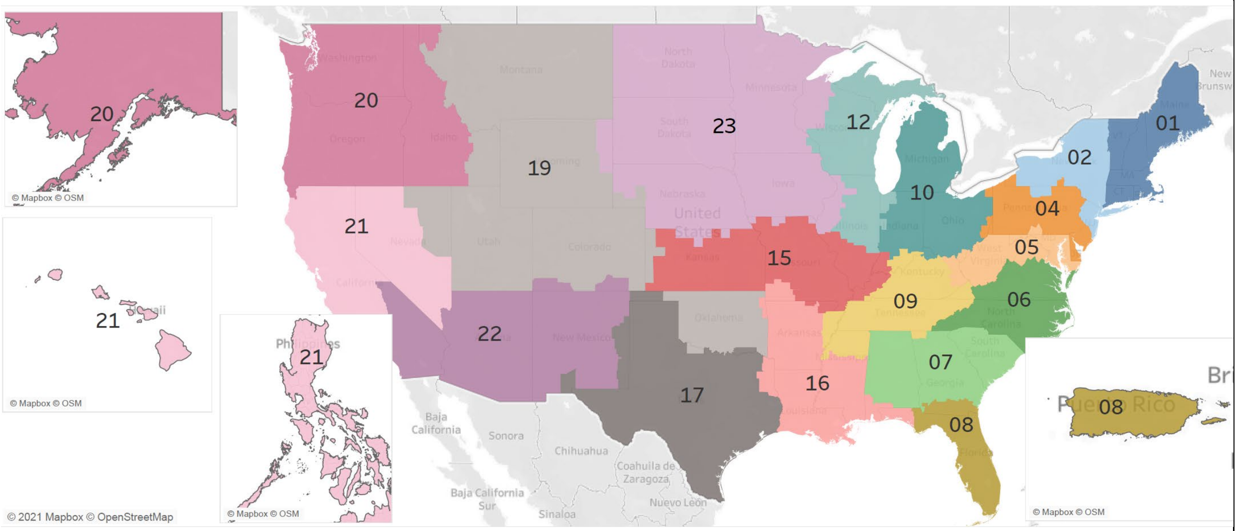
Active duty soldiers suffering SCI are often initially treated in military healthcare facilities (Weaver et al., 2009). If longer term care is required, they may be transferred to Veterans Health Administration (VHA) facilities for specialized SCI care. Most of these patients are discharged to home and do not return to service (Weaver et al., 2009).

1.4 VETERANS' HEALTH ADMINISTRATION

The Veterans Health administration (VHA) is a federally funded integrated healthcare system founded in 1930 (Law, 1997). Its primary mission is to provide for the healthcare of Veterans and their dependents. It is an integrated health system serving Veterans of the U.S. uniformed services. It consists of 1255 facilities, with a total census of 9 million patients nationwide (US Department of Veterans Affairs, 2021).

The facilities of the VHA are separated into 18 administrative regions referred to as Veterans Integrated Service Networks (VISN) (Figure 1) (US Department of Veterans Affairs, 2021). VISNs are semi-autonomous, control their own budgets and staff, and are evaluated autonomously of each other (The Curious Case of the VISN Takeover: Assessing VA's Governance Structure, 2018). The leadership of each VISN is responsible for pursuing performance targets relying on metrics established by the VHA Central Office (VHACO) (Hayward, 2017). The VHACO sets system wide priorities, defines metrics to be implemented by VISNs, and distributes resources to VISN leadership.

Figure 1 Map of VHA VISNs



Map of the existing 18 VISNs. Note VISN mergers have caused the retiring of some numbers, leaving 18 active VISNs, some with numbers above 18.

Since 1999, the VHA has had a single, nationwide, electronic health record (EHR) named the Veterans Health Information Systems and Technology Architecture (VISTA) (Evans et al., 2006). VISTA provides access to patient records across all VHA facilities as well as provides those facilities with necessary financial and process information on clinical activities. Since 2010, the VHA has expanded this internal capacity with a system wide Veterans Health Information Exchange (VHIE) (Donahue et al., 2018). The VHIE facilitate transmission of patient records to providers outside of the VHA. Currently, the VHA has begun implementing a replacement for their current EHR in the VA EHR Modernization Project (Veterans Health Administration, 2020).

The project is expected to complete in 2028, with the first implementations having gone live in October of 2020 (Kroupa & Veterans Health Administration, 2020).

1.5 VHA Services for Veterans with SCI/D

The VHA aims to provide comprehensive lifetime care to their SCI/D patients via a SCI/D system of care comprised of VHA medical and long-term care facilities across the nation (Oshinski, 2019). This requires maintaining a system of providers, facilities, and communications that surrounds these patients and can provide and coordinate services without unplanned disruption of care. This system of care is outlined below and codified in VHA Directive 1176 (Oshinski, 2019).

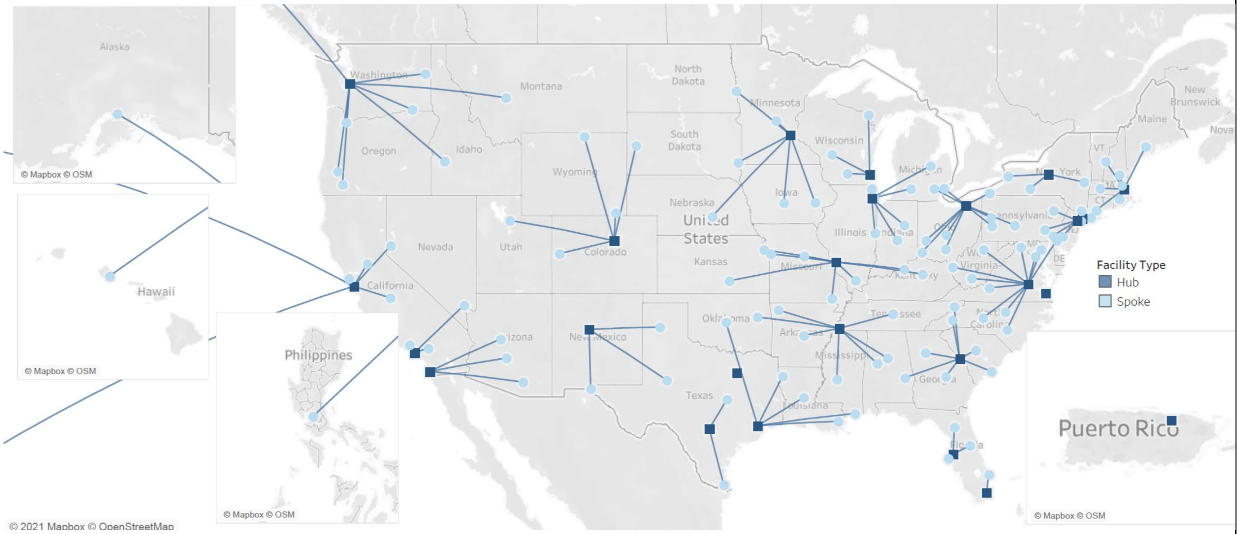
1.6 VHA Directive 1176

VHA Directive 1176 addresses policies, procedures, standards, requirements, and operations of the SCI/D system of care. This includes outlining the roles and responsibilities of inpatient care, outpatient care, home care, telemedicine, long-term care, the regional “hub and spoke” system, and support activities such as training, records management, eligibility, and performance measurement. Below we outline the structure of, and care coordination with, the SCI/D system of care as outlined in 1176.

1.6.1 Structure of the VHA SCI/D system of care

SCI/D care within the VHA is organized into catchment areas that include a designated SCI/D Center of care (hub). SCI/D hub facilities are responsible for providing primary and specialty services to SCI/D patients within their catchment area. There are currently 25 of these hub facilities in the SCI/D system of care (Figure 2.). Veterans may opt to seek care from outpatient VHA medical facilities that provide primarily outpatient SCI/D services with a geographic area around the hub (spokes). Spoke facilities are responsible for providing emergent and primary care to these patients and doing so via providers trained in the care of SCI/D affected patients.

Figure 2: Map of VHA SCI/D Hub and Spoke Facilities



Map depicting locations of VHA SCI/D hub and spoke facilities

Hub facilities in the SCI/D care system support specialized comprehensive care teams that may include medical, nursing, social work, psychological, occupational/behavioral therapy, rehabilitation, and other providers as needed to satisfy care needs of the patients (Lavis & Goetz, 2019). As part of participation in the program, SCI/D patients are examined by the team annually. Additionally, because of the robustness of the hub facilities and their care teams, they are preferred for inpatient and specialized procedures. Spoke facilities, on the other hand, provide more local care, but may not be capable of providing the full range of services needed.

