Experiences With Navigating and Managing Information in the Community Following Spinal Cord Injury

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Background: People living with spinal cord injury (SCI) have reported difficulties managing information in the community, which can negatively impact their functional independence and ability to prevent secondary complications. **Objective:** This exploratory qualitative study aimed to describe the experiences of people living with SCI with navigating and managing information in the community from their perspective. **Methods:** Participants were recruited through the Australian Quadriplegic Association. Twenty-two semi-structured in-depth interviews were conducted with purposively selected participants to ensure representation of age, gender, SCI level, and compensation status. Data were thematically analyzed using a framework approach. **Results:** People living with SCI reported using multiple, complementary sources of information to prevent and manage secondary conditions. Over time, they learned to appraise the content, relevance, timing, and sources of information. Information delivered by health professionals in the rehabilitation setting was appraised as lacking personalization, but it acted as a springboard to search for more relevant information. Participants described the process of becoming experts about their condition to overcome the lack of knowledge of many general practitioners, guide their own care, and act as a source of information for others. Due to a lack of information provision, some participants missed health improvement opportunities and experienced frustration at the uncertainty of their future with SCI. **Conclusion:** Greater support is required for individuals with SCI to navigate information sources in the community. Rehabilitation is an opportune time to provide education related to finding and appraising information. Improved access to community health providers with SCI knowledge is also required. **Key words:** community care, disability, health literacy, information seeking behaviour, secondary conditions, spinal cord injury

After sustaining a spinal cord injury (SCI), individuals can develop debilitating secondary conditions, including urinary and bowel complications, chronic pain, and pressure areas.^{1,2} Within the first 2 years following SCI, 40% of patients in Victoria, Australia, were readmitted to hospital with a secondary condition, while 27% visited the emergency department.³ Over the 2 years, the costs of ED visits and readmissions were AUD\$87,790 and AUD\$5.6 M, respectively. While secondary conditions are common and costly, many are preventable.³

To learn how to prevent and manage secondary conditions, individuals living with SCI require information and education.⁴ While they receive large amounts of information and education during their acute hospital and rehabilitation stay,⁵⁻⁷ alterations in management may be required as new techniques

are developed, management recommendations are updated, or personal circumstances change.⁸ Therefore, informational needs are ongoing, and up-to-date information is required to effectively prevent and treat secondary conditions.⁹ However, people living with SCI have reported difficulties managing information about their condition in the community,⁴ which could negatively impact on their independence and quality of life.¹

Previous studies have revealed that people living with SCI express unmet needs for information about preventing and managing secondary conditions years after injury, despite using a variety of sources.^{4,10} Other studies have suggested that people living with SCI have preferred sources of information, but these are not always used, often due to lack of accessibility to health professionals.^{9,11}

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While some qualitative studies have been published exploring perceptions about SCI-related education and information, they do not comprehensively explore long-term resource searching in the community as they were specific to one secondary condition¹² or focused on the rehabilitation setting.^{13,5} Manns and May⁶ conducted a Canadian study that addressed the information needs and barriers of people with SCI in the community. They found that people living with SCI had difficulty locating resources in the community and that community health care providers lacked SCI knowledge. However, there is a need for greater understanding about the current challenges faced by people living with SCI in an Australian health and community care context. Therefore, this exploratory qualitative study aimed to describe, from the perspective of people living with SCI, their experiences with navigating and managing information in the community. Managing refers to accessing, processing, and organizing information in order to make health care decisions.

Methods

Study design and ethics

Ethical approval for this exploratory qualitative study was granted by the Monash University Human Research Ethics Committee. Participants were recruited through the Australian Quadriplegic Association (AQA) Victoria, a non-profit organization that provides support and services to people with SCI. The study was advertised on the AQA Facebook page, in their regular

newsletter, and via email to their members. Potential participants contacted researchers at Monash University via email or telephone to express interest. Participants were purposively selected to ensure representation of age, gender, SCI impairment level, and compensation status. The eligibility criteria were:

- ≥18 years of age,
- English-speaking,
- Experience with secondary conditions following SCI, and
- Received most health care services within the state of Victoria, Australia.

Twenty-two of the 26 individuals who expressed interest in the study consented to participate. Four potential participants were not able to be contacted or expressed interest in participation after recruitment had closed. In-depth semi-structured telephone interviews were conducted between September and October 2015 by three female interviewers (including the first and last authors), trained in qualitative interviewing, using a topic guide (see **Table 1**). The topic guide was developed by the expert SCI investigator team and tailored to the study aims, based on previous research. Further questioning led by participants' responses yielded additional information. Interviews were conducted until no new themes emerged. All interviews lasted between 30 and 60 minutes, were audio-recorded, and were transcribed including consent for participation at the start of the interview. Interview transcripts were loaded into NVivo (QSR International, Doncaster, Victoria) for data management.

