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Can SCI Databases Inform Clinical Care? Identifying Gaps Between Clinically Relevant Variables and Those Captured in Rehabilitation Data Systems

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Abstract

Study Design Exploratory, hypothesis-generating mixed-methods study combining qualitative thematic analysis and quantitative survey ratings.

Objectives Identify variables clinicians consider most important for individualized rehabilitation for adults with spinal cord injury (SCI) and compare these priorities with variables in major SCI rehabilitation datasets, highlighting gaps that may limit predictive modeling.

Setting SCI rehabilitation clinicians working in inpatient, outpatient, and community settings across Canada, with comparisons to major North American SCI rehabilitation datasets.

Methods Semi-structured interviews with three clinicians were analyzed using inductive thematic analysis. Clinicians rated the importance of 58 variables for SCI rehabilitation planning. Variables were compared with the Spinal Cord Injury Model Systems (SCIMS) database and the Canadian Rick Hansen Spinal Cord Injury Registry (RHSCIR), assessing clinical importance, dataset availability, and feasibility of capture.

Results Twenty-two clinicians were surveyed (n=19) and interviewed (n=3). Eighteen high-priority variables and five qualitative themes emerged: clinical factors; patient motivation and engagement; caregiver support and environmental readiness; funding/system barriers; and goal alignment. Patient motivation and goals received the highest priority rating, followed by neurological injury level, paraplegia/tetraplegia status, and the American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade. Family supports, home accessibility, living conditions, and discharge destination were also rated highly. Only 6 of the 18 high-priority variables were adequately captured by SCIMS or RHSCIR.

Conclusions Clinicians rely on multidimensional variables beyond existing SCI rehabilitation datasets. Psychosocial, environmental, and system-level factors remain underrepresented despite their perceived importance. Incorporating these factors into data collection and predictive models may improve personalized SCI rehabilitation planning.

Introduction

Rehabilitation planning for individuals with spinal cord injury (SCI) is a multifaceted process that has evolved over several decades from impairment-focused models toward more holistic frameworks that integrate functional, psychosocial and contextual determinants of recovery into individualized care pathways [1–4]. Despite this shift, existing research datasets continue to capture primarily demographic and functional metrics, with limited representation of psychosocial or environmental factors such as patient motivation, caregiver support, or access to resources [5, 6]. These omissions create a gap between the information available for predictive modeling and the realities of clinical decision-making. Clinicians frequently rely on experience and judgment to tailor plans, but these processes are not systematically documented or linked to outcomes [7, 8].

Identifying which variables clinicians view as most critical is essential for advancing rehabilitation planning across inpatient, outpatient, and community settings [9], yet existing tools often overlook the context-dependent factors shape individualized care. This exploratory study explores clinical decision-making variables with the goal of generating hypotheses to inform more comprehensive predictive models.

Methods

Study Design

The study protocol, including both the interview and survey components, was reviewed and approved by the University of New Brunswick Research Ethics Board (REB 2025 – 169). Interview participants provided written informed consent. Survey participation was voluntary and anonymous; completion of the electronic survey established implied consent in accordance with REB approval.

This study employed a mixed-methods design combining semi-structured interviews to elicit clinician insights and a complementary survey to quantify variable importance across roles and settings. The survey was developed independently through review of existing SCI data dictionaries and consultation with clinicians and the SCI community.

Participants and Recruitment

A total of 22 clinicians participated in the study, comprising three interviewees and nineteen survey respondents. Interview participants included a licensed psychologist, a physical therapist, and an occupational therapist, each actively engaged in SCI rehabilitation planning. Survey respondents represented a broader range of clinicians across inpatient, outpatient, and community-based rehabilitation settings. Eligibility criteria required participants to be at least 19 years old, fluent in English, and engaged in rehabilitation planning for adults living with SCI. Participants were recruited from inpatient, outpatient, and community-based rehabilitation settings across Canada.