1.6.2 Coordination of care within the VHA SCI/D system of care

As part of the larger integrated VHA system, Veterans may receive care at any facility, receive SCI/D services at any SCI/D facility, and complete their annual reviews at any hub (Oshinski, 2019). Ultimately, coordination and care of the patient is the responsibility of the team at their designated SCI/D hub. If an SCI/D patient is received at a non-SCI/D facility, the receiving care team is required to coordinate with the patient's SCI/D care team, and, if necessary, transfer to the nearest and able SCI/D facility is to be arranged. If this is a spoke, and not a hub, the patient may be transferred again to their designated hub facility.

In addition to receiving care at an SCI/D facility, patients within the SCI/D system of care may be enrolled in SCI/D Home Care (SCI/D-HC). In this mode of care, the care team and covered services extends to include providers, services, and equipment that provide care in the patient's residence. The designated hub facility is responsible for confirming the availability of sufficient care and coordination of care for these services. Circumstances, such as an inability to meet care needs, non-compliance of the Veteran or their caregivers, or extended hospitalization, may result in discharge from SCI/D-HC.

Active-duty service members (ADSM) who suffer SCI/D may qualify for care at a VHA SCI/D hub facility. The coordination of care for these patients is jointly shared by VHA SCI/D and Military

Health System (MHS) staff. The goal is to provide ADSMs who suffer related injuries high quality SCI/D care while they are still in active-duty status. This process begins once the ADSM has been stabilized and is able to be transferred safely from their MHS facility to a VHA SCI/D hub facility. After treatment is complete, the hub is required to submit records to the MHS so that a disability decision can be made regarding the ADSM.

Veterans may be evaluated for transfer into the SCI/D system of care by any hub facility. Referral to the hub facility can be from any provider and is received by the SCI/D coordinator of the admitting facility. The referring provider should include a complete patient history, and the coordinator provides progress on the hub's evaluation of the patient and decision to admit into SCI/D care. A VHA patient who is identified as having a new or acute SCI/D is to be transferred to a SCI/D hub facility when safe to do so. SCI/D Veterans can seek care at any hub but are encouraged to select a hub facility that is assigned to the area they reside at.

In the event that the patient prefers, SCI/D hubs may collaborate with the patient to discharge to a long-term care (LTC) facility. Directive 1176 specifies that the receiving facility must meet requirements set by the SCI/D care team and that the SCI/D team is responsible for further education of the LTC facility teams and for quarterly follow up with the patient.

The VHA SCI/D system of care is a complex system of formally and informally integrated components. This complexity presents challenges in delivering quality care to SCI/D patients in the System. Factors such as the service status of the patient at the time of injury, patient awareness of services, the patient's distance to SCI/D hub facilities, and facility staffing, all play a part in successful coordination of service delivery for these patients (Annual Legislative Presentation, 2020; Department of Veterans Affairs Office of Inspector General, 2004; Pai et al., 2012; Stillman et al., 2014; Sujuan, 2017). The continued study and improvement of this system is an ongoing area of interest to the VHA with goals of improving safety and outcomes while reducing costs (Weaver et al., 2000).

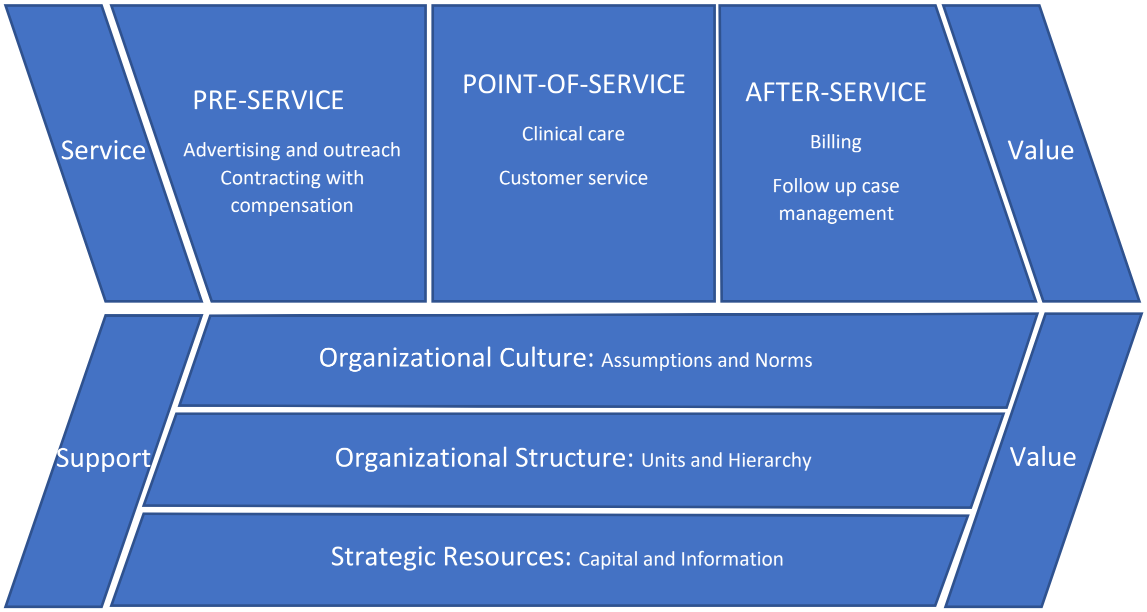
1.7 THE RESOURCE BASED VIEW OF THE FIRM AND THE VALUE CHAIN MODEL

To better understand and model the relationship of care coordination activities to performance we rely on models from organizational theory. The resource-based view of the firm (RBV) is a family of approaches to analyzing businesses that attempts to measure internal characteristics of the firm that distinguish it from its competitors (Barney, 1991; Porter & Porter, 1983). This view is distinct from models of Industrial Attractiveness, which prioritize the environment in which the firm operates. In resource-based models, the firm is characterized as a collection of resources. Resources are broadly defined to include all assets, capabilities, and skills that the firm controls and can implement. RBV models are used to assess competitive advantage, which is the outcome of the firm deploying resources to generate value in ways unmatched by competitors. This may be further defined as a sustained competitive advantage if competing firms are unable to emulate the value generating strategy.

Michael Porter, an industrial researcher and major contributor to the development of the RBV, developed the Value Chain Model as an expansion upon the RBV of the firm. It describes the relationship between distinct economic activities within an organization that ultimately lead to value for the organization (Porter, 1985). In Porter's model, activities are divided into support activities and primary activities. Primary activities are depicted as a chain with each activity providing inputs into the next. Support activities extend across all primary activities and support the primary activities. At the end of this chain of activity is the value remaining to the organization after conducting the activities, called margin.

To adopt this model for healthcare service organizations, Peter Ginter, Duncan Jack, and Linda Swayne, developed a Value Chain Model (VCM) emphasizing chains of service activities and organization characteristics supportive of those activities (Figure 3) (Ginter et al., 2013). In his model, the sequence of primary activities is divided into three classes, pre-service, point-of-service, and after-service, while support activities are divided into three classes, organizational culture, organizational structure, and strategic resources. Examples of pre-service activities include advertising and outreach to potential patients and referring providers, and facilitating compensation arrangements. Examples of point-of-service activities include care provided, and customer service. Examples of after-service activities include billing, and outreach for follow-up. Organizational culture includes the assumptions, values, and norms shared by members of the organization. Organizational structure refers to the functions of, and relationships between, individuals and units in the organization examples include the various defined organizational units, and the hierarchy of executives, managers, and direct contributors. Strategic resources are those capital and informational resources available to the organization, examples include department budgets, physicians, auxiliary staff, and medical equipment. This approach is well suited to the analysis of performance and quality as resources are utilized across healthcare organizations.

Figure 3: Value Chain Model for Healthcare Service Organizations



Ginter et al. health services value chain model, adopted from Porter's original model. Depicts how various pre-, point-of-, and after-service activities, and their supporting activities of organizational culture, organizational structure, and strategic resources, lead to value for the organization.

Adapted from: Ginter, P. M., Duncan, W. J., & Swayne, L. E. (2013). The Strategic Management of Health Care Organizations (7th ed. ed.). San Francisco, CA : Jossey-Bass, Wiley.

1.8 RESEARCH QUESTION

Currently, gaps exist in the VHA's knowledge of practices in care coordination of SCI/D patients (Annual Legislative Presentation, 2020). By interviewing staff and providers across the VHA SCI/D system of care, we may fill gaps in our knowledge of activities along the value chain of SCI/D care coordination. By doing so we aim to further inform VHA improvement efforts and improve the lives of patients served by the SCI/D system of care.

Question: What are the perceived strengths and weaknesses in care coordination among VHA providers and staff involved in the VHA SCI/D system of care?