Table 1. Semi-structured topic guide

Interview topic	Interview questions
Information and services	What education or information have you received about managing and preventing any spinal cord injury conditions? <i>Who provided the information?</i> <i>Was it written or verbal?</i> <i>When was the information provided (eg, in hospital, at discharge, during rehabilitation, in the community, etc)?</i> <i>How useful was it?</i> <i>What other information would you have liked to receive?</i>
Barriers and facilitators to care	What helps the most with accessing the information that you need to prevent and manage spinal cord conditions? What makes it harder for you to access the information that you need?
Overall perceptions and future	What informational needs do you think you will have in the future? <i>How could these needs be met?</i>

Note: Questions in italics are potential probing questions based on responses provided.

A qualitative thematic framework approach was used to analyze the data.¹⁴ This process commenced with repeatedly reading the transcripts to ensure familiarization. Repetitions in text and meaning were identified and coded. Through an iterative process, key themes and subthemes were formed based on patterns and connections within and between transcripts. Similar themes were clustered. The resulting framework was applied to the original transcripts to check for meaningful links and connections and make adjustments to ensure accurate representation. Two researchers (first and last author) performed the analysis independently. The framework was developed through regular discussion until complete agreement was achieved, which resolved any differences in interpretation of the findings.

Results

Most participants were male ($n = 16$; 73%), over 50 years of age ($n = 12$; 55%), and lived in a metropolitan location ($n = 15$; 68%). At the time of interview, over half of the participants were injured more than 15 years ago ($n = 12$; 55%) and most had transport-related injuries ($n = 11$; 50%). Fifteen participants were living with tetraplegia (8 complete and 7 incomplete) and seven were living with paraplegia (complete and incomplete). Approximately one-quarter of participants had not completed secondary school, 41% held advanced diplomas, and the remaining participants held undergraduate or postgraduate qualifications. Three main themes and multiple subthemes were identified. See **Table 2** for excerpts supporting themes and subthemes.

Sources of information

Multiple sources of information

Most participants used multiple, complementary sources of information at different stages throughout their recovery. The most common sources were health professionals, peer support networks, and the Internet. Health professionals, such as nurses, general practitioners (GPs), spinal consultants, and allied health professionals, provided verbal and written information and were generally available to answer questions in

the acute hospital and rehabilitation settings, as well as during appointments, scheduled visits, or sometimes via telephone.

Spinal support organizations were often accessed in the community for support and connection with services, as well as to remain up-to-date with spinal news and developments via newsletters, websites, and informational events. Spinal support organizations also developed peer support networks that consisted of paid peer support workers or volunteer peer mentors who visited newly injured people in hospital and/or rehabilitation. Other people with SCI met during acute hospital or rehabilitation stays, in the community, or via social media were also part of peer support networks. Participants relied on these networks for support and advice on numerous topics, such as managing secondary conditions and psychological issues. A few participants stated that they were referred to a number of websites at rehabilitation discharge, and most participants reported searching for their own SCI-related information on the Internet upon returning to the community.

Some sources were useful at different times and served different purposes. Generic information from health professionals was useful at the beginning as a way to learn the essential information pertaining to their condition. Further down the recovery pathway, people living with SCI then expressed the need for more individualized information in the community.

Desire to act as a source of information and share knowledge

As they gained knowledge and experience, many people living with SCI became sources of information for others with similar injuries. Some participants developed networks with other individuals living with SCI in order to share information and help others problem solve, while others took on formal roles and gained employment (paid or voluntary) as peer support workers for spinal support organizations. Participants described their information networks as reciprocal relationships through which they could teach others and learn simultaneously. Some remarked on the utility of social media for sharing information and experiences.