Interview Procedures

Interviews were conducted by the first author, a female research engineer (MSc, electrical engineering) with anthropology coursework but no clinical background, who had not previously worked with any participant. Interviews followed a semi-structured guide developed based on prior literature and through expert consultation with SCI rehabilitation clinicians and study team members with SCI lived experience (see Appendix B). The guide was organized into domains: clinician role and background, clinical and functional factors, demographic and psychosocial influences, decision-making tools, and final reflections. Each domain contained open-ended questions with prompts to elicit detailed responses, ensuring consistency across participants while allowing flexibility for elaboration. Interviews lasted approximately 45–60 minutes, were conducted virtually or in person, and were audio-recorded with participant consent. Recordings were transcribed verbatim, deidentified, and deleted once transcripts were verified.

Survey Procedures

In addition to interviews, nineteen clinicians completed a survey presenting 58 distinct variables spanning demographic, clinical, functional, psychosocial, and system-level domains (see Appendix C). These variables were developed through an iterative process that included reviewing data dictionaries from established SCI databases and consulting with clinicians and individuals living with spinal cord injury, separate from the semi-structured interviews described above[10–13]. An open-ended field invited respondents to identify missing variables; none were suggested. Respondents rated each variable on a scale from 1–10 (1 indicates least relevance and 10 indicates highest relevance) for perceived relevance to rehabilitation planning for patient care. Surveys were administered electronically through Google Forms, and responses were anonymous.

To facilitate interpretation on our 10-point Likert scale, we applied Delphi-style consensus principles from the RAND/UCLA Appropriateness Method (RAM), which determines consensus using distributional criteria (median and interquartile range).

Variables were grouped into three tiers: High (median ≥ 9), Medium (median 6-8.99), and Low (median < 6) [14].

Data Analysis

Qualitative data from three interviews, conducted with an occupational therapist, physiotherapist, and psychologist, each with 13 + years of clinical experience, were analyzed using NVivo 15 for inductive thematic analysis [15] and MATLAB R2023b for statistical calculations [15]. An open coding approach was used to allow themes to emerge inductively. Initial codes were reviewed iteratively to refine the coding framework, which was then applied to the full dataset. Codes were grouped into broader categories and synthesized into five core themes. Survey data from the nineteen respondents were analyzed descriptively to identify patterns in variable prioritization. These themes were subsequently mapped onto the WHO International Classification of Functioning, Disability and Health (ICF) and Andersen's Behavioral Model of Health Services Use to support interpretation and facilitate translation into measurable constructs [4, 16, 17].

Database Comparison Procedures

To assess the feasibility of incorporating high-priority variables into predictive models, the availability of each variable was compared against two established spinal cord injury datasets: SCIMS and RHSCIR [18, 19]. These databases were selected due to their national scope, structured data collection protocols, and relevance to rehabilitation research. Variable availability was assessed using publicly available data documentation for each registry: for SCIMS, the *Data Dictionary for the National Spinal Cord Injury Database 2021–2026* (v8/2025; National Spinal Cord Injury Statistical Center, August 2025; accessed March 19, 2026) was reviewed; for RHSCIR, the *Detailed Data Element Checklist* (Version 3.0; Praxis Spinal Cord Institute, updated June 11, 2025, available upon request) was reviewed. For each variable identified through interviews and survey ratings, two investigators independently reviewed the SCIMS and RHSCIR documentation and classified the variable as directly captured, partially captured through proxy fields, or absent, according to the predefined criteria below. Disagreements were resolved through discussion until consensus was reached.

Criteria were defined as follows: a variable was classified as directly captured when a dedicated field records the construct itself; partially captured when only a related proxy field is available (e.g., marital status as a proxy for family support); and absent when neither a direct field nor a usable proxy exists. Constructs for which validated instruments exist but are not routinely recorded (difficult to measure) were distinguished from those not readily operationalized in structured form.