2 METHODS

2.1 LITERATURE REVIEW

As part of our preparation to research, we conducted a structured literature review. This review was aimed at discovering available literature discussing continuity and quality of SCI/D care delivery within the VHA. Inclusion criteria included terms for costs, outcome measurement, patient experience, barriers to care, and availability of resources. Exclusion criteria included non-clinical care, not being SCI related, non-US care and comparisons to non-US care, end of life care, research on clinical and nursing procedures or devices. Queries were developed for google scholar, EBSCOhost, JSTOR, Proquest, Web of Science, and PubMed that met these criteria. This resulted in 3395 matching results (Figure 4). Two members of the team validated the title search by independently classifying 10% of the results for inclusions and exclusion and then meeting to discuss decisions and better define criteria until full agreement was reached on the 10%. Researchers then independently applied inclusion and exclusion criteria to the remaining titles. A similar approach was used for abstract and full text review; however, full agreement was sought at each of these stages. This left 110 articles for analysis. An additional 35 articles were identified by collaborators as valuable for inclusion. These included legal and policy documents, congressional hearings, and selected literature on nursing practice in SCI/D care.

Figure 4: Literature Review Process Diagram

SCI/D Literature Review Process Diagram

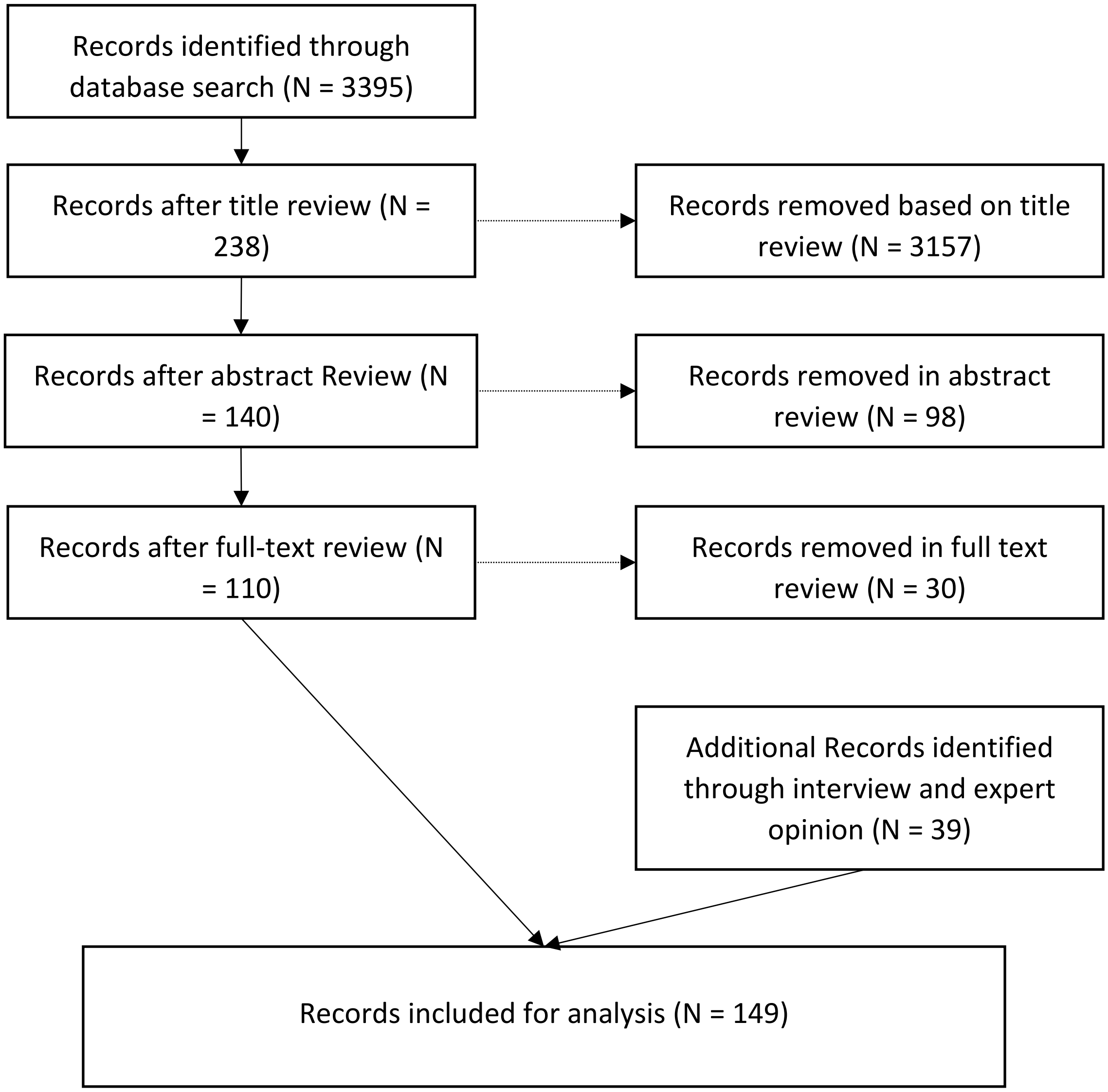


Diagram depicting the stages of literature review and the number of articles rejected and kept at each stage.

The resulting 145 articles were read and analyzed for content. We classified articles by component of the value chain addressed (pre- point-of-, or post-service), if it addressed access, attitudes, or service delivery, if it primarily analyzed patients or the system, if it primarily analyzed the MHS, VHA, or civilian care, the number of subjects, and its' topical focus (Appendix A).

2.2 CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH (COREQ) FRAMEWORK

This study was reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) framework (Tong et al., 2007). The COREQ framework is a reporting checklist for purely qualitative research featuring interviews or focus groups for data collection. Its purpose is to encourage complete reporting of methods and is structured using three domains of content: 1) research team and reflexivity, 2) study design, and 3) analysis and findings. Appendix B shows the full COREQ checklist with the content to be addressed in each domain.

2.3 STUDY TEAM AND RESEARCH APPROACH

This analysis was part of a larger study of staff and patients participating in SCI/D care within the military and Veterans Health Services. This larger study was funded by a research grant from the Department of Defense (DoD) with the aim of improving care provided to the SCI/D population. That study received approval from the University of Washington Institutional Review Board as a minimal risk study (STUDY0008731) on 11-18-2019. The study was additionally approved by the U.S. Army Medical Research Acquisition Activity (USAMRAA) Human Research Protection Office (HRPO).

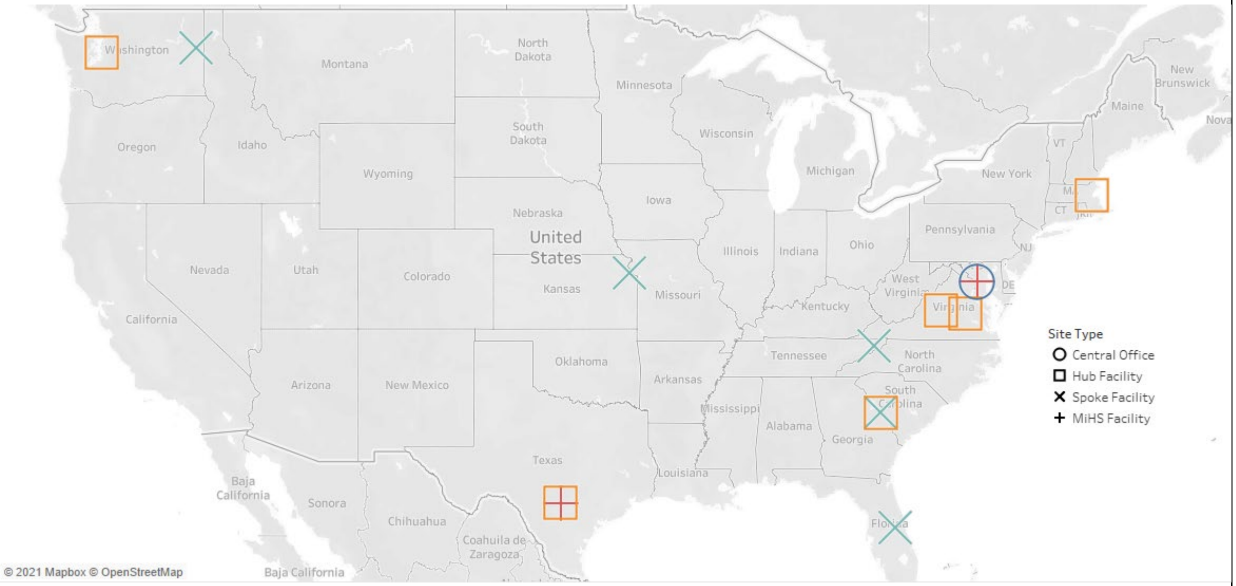
The study was headed by a female health administration researcher and military officer serving appointments both as academic faculty and as military personnel with 30 years of experience in healthcare administration in the MHS. Because of the principal investigator's (PI) history, she had prior professional relationships with some staff interviewees, particularly on the military side. As PI, she conducted all interviews and introduced herself as both an academic researcher and military officer to participants.

