

Archives of Rehabilitation Research and Clinical Translation

Archives of Rehabilitation Research and Clinical Translation 2020;2:100032 Available online at www.sciencedirect.com

Original Research

# The Value in Mental Health Screening for Individuals With Spinal Cord Injury: What Patients Tell Us

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<b>KEYWORDS</b> Mental health; Rehabilitation; Screening; Spinal cord injuries	Abstract Objective: To gather consumer perspectives of a mental health screening protocol and to identify the incidence of previously unrecognized mental health concerns (case finding). Design: Pilot study using mixed methods: quantitative (survey) and qualitative (interviews). Setting: Primary care health team in Kitchener, Ontario, Canada. Participants: Patients (N=15) with spinal cord injury living in the community. Participants ran- ged in age from 21 to 81 years of age (mean=46); 12 were men, 8 had tetraplegia and 5 para- plegia. The number of years since injury ranged from 1 to 32 (mean=13). Intervention: Implementation of a mental health screening protocol consisting of standardized screening tools for depression, anxiety, substance abuse, social isolation, somatoform disor- der, functional status, chronic pain, and cognitive impairment. Main Outcome Measures: Positive results on screening tool, acceptability of the screening pro-
	der, functional status, chronic pain, and cognitive impairment.
	<i>Results:</i> Screening identified 11 of 15 individuals with a chronic pain condition; 1 individual screened positive for depression, 1 for anxiety, 3 for potential substance abuse, and 1 for social isolation. Most of the participants (12/13) rated the screening protocol as <i>very acceptable</i> . All but 1 individual intended to follow resulting treatment recommendations. Interview

*List of abbreviations*: SCI, spinal cord injury; PID, patient identification number. Supported by the Ontario Neurotrauma Foundation, Toronto, Ontario. Disclosures: none. Cite this article as: Arch Rehabil Res Clin Transl. 2020;2:100032.

https://doi.org/10.1016/j.arrct.2019.100032

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analyses generated themes related to disclosure of experiences that were incomplete that concealed important information and perceptions that the screening protocol failed to assess resiliency. Although perceived as valuable, participants felt screening tools alone did not capture information important to them.

*Conclusions:* Screening tools alone may not identify mental health issues. Interviews in addition to screening tools are needed to accurately identify mental health issues in this population. Identification of mental health issues is critical to ensuring access to effective interventions and improving health outcomes and quality of life for individuals with SCI. © 2019 The Authors. Published by Elsevier Inc. on behalf of the American Congress of Rehabilitation.

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Individuals with spinal cord injury (SCI) are at higher risk for emotional disorders than the general population.<sup>1,2</sup> Depression and anxiety after SCI have been associated with poor health outcomes, such as pain and fatigue, poor coping, catastrophizing, increased risk for secondary complications, and greater health system resource use.<sup>2,3</sup> High substance (alcohol, drugs) misuse and abuse is not uncommon among individuals with SCI.<sup>4</sup> Despite this high prevalence of emotional distress, psychological disorders remain underrecognized and undertreated in the SCI population.<sup>5</sup> Individuals with SCI have difficulty accessing primary care due to limited physician knowledge about specific disabilities and how these affect activities of daily living and health and poor communication with physicians leaving patients with unmet needs and potentially inappropriate care.<sup>6</sup> There is much support for routine screening of substance abuse, mental health issues among individuals with SCI,<sup>4</sup> particularly because mental health issues after SCI are not necessarily inevitable<sup>5</sup> and cannot be predicted by the type or severity of injury or demographic characteristics.<sup>1</sup> Identification of mental health issues is critical to ensure access to effective interventions aimed at reducing psychological symptoms and improving quality of life and health outcomes.

The purpose of this pilot study was to gather consumer perspectives of a mental health screening protocol for routine use in multidisciplinary primary care settings and, secondarily, identify the incidence of previously unrecognized mental health concerns (case finding). Identifying those with previously unrecognized mental health issues could allow for triage of individuals at higher risk of poor outcomes and tailoring intensity of management accordingly, consistent with ideal models of chronic disease management.