Results

Qualitative Themes

Theme 1: Clinical Factors

Participants described clinical factors as the foundation of rehabilitation planning, shaping expectations for recovery and guiding the selection of assessments and interventions. Across interviews, the level of injury and completeness were consistently identified as the most influential determinants of functional potential. One clinician noted that *"the ASIA score* [International Standards for Neurological Classification of Spinal Cord

Injury, or ISNCSCI] *is huge — level of injury and completeness guide whether I'm aiming for leg function recovery or wheelchair-based independence."* Another emphasized that *"level of injury is number one. A straightforward paraplegic with full arm and trunk function is completely different from a high cervical tetraplegic with autonomic issues and minimal function."*

Secondary medical considerations — such as bracing requirements, movement precautions, and autonomic instability — were also central to planning. Participants described beginning with *"bracing — cervical collars, TLSOs* [thoraco-lumbo-sacral orthoses] *— and understanding movement precautions,"* while also monitoring *"autonomic dysregulation… blood pressure, temperature regulation, and so on."* Cognitive functioning further shaped assessment and intervention choices. One clinician explained that *"cognition definitely does [matter]. It affects what assessment tools I choose,"* while another noted that cognitive limitations influence participation in mental health services, requiring adaptations such as *"written supports if they have memory challenges"* or involving family to assist with carryover. Clinicians also highlighted the unpredictability of recovery in incomplete injuries, noting that frequent reassessment was necessary to adjust interventions accordingly. Together, these clinical factors formed the backbone of rehabilitation planning and anchored decisions about prognosis and resource allocation.

Theme 2: Patient Motivation and Engagement

Patient motivation emerged as an important determinant of rehabilitation intensity and progress. Participants consistently described motivation as central to predicting adherence and engagement, yet difficult to measure formally. Participants explained that motivation is often inferred from referral information, such as notes indicating *"participates well," "low mood,"* or *"needs sitter."*, or from behavioral indicators during therapy, including *"carryover of recommendations, self-advocacy, and insight."*

Motivation was described as dynamic, closely tied to mental health, and not easily predicted by demographic characteristics. One clinician reflected that *"some people naturally push themselves, others don't, and it doesn't always correlate with education or job type."* Because of this variability, clinicians often sought collateral information from family or friends, though *"it's not a formal measure."* Across interviews, motivation was viewed as a key predictor of treatment intensity, summarized by one clinician as *"willingness to engage is often the biggest predictor of intensity."*

Theme 3: Caregiver Support and Environmental Readiness

Participants frequently linked patient motivation to the broader context of caregiver involvement and environmental readiness. Caregiver support was described as essential for enabling individuals to participate fully in rehabilitation and maintain progress outside scheduled sessions. One clinician explained that *"family and caregiver support are critical. Some equipment requires setup before the person can use it independently. Without support, it won't happen."*

Environmental readiness — particularly home accessibility — was also a major determinant of successful discharge and ongoing participation. One participant described a case where "*his discharge was unsuccessful because renovations weren't completed and the environment wasn't adapted*." Participants emphasized that socioeconomic factors including financial resources, housing accessibility, employment status, and education level, intersect with caregiver and environmental supports and were viewed as inseparable from clinical decision-making.

Theme 4: Funding and System Barriers

While Theme 3 highlights the role of caregiver and environmental supports in enabling rehabilitation activities, clinicians also emphasized structural barriers related to equipment access and funding. Access to equipment emerged as a persistent barrier that directly affected rehabilitation timelines, independence, and discharge planning. Participants described frequent delays due to funding limitations, insurance processes, and administrative bottlenecks. One participant stated that *"access to equipment is a major barrier — delays in funding, insurance, or paperwork slow everything down."*

Funding inconsistencies across regions and programs further complicated access — as one clinician explained, *"SCI has fewer funding sources than other diagnoses. Funding across Canada is inconsistent"*, and these delays had cascading effects on an individuals progress, caregiver burden, and the ability to implement recommended interventions.