The research followed a participatory action research (PAR) approach (Baum, 2006; Creswell & Creswell, 2007). PAR is aimed at having impact on the activity or environment under study and places the researcher as an advocate and facilitator in the process. PAR pays special attention to power dynamics such as those between the researcher and the participants, and participants and other stakeholders. Where traditional research is concerned largely with avoiding harm to participants, PAR is interested in actively improving the circumstances under study. Along with making their observations, the researcher engages in reflection and planning to affect changes in the system, reevaluates the focus of the research, and then continues their observations. The approach relies heavily on collaboration with study participants to inform this process and identify valuable action items and evolutions of the study.

2.4 SETTING

Study participants represented a sample of multiple VHA and MHS facilities (Figure 5). These facilities included the VHA Central Office, 6 VHA hub facilities, 5 VHA spoke facilities, and 2 military facilities hosting VHA coordinators. Prior to data collection, the 2020 SARS-Cov-2 virus was identified, and social distancing policies became standard practice across the country. This necessitated all interviews being remote, with researchers in their homes and participants in their homes or facilities.

Figure 5: Locations of Participants



© 2021 Mapbox © OpenStreetMap

Geographic locations of study participants with facility type indicated by shape.

2.5 RECRUITMENT

Purposive sampling was used to select administrators and clinical executives from SCI/D MHS and VHA facilities. Participants were included for their experience with MHS and VHA populations, being English speaking, and for their ability to consent to participation in the study. Exclusion criteria included not being affiliated with the MHS or VHA facilities for treatment or rehabilitation of SCI/D patients, not having experience with SCI/D patient populations, being unable to comply with instructions, or being unable to provide consent to participate. Additional exclusion criteria for this analysis included not being employed by the VHA. These staff came from clinical and administrative roles across the VHA (Table 1). One third were clinical providers in lead roles, two thirds were support staff or auxiliary care, and one was an administrator. A majority, three fifths, were female, and the rest male. None identified as non-binary. Approximately 68% identified as white or Caucasian, others identified as Black, Asian, or Hispanic. Over one third held terminal degrees, a majority held masters level degrees, and one fifth held bachelors level degrees.

Table 1: Participant Demographics

Role	Lead Providers (MD, PhD)	8
	Support Staff (RN, LCSW, PT, etc.)	16

	Administrators (CEO, President, Service Officer, etc.)	1
Site	VHA Central Office	1
	SCI/D Hub Facility	14
	SCI/D Spoke Facility	6
	MHS Liaison Office	4
Gender	Male	10
	Female	15
	Non-binary	0
Race	White	19
	Non-white	6
Highest Degree	MD//DNP/PhD	9
	MS/MSW/MSRN	11
	BS/BSN	5

Table of participant demographics.

Participant identities were anonymized with an indicator of their site, role, and a numerical sequence (Table 2).

Table 2: Participant Labels

Anonymous Identifier	**Description (Site / Role)**
CP (N = 1)	Central Office / Provider
HP (N = 5)	Hub / Provider
HS (N = 9)	Hub / Support Staff
SP (N = 2)	Spoke / Provider
SS (N = 4)	Spoke / Staff
LS (N = 4)	MHS Liaison Office / Support Staff

Table of de-identified labels used in reporting results.

2.6 DATA COLLECTION

Interviews were semi-structured. Interview times ranged from approximately 45 minutes to one and a half hours. The interview instrument was developed with expert opinion of the research team and an advisory board. Questions were devised that addressed six main constructs of the VCM for Healthcare Service Organizations: Pre-service, point-of-service, post-service, organization culture, organization structure, and resources. The instrument consisted of 15 questions. Five questions included probes to specify strengths and weaknesses. Responses to three of these questions and their probes were sampled for this analysis (Table 3).

Table 3: Sampled Interview Questions

Question	Role in the Value Chain Model
How might complex care (SCI/D) patients and/or caregivers learn about the services your organization provides?	Pre-Service
Describe any facilitators (people, process, or resources) that help or assist with the communication/coordination process? • Internal to the organization? • External to the organization?	After-Service
What are barriers to this communication/coordination process? • Internal to the organization? • External to the organization?	After-Service

Interview question used in this study and their intended reference to the Value Chain Model for Healthcare Service Organizations.

Semi-structured interviews (n=25) were conducted with VHA staff from across the country. These interviews were conducted from March 2020 to December 2020. Additional questions and probes were asked to triangulate information across participants and literature. Where a participant addressed a question prior to it being asked, the question may have been skipped in interview. All interviews were audio recorded and transcripts were created using the speech-to-text platform, Temi. Other members of the research team reviewed the audio recordings and corrected the transcripts to ensure they were representative of the audio recordings.

2.7 ANALYSIS

Prepared transcripts were loaded into Dedoose version 8.3.43 for analysis (SocioCultural Research Consultants LLC, 2021). For this analysis, only responses pertaining to pre- and post-service care coordination were included. Themes were identified within each of these constructs and reported below. Coding was performed by three members of the research team. Researchers validated each other's codes in a second round of coding while engaging in online meetings and correspondence via email to address confusion and misalignment in code applications.

A qualitative description (QD) approach with deductive content analysis was used in analyzing the collected data (Elo et al., 2014; Kim et al., 2017). QD is an analytical approach common to healthcare settings and is focused on describing and reporting on the phenomenon under study. Design and method are kept flexible to optimize the accuracy and richness of observations and their reporting. Deductive content analysis was performed according to the constructs of the VCM for healthcare service organizations.

3 RESULTS

The below findings were the result of analyzing content classified by the research team in response to questions about how patients learned about SCI/D services, facilitators of communications and care coordination of SCI/D services, and barriers to communication and care coordination of SCI/D services.

3.1 Q3 HOW DID PATIENTS LEARN ABOUT YOUR SERVICES

To assess pre-service care coordination, informants were asked to relate how SCI/D patients learned about the services provided. Informants described varying processes depending on if the patient arrived from MHS, VHS, private sector care, or directly pursued SCI/D care without a referral. Across all settings, emphasis was placed on the need for knowledge of SCI/D services to improve capture of, and reduce expenses to, qualified Veterans. This related to coordinating care between Military and VHA as described in the Directive 1176, as well as areas not addressed in 1176, such as direct outreach to Veterans who were not currently enrolled.

3.1.1 Referral from VHA facilities into SCI/D care

Four informants (SP1, HS7, HP1, and HP2) described referrals from primary care providers, neurologists, social workers, and units treating other degenerative disorders. SP1 noted, "**Some of it's their self-referrals or other people in primary care,** […] **someone who just had some neurosurgery** for like a central stenosis or whatever. Um, so that would probably [be] the three; a **social worker somehow finds them, primary care will recognize it and refer, or self-referral** from patients that we're seeing."

Multiple informants (HS2, HP1, and HP2) indicated, “It really **only comes from the case managers**“ in regards to informing Veterans of opportunities for SCI/D care.

Some informants noted strategies to identify patients who may qualify for SCI care. An informant from a spoke facility (SS4) described relying on their patient records to identify potential SCI/D patients. “**We try to find the ones that actually have some form of a spinal cord injury**. I just came across one today. […] I've actually tried to **track down one of our docs** and said, ‘Hey, would you please check this out just **to make sure that this guy is appropriate for SCI?** Because, if he's being missed, he's not getting the appropriate care.’”

One respondent (HP5) noted, “When they do the SCI registries, I know they go through [...]looking at diagnosis codes and **seeing some patients who were coded as spinal cord injury but maybe weren't being followed by the SCI registry**, and we reached out to those Veterans.”

3.1.2 Direct outreach to and from Veterans

Several informants described the importance of reaching Veterans to make them aware of VHA SCI/D services. Different strategies were deployed. SS1 described raising awareness by their rehab facility’s participation in paralytic sports. “Our recreational therapists go to a lot of games like the winter and summer sports games. **They find a lot of Veterans there**. They find a lot of people there and **they give them my phone number.** And so, they call back and they ask about getting involved.” A spoke-based informant (SS3) said, “**PVA has been a great help** to us in getting the word out that we have services available. And I work with other Veteran service officers in the community so that **they know that we're here and what we have**.”

One informant (HS1) discussed advertising and explained that “You're n**ot really allowed to spend those [marketing] dollars on marketing**. It is challenging. There are lots of barriers to that.”