Table 2. Themes, subthemes, and quotes

Theme	Subtheme	Quote
Sources of information	Multiple sources of information	<p>"The doctors give you all the medical facts and the nursing staff give you the practical skills that you need to learn... but I think the mentoring and peer support are equally as important." (female, >50 yrs, ≥16 yrs post injury, #920)</p> <p>"In rehab, you're inundated with information... it's useful at the time, but when you do your own research it's more relevant to you and the problems that you've got at the time." (male, 18-50 yrs, ≤5 yrs post injury, #918)</p>
	Desire to act as a source of information and share knowledge	<p>"What I'd like to do is to be able to tell some people who are coming through, the things they can avoid, without going through anything unnecessarily." (male, >50 yrs, 6-15 yrs post injury, #904)</p> <p>"I try and pass that information onto others." (male, >50 yrs, ≥16 yrs post injury, #912)</p> <p>"I'm learning from her (another individual with SCI), she learns from me, what not to do with me." (female, >50 yrs, 6-15 yrs post injury, #914)</p> <p>"I've actually been putting some things that I do on Facebook, and it's a good way of communicating because everyone can access it... it's a fantastic networking tool." (male, >50 yrs, ≥16 yrs post injury, #911)</p>
Using SCI information	Appraisal of SCI-related information	<p>"Probably a lot of the stuff I know better than they [GPs] do... If I was to go to a GP now that doesn't know me, I'd be cautious on the advice or treatment they give me... I'd take it on board but I'd sort of decide myself, only because I've gained a lot of knowledge over the years, so I listen to their opinion as a backup maybe." (male, 18-50 yrs, ≥16 yrs post injury, #915)</p> <p>"I didn't have pressure sores and things, so you listen to everything you're being told, but it's when it actually happens to you... that's when it really applies." (female, >50 yrs, 6-15 yrs post injury, #914)</p> <p>"My best resource is basically other people's spinal cord injury. They're living it and they've got the experience so they can help you and guide you better than anyone else who's not living with it." (male, 18-50 yrs, ≤5 yrs post injury, #918)</p> <p>"Good to speak to people who have done it and know that you're heading in a good direction." (male, 18-50 yrs, ≤5 yrs post injury, #913)</p>
	Learning to appraise information	<p>"If you get on the Internet and you have a look around and you learn how to filter it out, you'll work a lot of things out on there." (male, >50 yrs, ≥16 yrs post injury, #908)</p> <p>"Over time, I learn what's out there, what's good, what's bad." (male, 18-50 yrs, ≥16 yrs post injury, #915)</p> <p>"People who are injured are not necessarily academic people or people accustomed to sifting through good and bad information." (male, >50 yrs, 6-15 yrs post injury, #904)</p>
	Delivery of information in a useful format	<p>"...the written information, yes, it's handy to have that stuff to go back to... Learning how to self-catheterise isn't something you can learn from a piece of paper, you need it to be a demonstrative thing." (female, 18-50 yrs, 6-15 yrs post injury, #916)</p> <p>"It's got to be a format where someone goes... 'What do I do, I've got this?' and then they answer. They [people with SCI] learn much better that way... Because a lot of them are plumbers and motorbike riders and stuff who have never been to lectures for long periods of time." (male, >50 yrs, 6-15 yrs post injury, #904)</p>
	Information used as a springboard for further searching	<p>"It might not always be exactly what I'm after, but it [information found on the Internet] gives me a good start." (male, 18-50 yrs, ≥16 yrs post injury, #922)</p> <p>"I don't always take it [information found on the Internet] as pure fact, I'll use that with my doctor or my services to talk to them as to what's best." (male, 18-50 yrs, ≥16 yrs post injury, #922)</p>
Issues encountered	Feeling isolated	<p>"It would be good to have a little bit more freedom to learn those things [management of secondary conditions] and know that it's [inpatient care] there as a safety net, with a primary caregiver... So transition a bit more rather than going from one extreme of full-time care to needing to manage things yourself." (male, 18-50 yrs, ≤5 yrs post injury, #913)</p> <p>"Not 26 years ago. It's just like oh you're going home today, see you, bye... They didn't think we should inform this guy when he goes home that he might face this, this and this. They do it now but 25 years too late." (male, >50 yrs, ≥16 yrs post injury, #912)</p> <p>"A lot of it is finding your own way because everyone reacts differently to the situation and to the changes and everyone has different things they need to deal with too." (male, 18-50 yrs, ≤5 yrs post injury, #913)</p> <p>"I don't think they can do anymore other than give you all the tools and say there you go, go out into the big wide world...." (male, 18-50 yrs, ≤5 yrs post injury, #901)</p>

(Continued)

Table 2. Themes, subthemes, and quotes (CONT.)