Theme 5: Goal Setting and Alignment

Goal setting was described as a central and ongoing component of rehabilitation planning, functioning as both a clinical guide and a communication tool. Clinicians emphasized the importance of understanding what matters most to patients and families. As one participant explained, *"I also get a sense of the patient's goals and the family's goals so we're working toward things that matter to them."* Structured processes such as early "*goal huddles*" helped align expectations and maintain consistency across the care team. One clinician described how written goals from these huddles became "*our roadmap*" for case conference discussions.

Despite this structure, clinicians frequently encountered mismatches between patient goals and clinical expectations. One participant noted that *"patient-centred care is important, but sometimes there's a mismatch between what patients hope to achieve and what we think is achievable… It's a hard line to walk."* Family perspectives also complicated these discussions, as clinicians navigated the tension between preserving hope and helping patients understand realistic prognosis. Goal setting was therefore viewed as both essential and emotionally complex, requiring ongoing negotiation, empathy, and clear communication.

Survey Ratings

Survey respondents rated 58 variables on a 1–10 scale based on their relevance to rehabilitation planning. Clear prioritization patterns emerged across three tiers. High priority variables (median ≥ 9) included both clinical and contextual factors: patient motivation and goals received the highest median score (10, IQR 10–10), followed by neurological level of injury (median 10, IQR 9–10) and paraplegia/tetraplegia status (median 10, IQR 8.25–10), family supports (median 10, IQR 8.25–10), home accessibility and modifications (median 10, IQR 8–10), and discharge destination (median 10, IQR 8.25–10), social supports (median 10, IQR 8–10) and daily assistive device use (median 10, IQR 8–10). In total, 18 variables met the high-priority threshold, spanning injury severity indicators alongside psychosocial, environmental, and systemic factors — reflecting the multifaceted nature of rehabilitation planning.

Medium-tier variables (median 6–8.99) encompassed comorbidities, transportation access, food security, and psychosocial measures such as depression and anxiety scales. Low-tier variables (median < 6) were primarily demographic descriptors, including sex, gender, ethnicity, race, and sexual orientation, which clinicians did not view as central to planning. Variables such as language, marital status, and spirituality also received lower median scores and wider IQRs.

Integration of Findings

The qualitative and quantitative findings converged on three domains. Clinical severity indicators, particularly neurological level of injury, completeness, and secondary medical considerations — were foundational across both methods. Patient-driven and contextual factors showed strong alignment: motivation, goals, caregiver support, and environmental readiness were central in interviews and mirrored in the survey's highest-rated variables. System-level considerations also emerged in both datasets, with equipment procurement, community resources, and geographic constraints corresponding to high survey ratings for assistive devices, community supports, and geography.

Data Availability Across Major SCI Datasets

Many variables considered critical by clinicians such as patient motivation, caregiver support, and environmental readiness, are not routinely collected in major SCI datasets and are often difficult to measure directly. To clarify which constructs can be captured in structured form, Table 1 identifies whether each variable is directly measurable within existing data systems, and where a variable cannot be measured outright, a corresponding “Proxy Available” field outlines alternative indicators. The table compares availability within two large SCI datasets (SCIMS and RHSCIR) [10–13]. Of the 18 high-priority variables identified in this study, only 6 are directly captured in either dataset. Of the remaining 12, none are fully captured in either database, and while proxy indicators exist for several, none provide complete or direct measurement of the underlying construct. These missing variables fall almost entirely within the psychosocial, environmental, and system-level domains, whereas SCIMS and RHSCIR perform well only in capturing core clinical severity indicators.

Table 1

Ranked list of 18 highest priority rehabilitation planning variables based on clinician ratings (median, Q1–Q3), integrated with data availability in SCIMS and RHSCIR and categorized according to ICF and Andersen's Behavioral Model of Health Services Use.