It also happened that Veterans became aware of services through other means and sought out VHA SCI/D care directly. Informant SP2 described, “Some of our referrals come from internal; where **the Veteran will call directly because we've posted my name and number** to the clinic here or through a local VA employee here that contacts us. **Maybe they got a referral of our community living cente**r, or maybe got a referral from an outside hospital for a new spinal cord patient”. Another informant (CP1) noted that, “We have an open a line **through our internet sites**. And we get messages that come into our office. ‘Hey, **I'm the sister of Joe Blow who has had a spinal cord injury**, and he's doing terribly, **can you help us?’**”

Informant (SS1) described encountering patient enquiries in the VHA facility, “A lot of people think just because they have back pain, they are a spinal cord patient. **They stop by all the time,** and what I do is I ask them, ‘who's your primary care provider?’ Cause obviously they're here in the VA, so somebody here is their primary care provider. **I normally shoot that primary care provider an email, letting them know**, ‘**Hey, one of your patients came** by. This is his name. He inquired about being a part of SCI services. If you feel like this is appropriate or you feel like this is something you want us to look into, **will you please set up a consult?’**”

3.1.3 Referral from the private sector

Respondents HS6, SS3, and HS7 noted that referral from the private sector depended on the referring provider being aware of the VHA and SCI/D system. One SCI/D Hub informant HS6 described that, "A lot of the doctors here will rotate through all the hospitals. So, **they've worked at the VA** and they understand the specialty services that we provide." A social worker (HS7) noted, "**My service specifically is by word of mouth,** or, my colleagues, other social workers, or other disciplines, and **educating them about all of this**." A spoke informant (SS3) described educating local providers about VHA SCI/D care. "**We just kind of started to slowly put the word out that this was available.** There were some things that we could pull off the internet, you know, specifically about ALS. It was an easy thing to just drop by and drop off a flyer or something to say, 'Hey, please let us know if you run across someone that you think we could be helpful.' And then a**fter we got one or two referrals, then word spread very quickly.** It didn't take long for doctors in the community to figure out that **we really could provide things that otherwise patients could not afford.**"

Several respondents (HP3, HP4, HS1, SP2, CP1) noted that private facilities may not refer patients out until after exhausting the patient's insurance. One informant (HP4) intimated, "Sadly there are times that people are seen in a community hospital and **they're not aware that the person is a Veteran.** […] There are also times **somebody may notice the person is a Veteran, but they keep them in that program.** And then **once their insurance runs out, they refer them to us.**"

3.1.4 Referral from Military Health Services

Regarding MHS referrals to the VHA, a liaison (LS1) reported,

> *"The way that I get the referrals is that I work with the PEBLO people and the IDES folks at the medical evaluation board. They **basically give me a list of all the folks that have gone through the medical evaluation board.** And I call the patients up and I tell them my role and I introduce myself. **I ask them if they would like to be linked to the VA** so that I can set them up with their medical care, and they agree to it. And then I go ahead and take the information and link them to the VA. A**nother way is through the case managers at the warrior's transition unit.** The nurse, the case managers, also make referrals to us."*

A different liaison informant (LS4) described that, "Here at Walter Reed, there's a **main social work service office but they have different divisions of social work**. Some deal with the wounded warrior, some inpatient. So, you may **have separate supervisors or separate persons that handle it depending** on what division."

LS1 also noted, "There are still **service members who are just out there and by word of mouth**, or somehow are requesting to get assisted even though they're not part of the warrior transitional unit or SRU or the medical board and, you know, they may have retired already."

Regarding eligibility of ADSMs, an informant, LS4, described that, “One **misconception** which may have been among all military staff is that, **‘If you served in the military, you're eligible for VA care.’** Once they understand that that may not be the case, they're able to speak better, or they'll at least refer to a VA person to explain that.” In addressing these misconceptions, several informants (HS1, LS4, and CP1) noted the need to train DoD staff. HS1 described that, “**We would send our spinal cord injury teams** and our polytrauma teams out **to the DoD** sites to do **face to face meetings with the potential referring physicians and clinicians.”** LS4 also noted, “With **VA staff now being on the** military base more, some of them were able to educate staff. **They're able to have a better relationship and questions answered.**” However, informant CP1 noted how the frequent movement of MHS staff to different post was a barrier to this training effort.

> *“We educate people [in the DoD], and then two years later, those people are gone and it's new people in their place. […] It's been very difficult to get traction in the DoD.”*

3.2 Q 9 DESCRIBE ANY FACILITATORS (PEOPLE, PROCESS, OR RESOURCES) THAT HELP OR ASSIST WITH THE COMMUNICATION/COORDINATION PROCESS

Multiple themes arose for facilitators to continuity of care. The “warm handoff”, coordination between hub and spokes, information technology, and external partners. Many of these features, particularly the coordination between MHS and VHA, and the communication and consults between hub and spokes, were outlined as requirements in 1176.

3.2.1 Warm handoff and discharge to VHA SCI/D Care

A “warm handoff” of Veterans and soldiers out of inpatient VHA care was indicated by several informants (SS1, LS1, HS4, LS4, HS2). LS1 described this warm handoff for a soldier discharging into Veteran status and VHA SCI/D care.

> *“We’ll make contact with their program manager where they're transitioning to **provide a warm handoff verbally and then email their packet of information** which consists of the VA referral form and the medical record. That program manager will **work with their team to coordinate the service member** to get a VA appointment while they're active duty for the Tri-Care authorization or after they're retired. Any additional information is transitioned at that time; medications, and any other services that part of the transition process. After that, **the service member is contacted** and notified of the appointment. Once they're notified of the appointment, the gaining VA would normally let us know as well. And **we'll let the case manager know the service has been connected** successfully.”*

HS2 gave an account as a receiving hub of a new SCI/D patient.

> *"Our physician is going to review and say, 'Yes, this service member definitely has a spinal cord injury and we have the services here to treat them.'* ***I communicate that with the case manager and then if*** *the* ***family*** *[…] We do all kinds of communication with them.* ***If the family wants to come in for a tour of the facility, we set that up****. So that way, that particular service member and family is getting an idea of what kind of services we provide and basically what they're going to be coming to. Once we've done that and the service members are agreeable to coming here, we'll set up an admission date. And then in addition to that, we're like,* ***'what are the needs of the family?' 'Does the service member have any family members that he wants to participate in the rehabilitation?'"***

A couple of informants (HP4, HS2) noted that discharge planning started before the patient was received. HP4 described how, "The whole time that they're here **we're continually preparing** on, 'What do we need to do **to make the person successful after they leave** here?'"

3.2.2 Coordination between hub and spokes

Regarding the relationship between hub and spokes, informant HS3 described that, "**They reach out to us with questions**, you know, things that they're not sure about. We have a good working relationship via email or telephone. And **we have training here for our spokes** and they're always very appreciative and give good feedback from the training that they received."

Some informants (HP5, HP3) described the benefits of being a centralized system. HP5 detailed that, "**We really don't have to go outside for much.** Just about everything that we provide, we provide internally as far as equipment, staff, and referrals. Um, so when we refer somebody for something, whether it's a medical issue, whether it's a specialized piece of equipment**, [the referral] almost always occurs within the VA**." They also noted particular ease in communications, "**We can have conversations with other providers very easily.** The communication is quick and easy, and discussions are easily had. **There's not a lot of phone tag.**"

Informants highlighted different strategies in the coordination of care between hub and spoke facilities. One informant (HP1) noted that, "The chief, the hub and spoke coordinator, and the social work supervisor, **the three of us, visit each of our spoke clinics at least once every two years** and make sure that we're all on board and working together. **This hub and spoke model really is** valuable and **essential to management**."

A spoke-based informant (SS2) noted the strategy implemented by a provider at their hub. "We meet with him **every week**. We **discuss patients** that we want **to transfer** or that are pending transfer **or that need** something. Um, so **the communication is awesome."** They went on to note that, "S**ome hubs and spokes** have very positive relationships and others **just don't** really seem to **have much of a relationship**."

3.2.3 Information technology

Informants described the use of various communication resources in the coordination of care including face-to-face meetings, video conference, telephone, email, and secure electronic messaging. Multiple informants also cited the VHA's electronic health record resources as critical to care coordination between VHA facilities.

An informant (LS2) noted that while providers could access medical records in the electronic health record, case managers relied on the VHA's Joint Legacy Viewer to view patient's MHS records, "The **JLV has been the new system that we used for a couple of years.** […] The case manager can go into Joint Legacy Viewer, which is a VA system, and see what's going on with the service member as well when they are connected."

A provider (HP3) highlighted other valuable features of the VHA's Joint Legacy Viewer.

> *"It's so **wonderful to have imaging and, like, lots legacy medical records and to be able to pull up records from another VA somewhere else** or even from the department of defense. And so, you know, people are so full of complaints about things, but to me, **it's almost magical in its' utility. I can get information at the tips of my fingers** that like, 20 years ago, would've been like a month-long process. So, I think it's incredible."*

Regarding instant messaging, SP2 noted that, "Because I don't have to pick up the phone. **I can have a Veteran right in front of me** and I can reach out and be like, 'Oh, hey, **let me just ask [a SCI/D hub physician] a question**. I'll just type in [the physician's] name and pull him up and **see if he's online and shoot him a message**. And then **that helps me coordinate the care**."