# Methods

#### Participants

Fifteen individuals with SCI, consecutively assessed within the Centre for Family Medicine Family Health Team, in Kitchener, Ontario, Canada, completed the screening protocol and participated in this study. The multidisciplinary mobility clinic, located within a Family Health Team, provides comprehensive assessment and management of mobility impairments.<sup>7</sup> (In Ontario, Canada, Family Health Teams are a primary care model consisting of groups of interprofessional care providers [eg, physicians, nurses, social workers, occupational therapists, pharmacists, dietitians and other disciplines] working together to provide care to patients.<sup>8</sup>) To participate in this study, participants had to complete the screening protocol, be older than 18 years and able to read and speak in English. The average participant age was  $46\pm18$  years, and the average time since injury was  $13\pm12$  years. About half of the participants (8/15) had experienced tetraplegia. Only 1 participant reported a previous history of mental issues (anxiety/panic attacks not formally diagnosed).

#### Measures and procedures

Standardized tools with demonstrated psychometric properties and that were easy to use were selected to screen for depression, anxiety, substance abuse, social isolation, somatoform disorder, pain, and functional impairment. The screening was conducted by a social worker and chiropractor with training in mental health screening.

The 2-step study protocol consisted of administering screening instruments followed by completion of a brief reaction survey (n=13/15) to assess acceptability of screening (5-point scale: 1=not at all, 5=very acceptable), level of agreement (5-point scale: strongly disagreestrongly agree) with various statement related to the value of mental health screening and intentions to follow resulting treatment recommendations (not at all, maybe, definitely). Time to complete the screening protocol ranged from 30 to 60 minutes. Several weeks later, an in-depth semistructured interview was conducted by a clinician trained in qualitative research (n=10/15) to gather their perceptions of the screening process and share their narrative or parts of their life experience they felt were captured or not captured by the screening tool. All interviews were conducted by a registered social worker, audiorecorded, and transcribed. Mixed methods were used to enhance the validity of study findings through convergence and integration of the results and to enhance the comprehensiveness of our understanding of the findings from both methods.<sup>9</sup> Using an exploratory sequential design, quantitative data were collected and analyzed first; priority was given to the qualitative data, which were augmented by the quantitative data.<sup>10</sup>

Table 1	Means $\pm$ SD for all	screening protocol	measures
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Measure	$\text{Mean} \pm \text{SD}$	Range	Frequency (%) Positive Screens
Depression <sup>12</sup>			
PHQ-2 (N=15)	0.73±0.88	0-2	1 (7)
PHQ-9 <sup>11</sup>	6	6	0
Anxiety <sup>13</sup>			
GAD-2 (N=15)	0.93±1.22	0-4	2 (13)
GAD-7 (n=2)	8.0±2.83	6-10	1 (7)
Substance abuse <sup>14</sup>			
CAGE-AID (N=15)	0.53±1.13	0-3	3 (20)
Social isolation <sup>15</sup>			
Duke Social Support Index			
Network subscale (N=15)	7.67±1.72	4-10	1 (7)
Satisfaction subscale (N=15)	15.93±3.11	6-18	
Somatoform disorder <sup>16</sup>			
PHQ-15 (N=15)	5.93±4.10	0-14	3 (20)
Chronic pain <sup>17</sup>			
Intensity (n=11)	4.64±2.38	1-8	11 (73)
Interference with activities of daily living $(n=11)$	4.45±2.51	1-10	
Functional abilities assessment <sup>18</sup>			
Texas Functional Living Scale $(n=3)^*$	50.0±13.86	42-66	2 (13) <sup>18</sup>

Abbreviations: CAGE-AID, CAGE-Adapted to Include Drugs; GAD, generalized anxiety disorder; PHQ, Patient Health Questionnaire. Low average performance.

Survey data were analyzed using SPSS to generate frequencies, means, and standard deviations. Transcriptions were analyzed using a narrative analytic framework.<sup>11</sup> which embraced the notion of "health narratives" as a way to understand the reformation of identity and related issues in the face of chronic or traumatic injury. The interviews were transcribed verbatim by 1 team member to ensure consistency and continuity with the data. To ensure trustworthiness and rigor, the transcripts were then independently coded by 2 team members (C.M., L.M.H.) as a form of interrater reliability.

This study was approved by the McMaster University Research Ethics Board. All participants provided informed consent.