Rank	Variable	Median (Q1–Q3)	Collected in SCIMS	Collected in RHSCIR	Directly Measurable?	Proxy Available	ICF Domain	Andersen Domain
1	Patient Motivation and Goals	10 (10–10)	No	No	No	Standardized scales†, goal-setting documentation†, therapy adherence	Personal Factors	Predisposing
2	Neurological Level of Injury	10 (9–10)	Yes	Yes	Yes	—	Body Functions & Structures	Need
3	Paraplegia/Tetraplegia	10 (8.25–10)	Yes	Yes	Yes	—	Body Functions & Structures	Need
4	Discharge Destination	10 (8.25–10)	Yes	Yes	Yes	—	Environmental Factors	Enabling
5	Social Supports	10 (8.25–10)	Partial	Partial	No	Social work documentation, living arrangement, standardized scales†	Environmental Factors	Enabling
6	Complete/Incomplete Autonomic Disruption	9 (8.25–10)	Yes	Yes	Yes	—	Body Functions & Structures	Need
7	Family Supports	10 (8–10)	Partial	No	No	Marital status†, household composition, caregiver presence	Environmental Factors	Enabling
8	Home Accessibility/Modifications	10 (8–10)	No	Partial	No	OT notes, discharge planning forms, housing type, postal code indices†	Environmental Factors	Enabling
9	Assistive Devices Used Daily	10 (8–10)	Partial	Partial	Yes	PT/OT notes†‡, SCIM†‡	Environmental Factors	Enabling
10	Neurological Description of Injury	9 (8–10)	Yes	Yes	Yes	—	Body Functions & Structures	Need
11	AIS Grade	9 (8–10)	Yes	Yes	Yes	—	Body Functions & Structures	Need
12	Other Injuries Sustained (e.g., TBI)	9 (8–10)	Yes	Yes	Yes	—	Body Functions & Structures	Need
13	Type/Availability of Community Support	9 (8–10)	No	No	No	Postal code†, regional directories, referral records	Environmental Factors	Enabling
14	Living Conditions	9 (8–10)	No	Partial	No	Admission forms, housing status, census-linked	Environmental Factors	Enabling

Note: 'Yes' indicates the variable is routinely collected in structured form. 'Partial' indicates the variable is approximated through proxy measures or captured for only a subset of timepoints within the database. 'No' indicates the variable is not collected. 'Directly Measurable' refers to whether a variable can be captured in a structured, quantifiable form in principle, independent of current dataset practices. 'Proxy Available' lists indicators that could approximate the underlying construct; proxies marked † are collected in SCIMS, and those marked ‡ are collected in RHSCIR. Where no proxy is listed, none has been identified in either database. '—' indicates no proxy is needed as the variable is directly captured. SCIMS = Spinal Cord Injury Model Systems database; RHSCIR = Rick Hansen Spinal Cord Injury Registry; AIS = American Spinal Injury Association Impairment Scale; SCIM = Spinal Cord Independence Measure; FIM = Functional Independence Measure; PHQ-9 = Patient Health Questionnaire-9; TBI = traumatic brain injury.

Rank	Variable	Median (Q1–Q3)	Collected in SCIMS	Collected in RHSCIR	Directly Measurable?	Proxy Available	ICF Domain	Andersen Domain
						socioeconomic data		
15	Distance from Clinical Centres	9 (8–10)	No	No	No	Postal code of discharge destination†	Environmental Factors	Enabling
16	Insurance Status	9 (7.25–10)	Partial	Partial	Yes	Primary payer field†, funding source codes	Environmental Factors	Enabling
17	Paramedical Practitioner Access	9 (7.25–10)	No	No	No	Referral records, billing data, service utilization logs	Environmental Factors	Enabling
18	Food Security	9 (7–10)	No	No	No	Income level†, postal code†, social work notes	Environmental Factors	Enabling

Note: 'Yes' indicates the variable is routinely collected in structured form. 'Partial' indicates the variable is approximated through proxy measures or captured for only a subset of timepoints within the database. 'No' indicates the variable is not collected. 'Directly Measurable' refers to whether a variable can be captured in a structured, quantifiable form in principle, independent of current dataset practices. 'Proxy Available' lists indicators that could approximate the underlying construct; proxies marked † are collected in SCIMS, and those marked ‡ are collected in RHSCIR. Where no proxy is listed, none has been identified in either database. '—' indicates no proxy is needed as the variable is directly captured. SCIMS = Spinal Cord Injury Model Systems database; RHSCIR = Rick Hansen Spinal Cord Injury Registry; AIS = American Spinal Injury Association Impairment Scale; SCIM = Spinal Cord Independence Measure; FIM = Functional Independence Measure; PHQ-9 = Patient Health Questionnaire-9; TBI = traumatic brain injury.