A hub-based informant (SS1) found themselves on the other side of these messages and described that, "We get **dozens of e-consults per day**. They are each one of our **spoke sites** just kind of **asking common questions, recommendations, 'what should I do', or asking permission to get something done locally.**"

VetConnect, a tool that connects providers, caretakers, and patients, was noted by another informant (HP5). "You kind of have the three-way communication. […] **It's a little bit easier now that we have things like the VetConnect** where we could actually set up a three-way call. We try to do that a lot more. We try to do that, particularly on admissions and discharges."

3.2.4 External partners

The Paralyzed Veterans of America was highlighted by multiple informants. A hub-based informant (HS4) noted that, "The **PVA is** pretty much **the only community-based organization** that I can think of that normally is working with our patients." A spoke-based informant (SS1) noted, "Sometimes they're **involved in our handoffs**." Informant HS6 described the PVA as an information resource. "The PVA, with anything with benefits, **is who I talk with regularly to try to just get updates** and see what they may be eligible for." Another (SS3) pointed out that, "PVA has been a **great help to us in getting the word out** that we have services available."

3.3 Q10 WHAT WERE BARRIERS TO COMMUNICATION/COORDINATION PROCESSES?

Responses to question 10 addressed barriers in care coordination as outlined in Directive 1176. These included themes of slow administrative processes, imperfect health record exchange, a lack of contracted partners and VHA care, and communication failures between hub and spokes.

3.3.1 Slow administrative processes

A hub-based informant (HS5) noted that there was inconsistency in documentation required for securing equipment for patients.

> *"**There's not a standardized way on how information is sent**. And so you could be getting it by phone call, fax, email, um, there's just not a consistent system and so **things can get missed or displaced."***

Another hub-based informant HS4 noted difficulties in procurement of prosthetics because, "**We only have one [purchasing agent]** and he purchases for all of our people, **for all 1300 patients that we follow** here. [...] If we were waiting on a ramp or waiting on a wheelchair part or whatever, and he hasn't heard back from the company, it may not trigger him. He may not trigger for a much longer time than we would want to wait to get back in contact with them."

3.3.2 Imperfect health record exchange

Electronic records outside the VHA were not necessarily interoperable. Informant HP1 described that, "We'll refer them to the university affiliate, but that's often a weakness in the link because **we don't always get that medical record embedded back into our medical record**. Um, and so that is a challenge there when we deal with outside-of-the-VA specialty services."

A coordinator (LS3) noted, "**Each military treatment facility has its own E-centrists or inpatient medical record system.** San Diego cannot read Walter Reed. You can't read Fort Brags. So, you can't read each other's [records] or the VA's. **So, what continues to happen is the VA receives faxed documentation.** […] We can land a bomb in a very specific window across the globe at 3:01 AM on a Tuesday, but we still have to fax documents."

3.3.3 Lack of contracted partners and VHA care

A lack of external partnership caused delays in care, as noted by a spoke-based informant (SS3) who was unable to secure equipment and home modifications in a timely manner.

> *"It's hard. And especially with ALS, I feel like I'm such under the gun with time because […] most of ours come to us fully involved and older. **We know time is of the essence.** I just had **a patient that died** about a month ago that had been **waiting for over a year for adaptations in their home.** They had been approved. **We could not find contractors to do the work.** He died without ever getting those things done."*

This same informant also noted that when contractors were available, paperwork could be a barrier to securing their work. “Many times, the contractors want to do the work, but **there's just a paper for this, a paper for that.** And we submitted this and then they didn't get it, and that was lost, and we had to do it again. And those are the kinds of things that I hear.”

A hub-based informant (HP5) described, “It is harder to work with external resources just because they have to be vetted in a certain way to be associated with the VA. So sometimes that can be a barrier as well. […] **The VA has kind of closed itself off in a lot of ways**.”

Nursing care was mentioned by multiple informants. One informant [LS1] noted that the VHA does not have nursing home type facilities for young adults who are not able to live at home. “Somebody with TBI or spinal cord injury, and they are 21, you know, the VA has a CLC, which is a nursing home, and also contracts with other facilities. But **those are nursing home types of places for older people**.”

A hub-based informant (HS7) described other limits where, “[A] majority of the **nursing homes out there cannot accommodate someone who has that device** or needs to use that device,” and that, “**Wound care is too expensive,** which means that it's **either too costly for them requiring too much staff time to do the dressing change**.” They went on to note the burden of this on the SCI/D unit, “We keep them […] and we just keep expanding our search. […] I've gone as far as a hundred-mile radius of where his family's from.”

Another hub-based informant (HS4) noted their strategy for addressing the limited care in nursing facilities. “**We send our SCI home care team in to follow up and kind of act as a bridge** for that patient. They can't do any hands-on care in the nursing facility, **but they can go in and review and see how the patient looks**. They will let them look at them to see if they have any wounds or anything that's developed**. We can provide education to the staff**.”

One informant (HS6) noted some attrition to contracts where, “We've had an adult family home that said that they felt comfortable after reviewing. But, **after they come in and see how much care that actually is, they've backed out**.”

One hub informant (HP4) noted the lack of psychiatric services for disabled patients within the VHA. “The nurses on those units aren't trained in taking care of people with spinal cord injury. Also, **because of the safety precautions,** they don't want a lot of the equipment and those sorts of things. They’re afraid that somebody would use things to harm themselves. So**,** they are facing a lot of restrictions in terms of what they can have and allow on their unit. But then essentially, **it's not open to a person with disability.**”

When considering broader community partnerships, a hub staff member (HS1) noted that the VHA lacked a mechanism for financially supporting community partners such as adaptive sports programs. “It was really hard to -- **it was always like we were just asking them to volunteer to help us out** when I was at the VA.”

3.3.4 Communication failures between hub and spoke

Several informants (HS5, SS2, HP5, and SP1) highlighted that there were not always high levels of communication between hubs and spokes. An informant (HS5) noted, “We had members from the spoke sites come to the spinal cord unit. **They were sharing struggles about communication, and handoffs, and then follow up on, whether it's equipment or placement issues**. You know, **there's just a breakdown and there has to be a better way** for us to communicate with one another.”

An informant from a spoke facility (SP1) described coordination challenges resulting from a patient going to a hub in a different region from their spoke.

> *“[A patient] has chosen to do his annuals in [a distant hub facility]. But **what happens then if something goes wrong** with a wheelchair, or the patient gets admitted as an inpatient? **All those records are in [that hub facility]. You can get to them, but it's not easy** to get to them or to find what's going on. […] I've talked to them about discharge service and sending them to us. And **some of that communication is just not quite there yet,** even though we've given that feedback.”*

Finally, one hub-based informant (HP5) noted, “A lot of times **the spoke facilities will have better understanding of what's available in their area**. You know, we're more of a metropolitan area […] whereas a lot of the Veterans are in more rural areas **and we're not aware of what's available,** and what's not available, in those areas.”

4 DISCUSSION

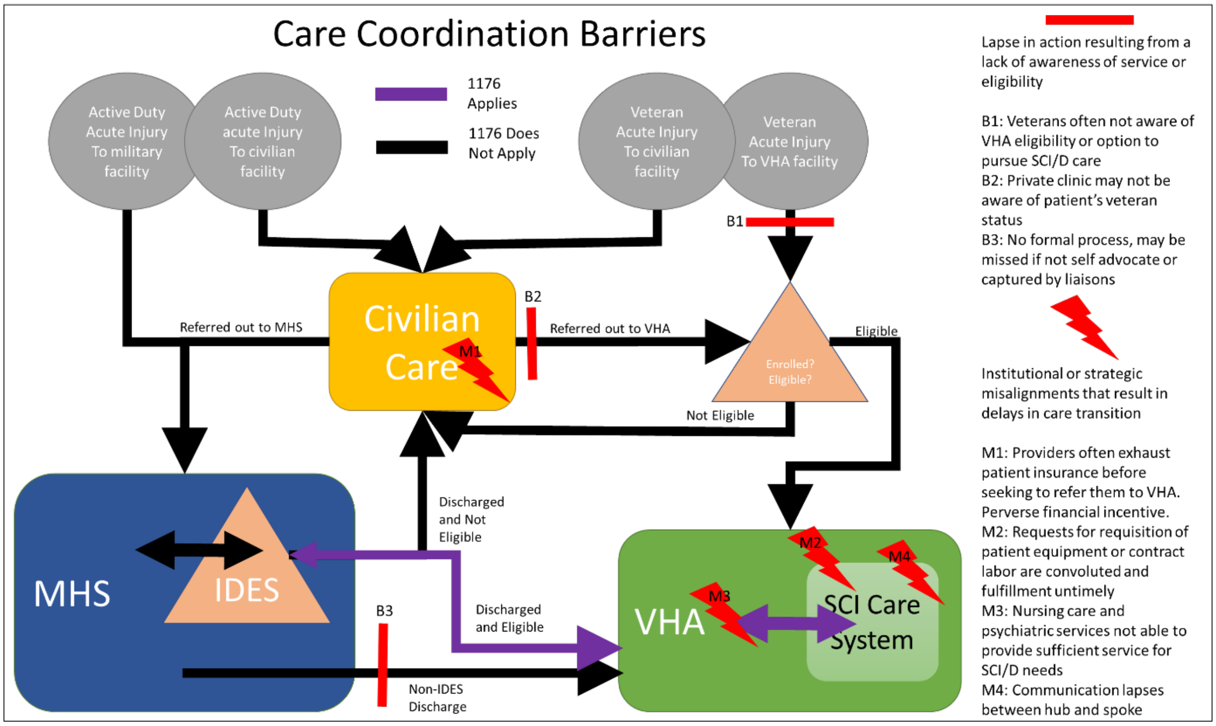
VHA Directive 1176 outlines multiple responsibilities and relationships across the SCI/D system of care. This includes the responsibility of the hub care team to coordinate care with the MHS, spokes, long-term care, and other providers to which their patients are referred. Additionally, 1176 details requirements and recommendations for structuring the relationship between these entities, such as requiring annual visits and training of spokes, training of staff and inspection of patients in long-term care facilities, and the collaboration between MHS and VHA of ADSM patient care. Despite this, 1176 is not fully descriptive of the practice of care coordination. By interviewing staff across the SCI/D system of care, we were able to record experiences of the actual practice of the coordination of care and identify how they relate to 1176.