## Results

Screening instruments identified 11 of 15 individuals as having a chronic pain condition (table 1). One individual screened positive for depression, 1 for anxiety, 3 for potential substance abuse, and 1 for social isolation. Most of the participants 12 of 13 rated the screening protocol as "very acceptable." Most of the participants perceived various aspects of the screening protocol positively (table 2), though almost a third were neutral about whether the screening would identify previously unidentified conditions. All but 1 individual intended to follow resulting treatment recommendations.

The qualitative interview analysis generated 3 key themes related to disclosure of experiences that were incomplete, concealed important information and failure of the screening protocol to assess resiliency. The screening protocol was perceived as not entirely capturing their experiences as noted by 1 participant: "The whole story wasn't there. The questions didn't let the person's experience to come out, to give a better understanding of why it is they feel the way they do" (patient identification number [PID18). In some cases, important information was concealed with participants deciding not to disclose potential issues, particularly around substance usage: "There is a lot of drug and alcohol use that is probably not going to get admitted ... the way some of the questions are being asked isn't going to capture an honest answer" (PID3). Lastly, participants criticized the screening protocol for not being able to reflect their resiliency and personal strengths in the face of adversity: "I like the person I've become and I realize that my spiritual growth is almost a kind of a minor evolution in the human spirit, to deal with challenges and to not get held back by these challenges" (PID1).

## Discussion

The results of this study highlight the value of using a mixed method approach to case find for previously unrecognized mental health concerns among this population. The quantitative data identified previously unrecognized mental health issues for 5 participants resulting in timely intervention. However, the qualitative data identified discrepancies between the positive ratings of the screening tools and the lived experiences of the participants through stories that either challenged the screening outcomes or provided alternative meanings. Similarly, although participants generally agreed that the use of screening instruments has high utility in primary care settings, a general sentiment stated during the interviews was that of frustration related to the lack of attention to personal resiliency and strengths. These discrepancies may suggest screening for this population should include both standardized tools but also an opportunity for people to talk about their psychological experiences. Screening protocols should also include measures that assess

health screenin Screening	Strongly		Neutral	Agree	Strongly
Aspects	Disagree	-		_	Agree
The screening process helps my care providers to better understand my health issues.	0	0	3 (23.1)	5 (38.5)	4 (30.8)
I feel it is important to be asked these questions because it may help to identify conditions that were not known before.	0	0	4 (30.8)	5 (38.5)	4 (30.8)
I think it is worth the extra time to have the screening completed.	0	0	1 (7.7)	6 (46.2)	6 (46.2)
I think the screening is a valuable addition to the regular care provided by my family doctor.	0	0	2 (15.4)	6 (46.2)	5 (38.5)

positive mental health and adjustment such as measures of purpose in life, well-being, and health-related quality of life. For example, the health-related quality of life measures assess mental health, physical, and social well-being; a number of different health-related quality of life measures have been tested for use with persons with spinal cord injury.<sup>19,20</sup> In this study, although we did expect to find a higher incidence of substance use among our sample, there was a reluctant to disclose such behaviors with health care providers, highlighting a poorly understood issue within this population and perhaps suggesting underestimated prevalence.

#### **Study limitations**

This pilot study is limited by a small size; further research is needed in this area to generalize findings. Despite this limitation, our study highlighted the discrepancies between the competing need for valid and guick screening tools and the need for tools that sensitively collect and pay homage to the experiences of the individual living with a SCI. Although the generalized anxiety disorder screening tool has been validated for use with persons with SCI<sup>21</sup> and the Patient Health Questionnaire used in an randomized control trial with a SCI population,<sup>22</sup> the tools within the screening protocol are not known to have been validated with a SCI population. More research is needed to validate commonly used screening tools with persons with SCI. Although this screening protocol was tested in a primary care setting, it is important to note that it is most relevant for use in multidisciplinary settings. Although family physicians are in a good position to identify the need for screening, administration of the protocol itself is most relevant to practice of nurses, social workers, occupational therapists and psychologists, and other disciplines trained in assessing mental health issues and who may have the time to administer such a screening protocol. Similarly, the screening protocol has applicability to other multidisciplinary settings such as rehabilitation and psychology units and outpatient clinics aimed the care of persons with SCI. Further research is needed to evaluate its use in other clinical settings.

## Conclusions

We advocate for the need to develop a more holistic screening protocol that is capable of navigating such issues to better support a vulnerable population in a timely yet meaningful and respectful way.

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