Discussion

This study set out to identify variables clinicians view as most important when planning rehabilitation for individuals with SCI and to assess how well these priorities align with what is captured in major SCI datasets. The findings reveal a consistent and consequential gap: clinicians rely on a multidimensional set of clinical, psychosocial, environmental, and system-level factors, many of which are not routinely documented in existing data systems. This gap has direct implications for the validity of predictive models built on those datasets, and for the quality of individualized care they are intended to support.

The pattern of clinician priorities identified here is consistent with prior work by Khan et al. (2019) and Håkansson et al. (2024), who documented the dominance of clinical severity indicators in SCI predictive models and called for greater integration of contextual and psychosocial variables[5, 6]. The present study extends this critique by specifying which variables clinicians consider most essential and where the most consequential gaps lie. Notably, patient motivation and goals, family supports, home accessibility, and geographic access all ranked in the highest tier alongside injury-specific clinical descriptors, underscoring how deeply clinicians embed social and environmental context into their decision-making, even when those factors cannot be formally documented.

The high-priority variables identified in this study align closely with the WHO International Classification of Functioning, Disability and Health (ICF), which organizes influences on health and rehabilitation across three domains: body functions and structures, activity and participation, and the contextual factors, both personal and environmental, that shape functioning [4]. Injury-specific variables such as neurological level of injury, AIS grade, and autonomic disruption correspond to body functions and structures; patient motivation, goal alignment, and daily assistive device use reflect activity and participation; and variables such as family supports, home accessibility, caregiver availability, and geographic access to services fall squarely within the ICF's environmental factors domain, while patient goals and coping capacity reflect personal factors. Critically, it is these contextual ICF domains — personal and environmental factors — that are most valued by clinicians yet most systematically absent from existing datasets, suggesting that current data infrastructure is structurally misaligned with a functioning-based model of care .

This misalignment is not only about what is being recorded but also how it is being recorded. Marital status, for instance, is a poor proxy for family support: it records a legal status but reveals nothing about caregiving availability, relationship quality, or the practical capacity of a household to support rehabilitation. Similarly, postal/zip code approximates geography but cannot distinguish between an individual who lives 200 kilometres from the nearest rehabilitation centre and one who lives nearby but lacks transportation. Addressing this gap requires data infrastructure that can accommodate subjective and relational dimensions of care.

Addressing this data infrastructure gap requires distinguishing two categories of missing variables. For variables that are directly measurable, such as discharge destination, assistive device use, or living conditions, improved and standardized data collection practices represent a tractable path forward. For variables such as patient motivation or caregiver support, the challenge is more fundamental: these constructs are not yet operationalized in ways that translate reliably into structured data fields. Potential approaches include standardized psychosocial screeners

integrated into admission workflows, patient-reported outcome measures (PROMs) capturing motivation and goal alignment at intake, and structured fields for caregiver availability and home accessibility, an approach with precedent in stroke rehabilitation registries, where such data have supported multivariable predictive models of rehabilitation outcomes [20].

An additional avenue for expanding variable capture is linkage of registries to electronic medical records (EMRs) at the participant level. EMRs routinely document variables outside the scope of most research registries and linking registry records to EMR data could increase the number of high-priority variables available for research. However, variables in the psychosocial, motivational, and contextual domains (patient motivation and goals, caregiver support quality, home accessibility) would remain largely absent even with EMR linkage, as these are not yet systematically collected as part of routine clinical documentation.