4.1 COMPARING SCOPE OF 1176 AND SCOPE OF SCI/D CARE COORDINATION

Many of our informants indicated care coordination activities that extend beyond what was formalized in 1176. Directive 1176 primarily addresses SCI/D care coordination within the SCI/D system and between the SCI/D system and the MHS. However, in our interviews we found that

SCI/D outreach extended into civilian care and to Veterans who were not attached to SCI/D care but may benefit from enrolling. This limitation of the scope of 1176 relative to care coordination pathways into the SCI/D system is illustrated in Figure 6 along with key barriers and facilitators in care coordination discussed below.

Figure 6 Diagrams of Care Pathways, and Barriers and Facilitators of Care Coordination Within the SCI/D System of Care

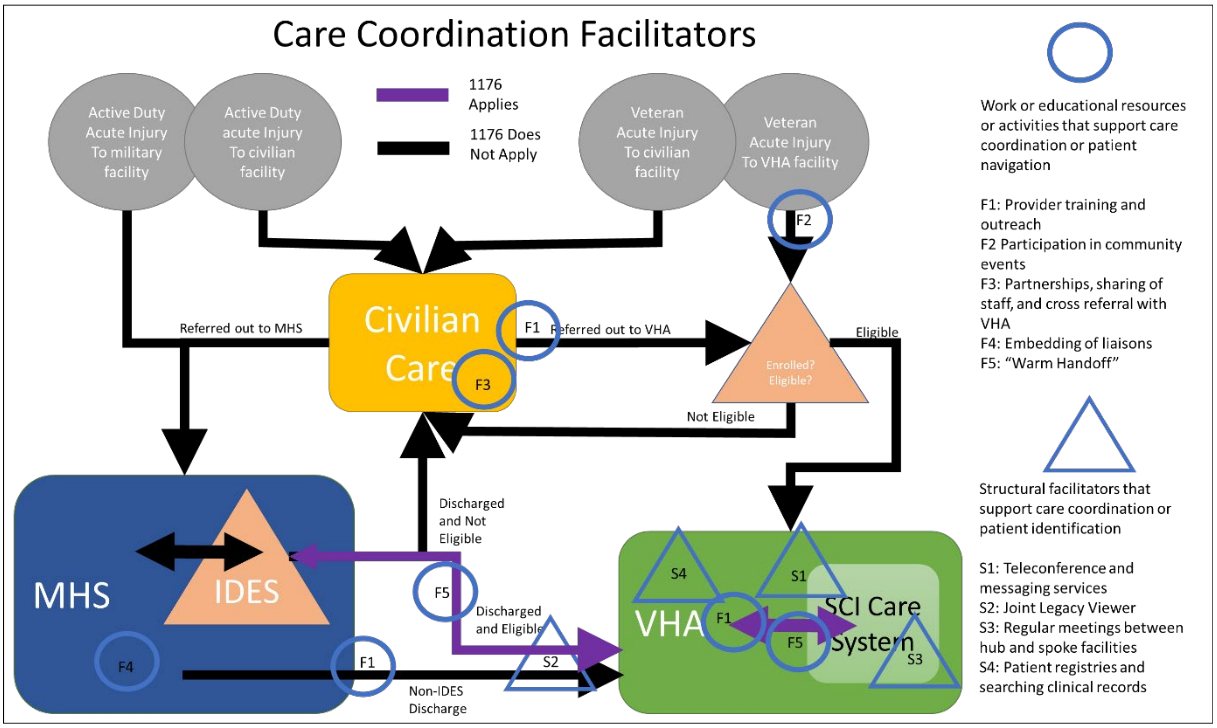


🟥 Lapse in action resulting from a lack of awareness of service or eligibility

B1: Veterans often not aware of VHA eligibility or option to pursue SCI/D care
B2: Private clinic may not be aware of patient's veteran status
B3: No formal process, may be missed if not self advocate or captured by liaisons

⚡ Institutional or strategic misalignments that result in delays in care transition

M1: Providers often exhaust patient insurance before seeking to refer them to VHA. Perverse financial incentive.
M2: Requests for requisition of patient equipment or contract labor are convoluted and fulfillment untimely
M3: Nursing care and psychiatric services not able to provide sufficient service for SCI/D needs
M4: Communication lapses between hub and spoke



Diagrams of care pathways and their barriers and facilitators relative to VHA SCI/D care. Pathways addressed by 1176 are in purple, other pathways are in black. The upper diagram highlights key barriers to care coordination and locates them along relevant pathways and stakeholders. The lower diagram highlights the same but for key facilitators of care coordination.

4.2 Awareness of SCI/D Services And Referral to SCI/D Care

While 1176 provides guidance on the transfer of Veterans into the SCI/D system of care, it does not specify how qualified Veterans may be initially identified for referral. Referrals into VHA SCI/D care may come from VHA, MHS, or private care and informants discussing all three settings highlighted the role of provider awareness of the SCI/D system in promoting referrals. By their presence, VHA liaisons provided insight into VHA services and opportunities for informal training among MHS staff. Similarly, partnerships between VHA, private sector hospitals, and community organizations appeared to promote referral from civilian sources. While several informants discussed the benefits of these activities, there was no standard that they be conducted or how.

4.3 Lack of Referral from Private Hospitals

One concerning highlight was the tendency of civilian hospitals to retain Veterans as patients until they were unable to pay. This may have been capitalizing on the information asymmetry between patients and provider, where patients, unaware of the ability and quality of VHA SCI/D care, do not request it, and providers, unincentivized, do not proactively request patient's Veteran status and refer early if qualified. Regardless of motive, informants agreed that referral from private hospitals tended to come after the Veteran incurred substantial out-of-pocket expense and had exhausted their coverage for private hospital care. This appears to be an otherwise undocumented problem for the VHA, and their patients, and is not addressed under 1176. Other policy efforts may be needed to incent private facilities to pro-actively confirm Veteran status and offer to transfer patients who qualify.

4.4 OUTREACH TO VETERANS

Veteran awareness of service was indicated as a route to referral and potential enrollment into SCI/D care. However, there were no standard pathways indicated to inform Veterans of the option. It was clear from responses that Veterans may learn of services from a variety of media and social activities, and this might prompt them to enquire. Informants did note that when Veterans self-identified as potential SCI/D enrollees, SCI/D staff then referred them back to their primary care provider for referral in accordance with 1176. Best practices in outreach should be identified and, where possible, made more common across the SCI/D system of care and the VHA at large.

4.5 ALIGNMENT BETWEEN HUB AND SPOKE

At the heart of coordination of care within the SCI/D system is the ability of spoke and hub facilities to collaborate in providing care to their patients. Informants noted coordination challenges and delays between hub and spoke facilities. While some informants described that they engaged in meetings with spokes in order to identify problems, the effectiveness of these efforts was unclear. Timeliness of communication and care coordination efforts is addressed under 1176 but this may not be sufficient or practicable. Further work should identify where structural features are causing common errors in care coordination between hub and spoke facilities, and how practices in communication can be improved.

4.6 TECHNOLOGY AND COMMUNICATIONS

Information technology played a critical role in care coordination and informants noted multiple systems that supported their work. The Joint Legacy Viewer was noted by informants as important for the work of case managers taking on patients from the MHS. The VetConnect telehealth platform was valued for facilitating the complex meetings between multiple stakeholders and the patient. And, instant messaging platforms were noted for speeding the rate of consults between spokes and hub. Currently the VHA and MHS are undergoing long-term projects to upgrade their health information infrastructure and attention should be given to how implementation of new systems and de-implementation of old systems will affect care coordination activities.