Expanding registry content also raises important ethical considerations. Collecting more granular psychosocial and contextual data increases re-identification risk, and research ethics boards overseeing consent-based registries have recognized that overly detailed data collection can deter participation, particularly among marginalized groups for whom inclusion in research infrastructure may feel like a risk rather than a benefit. Prior research has demonstrated that participants who decline registry consent tend to have worse outcomes, meaning consent-based designs can introduce selection bias that undermines the analyses the registry is intended to support [21]. Where such barriers cannot be resolved through study design alone, privacy-preserving approaches such as synthetic datasets may warrant future exploration, though they lie beyond the scope of the present study.

A finding that warrants careful interpretation is the consistently low ranking of demographic variables such as ethnicity, race, indigeneity, and culture. These ratings should not be read as evidence that these factors are clinically inconsequential. Aggregate ratings reflect average prioritization and do not capture the significance of these variables for specific populations or contexts. Research has demonstrated that ethnicity is associated with differential rehabilitation outcomes [22], and that cultural background shapes patient goals, communication styles, and care engagement in ways that standardized clinical frameworks often fail to accommodate [23]. A related concern is that clinician behavior is shaped by implicit bias. or instance, interpreting self-advocacy as motivation while underestimating patients from groups where self-advocacy is socially discouraged, predictive models built on clinician-derived variables may replicate rather than correct these inequities. This potential suggests the importance of critically examining not only which variables are collected, but whose perspectives and behaviors shape how importance is assigned to them.

Limitations

Several limitations warrant consideration. The qualitative component involved three experienced clinicians representing key rehabilitation disciplines from a single country, which limits transferability and precludes saturation claims. The perspectives of these participants and the nineteen survey respondents may not reflect the full range of clinical experience across SCI rehabilitation, and variation in experience, specialization, and recency of training may have influenced reported priorities. The survey sample of nineteen clinicians is also not large enough to support generalizations across all rehabilitation roles and settings. Patient priorities were not directly examined; individuals living with SCI may weight variables differently, particularly those related to psychosocial wellbeing, community participation, and goal alignment. Finally, the database comparison relied on publicly available data dictionaries; some variables may be collected informally at the site level in ways not reflected in national documentation, and future work should involve direct engagement with database custodians to verify variable-level completeness. These limitations suggest the findings should be interpreted as exploratory and hypothesis-generating. Whether high-priority variables are captured as part of routine clinical care — which would inform whether gaps require new data collection versus registry linkage — was not assessed in this study and represents an important direction for future work.

Conclusion

This exploratory study provides preliminary evidence of a gap between the variables clinicians consider most important in SCI rehabilitation and those captured in the data systems increasingly used to inform care. The persistence of this gap, particularly for psychosocial, environmental, and systems-level factors, has direct implications for the validity of predictive models built on these datasets. In the near term, linkage across existing data sources, including clinical charts and complementary registries, may offer a practical path toward more complete variable capture without requiring new infrastructure. Closing the gap more fully will require deliberate collaboration between clinicians, data scientists, and registry stakeholders to ensure that what is collected preserves enough clinical nuance to be useful, and that the resulting infrastructure supports tools that are not only statistically sound, but clinically meaningful.

Declarations

Data Availability Statement: Data from this study are available from the corresponding author on reasonable request.

Author Contribution Statement:

KRC conceived and designed the study, led participant recruitment and data collection, conducted data management and analysis, prepared the original manuscript draft, and led manuscript revision. VKN contributed to data analysis and interpretation, provided methodological guidance, contributed to conceptual development of the study, and critically reviewed and revised the manuscript. SD, JWS, SM and CO provided methodological guidance, contributed to conceptual development of the study, and critically reviewed and revised the manuscript. JH, SN and JRF provided insight on perspectives and resources. LAD, KM and ES provided methodological guidance and critically reviewed and revised the manuscript. HA critically reviewed and revised the manuscript and critically reviewed and revised the manuscript. KLD supported institutional and administrative processes. KALC and DW critically reviewed and revised the manuscript.

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Ethical Approval: We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

Competing Interests: The authors declare no competing interests related to this work.

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Supplementary Files

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- AppendixA.docx