4.7 PARTNERSHIPS AND REFERRALS

The lack of availability and lack of ability to work with contractors and nursing facilities was a significant pain point for informants. Skilled nursing was an area with deficiencies already documented in 1176. As written, 1176 recommended relying on lesser skilled facilities. However, informants described facilities backing out of care of SCI/D patients and having to search the limits of their catchment area to find a facility that could cooperate. This suggested a structural deficiency that may require investment in providers and facilities to provide this care to SCI/D patients. Paperwork and bureaucracy were noted as major barriers to procurement of medical devices. Informants expressed distress and frustration with delays and inconsistent processes. This too appeared structural. Finally, one informant noted a lack of inpatient psychiatric wards that could tolerate the additional equipment of SCI/D patients. They noted it was seen as a safety issue. This may speak to the need to expand SCI/D specific psychiatric capabilities within the VHA.

Partnerships with community and support organizations played a role in supporting Veterans and outreach. The work of the PVA was noted as addressing multiple coordination and informational challenges. Within 1176 the PVA was granted access to SCI/D patients and facilities, and no barriers to that access were noted by informants. On the other hand, the VHA does not fund community organizations and could be missing opportunities to work with others that cannot offer their services for free.

5 CONCLUSION

Prior to this work, the experiences of staff engaged in care coordination within the VHA SCI/D system of care was largely undocumented. By collecting and examining the observations of our informants, we were able to elucidate how many care coordination processes were performed across the VHA SCI/D system of care. In doing so, multiple barriers and facilitators were also identified, highlighting opportunities for improvement in how the VHA coordinates the care of Veterans with SCI/D.

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7 APPENDICES

7.1 APPENDIX A: LITERATURE REVIEW RESULTS

Literature Review Frequency Results

Variable Name	Variable Option	Description	Freq
General Themes		Dominant theme, choose 1	
	Access	Topics of access to care either through awareness, coverage, or geography	10

	Attitude	Topics of attitudes and cognitive behaviors (e.g. beliefs that affect utilization)	35
	Service Delivery	Topics of performance or availability of services	80
Stakeholder		Indicate if study is of patients or of system, choose one	
	Patient	Focus of analysis is patient or nonprofessional caregiver	72
	System	Focus of analysis is provider, staff, facility, payer	75
Service		Indicates which healthcare systems are included in study, select all that apply, or "unknown"	
	Military		35
	Veterans		70
	Civilian	If not specified as other	44
	unknown		4
Scale		Indicate number of subjects analyzed and approached, also include type of unit (e.g. "hospital") if not individual persons. If no analysis was conducted, such as reporting on a standard operating procedure, scale = 0	
	#	Mean number of individuals included in across studies	52
Diagnosis/Focus		Codes that indicate content features of the study's contribution/analysis, may select more than one	
	Accessibility	ADA and medical device use	6
	Acute trauma		4
	Barriers	Explicit discussion of barriers to care or performance	14
	Burnout		7
	Care coordination		7
	Care of LGBT		1
	CIH	Complementary and integrative health	1
	Civilian care	Issues of use of civilian care by Military/Veterans	3
	Comorbidity		6
	Cost		7
	Data quality	issues of information quality and attribution	4
	Demographics	Description of populations	13

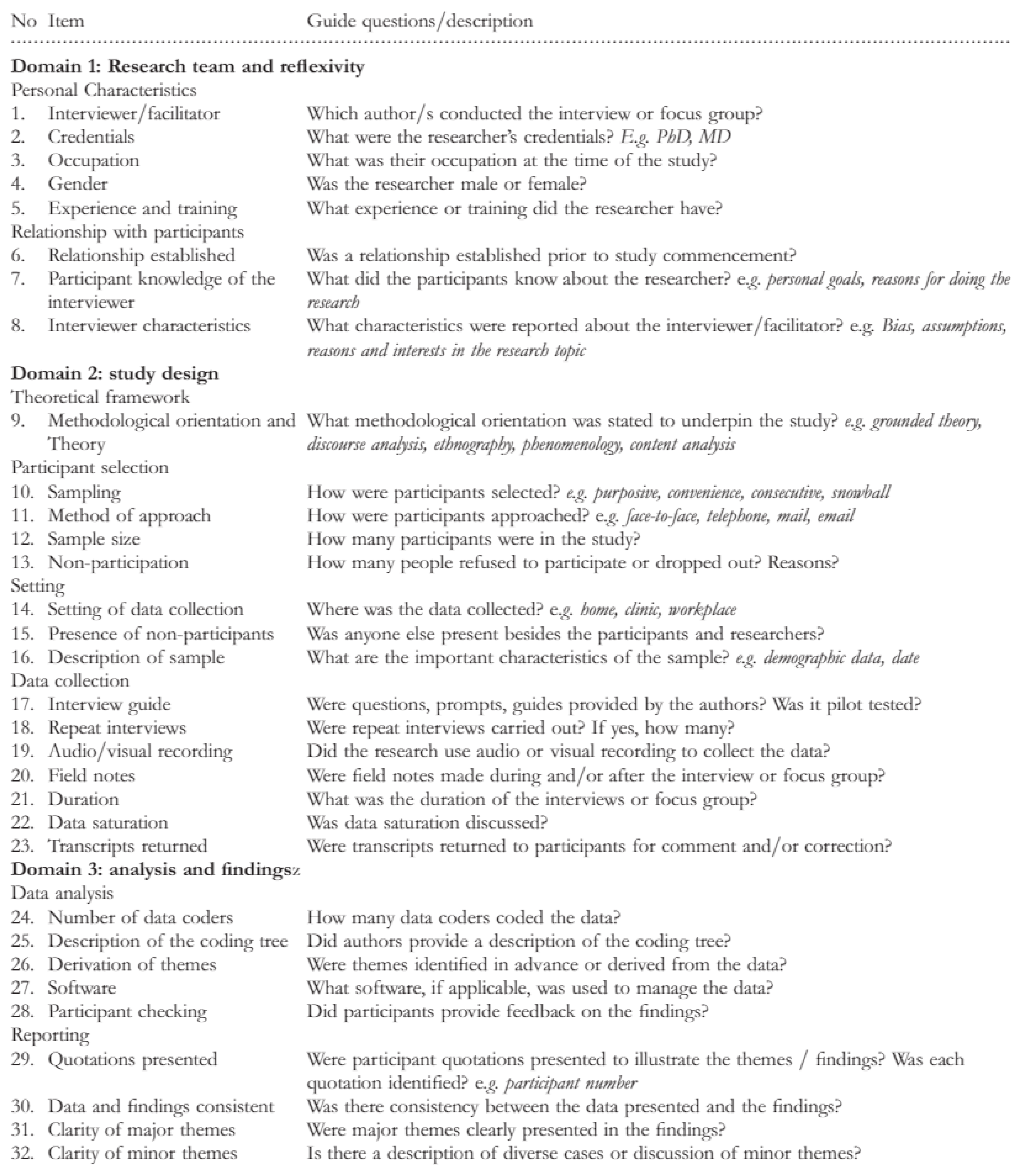
	Disparities	Issues of differences in care, comparative effectiveness	18
	Distance		7
	Eligibility		9
	Ethics		1
	First year care		2
	Health literacy		1
	Health seeking behavior		7
	In-home-care		5
	Liability		1
	Long term care		3
	Loss to follow up		2
	Mental health		4
	Minorities		4
	Nursing		13
	Org change		1
	Pain		1
	Primary care		1
	PCC	Patient centered care, client centered care	2
	Policy		5
	Post-discharge		2
	Prevention		3
	Rehab	Rehabilitation and physical therapy services	11
	Safety	Safety and quality issues	12
	Satisfaction	Issues of patient or staff satisfaction and emotional valence with service	13
	SCI	Spinal Cord Injured	75
	Sexuality		3
	Social work		1
	SOP	Describes standard operating procedures, evaluation of an implemented program, or how the system should function	30
	Substance abuse		1
	TBI	Traumatic brain injury	1
	Telehealth		4
	Training	Staff and clinician training programs	2
	Transitions in care		7
	Utilization		46
	Women		11

Value Chain Themes		Indicates where in service chain the study focused/contributed insight	
	PS	Pre-service	37
	POS	Point-of-service	114
	AS	After Service	27
Search Method		Indicator of which textual search process brought the article into the study	
	Systematic Keyword		110
	Manual General Search		17
	Manual Nursing Search		13
	Manual Gray Literature Search		9

Classification and frequencies of articles identified in literature review.

7.2 APPENDIX B: COREQ CHECKLIST

COREQ Checklist



No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

The COREQ survey instrument detailing content to be addressed by researchers when reporting qualitative results. Adapted from Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care, 19(6), 349-357. doi:10.1093/intqhc/mzm042