Theme	Subtheme	Quote
	Difficulties encountered with access to information through health professionals	<p>"It took me at least six or seven doctors to find one who had half a clue about spinal cord injuries." (male, 18-50 yrs, ≤5 yrs post injury, #918)</p> <p>"Some of them don't have the knowledge as well, because it's a very small... because every GP would have maybe one or two quadriplegic patients at most." (male, >50 yrs, 6-15 yrs post injury, #904)</p> <p>"I would have liked to have seen my spinal specialist a lot more often... she said she'd put me on the list and make sure that I was seen soon, but that was some time ago so I don't know what's happening there... just to talk to somebody who knows what you're talking about." (female, >50 yrs, ≤5 yrs, post injury, #910)</p> <p>"Well I haven't seen the spinal specialist since I left hospital... I don't want to travel, so it's my own fault." (male, >50 yrs, 6-15 yrs post injury, #907)</p> <p>"There's been no use bringing up if you've got any psychological issues because you'll just get replied to that everybody has them." (male, >50 yrs, ≥16 yrs post injury, #908)</p> <p>"Our sexual needs need to be worked on or improved on ... no one really wants to know." (male, >50 yrs, ≥16 yrs post injury, #911)</p>
	Lack of information led to missed opportunities	<p>"No one ever mentioned the fact that from the beginning I should have been receiving medication to stop the osteoporosis from happening... that would have saved me a lot of grief... I'm left with absolutely cruddy, crumbly bones." (female, >50 yrs, 6-15 yrs post injury, #909)</p> <p>"When I was stronger and I was really showing progress... if I'd been told more about the stuff [SCI treatments and programs] in America, I would have gone." (female, >50 yrs, 6-15 yrs post-injury, #914)</p>
	Frustration at the uncertainty surrounding SCI	<p>"You just go in [to hospital], well it's mainly the pain that you go in for and then when you go in they [the doctors] can't find it." (male, >50 yrs, ≥16 yrs post injury, #903)</p> <p>"They [the doctor] don't have all the answers unfortunately, why you get infections and stuff. An infection doesn't come with a thing saying this is caused by this. They do the best they can." (male, 18-50 yrs, ≥16 yrs post injury, #919)</p> <p>"There's a lot of trial and error in it." (female, >50 yrs, ≥16 yrs post injury, #902)</p> <p>"I think it's hard to predict at this point because it's still unknown how much independence I'll have with it [bladder management]." (male, 18-50 yrs, ≤5 yrs post injury, #913)</p> <p>"A bit of the unknown in the future, that's my one beef... no one can tell me whether I'll be cared for." (male, >50 yrs, ≥16 yrs post injury, #912)</p>

Using SCI information

Appraisal of SCI-related information

Participants appraised the content, relevance, timing, and sources of information that they received. Some participants described the need to "become your own expert" (male, 18-50 yrs, ≥16 yrs post injury, #915), which typically involved drawing on personal experience, and appraising independently gathered information, as well as that provided by others. Those who had gained extensive knowledge about their condition over time felt more informed than some of the health professionals they consulted, as some reported preferring to make decisions based on their own knowledge.

Those with less SCI experience described appraising information for its relevance and timing. Generic information delivered by health professionals during acute hospital and

rehabilitation admissions often appeared to lack personalization and therefore did not seem applicable.

Several participants appraised the information provided by others living with SCI as extremely valuable due to its practicality and relatability. They valued the opportunity to connect with someone who had experienced and understood what they were going through.

Learning to appraise information

Some participants stated that learning to appraise information was necessary in order to determine the utility of information. This learning process was described as something that occurred over time, particularly in relation to information found on the Internet.

Some participants suggested that education on how to appraise online information is required,

given that not all individuals living with SCI were experienced with this process.

Delivery of information in a useful format

Information was often provided in verbal and written formats, and participants reported that both were useful and complementary. Verbal information was considered important when learning practical skills, however written information was useful to refer back to at a later stage. Some participants emphasized the importance of the format suiting the nature of the information to enhance utility, while others suggested that information received in rehabilitation should be individualized and tailored to varying learning styles.

Information used as a springboard for further searching

A number of participants reported receiving a significant amount of information during their rehabilitation stay. This gave them a basic understanding of their injury and acted as a springboard to search for information that was relevant to their specific issues. Participants' independent searches for information, mainly using the Internet, did not always yield the specific information they were looking for, but did guide further searches.

Some participants mentioned that they used independently resourced information as a starting point for discussion with health professionals prior to making any health-related decisions.

Issues encountered

Feeling isolated

Some participants voiced the need for an extended transition period from rehabilitation to aid settling back into the community. Upon returning home, participants felt that they were left on their own to manage their condition without ease of access to health professionals' advice. In the community, participants had to seek information out for themselves. The feeling of being left alone and unsupported after rehabilitation discharge was more prominent among participants who were injured more than 15 years ago. They stated that almost

no information was provided during inpatient rehabilitation, thus they did not have an information base to build on or refer back to after discharge.

Some participants suggested that being left on their own was necessary in order to settle back into their home life. They realized that they would no longer have the constant informational support from health professionals. Consequently, they needed to learn to do things for themselves and determine how to apply the information they received outside of the controlled rehabilitation environment.

Difficulties encountered with access to information through health professionals

Many participants reported that accessing SCI information to manage their health could be difficult in the community. This issue was attributed to the small number of spinal patients in the population, which meant community health professionals, such as GPs, often had limited knowledge regarding the management of spinal patients. Furthermore, some participants described attempting to obtain information from spinal consultants as challenging. While spinal consultants had spinal-specific knowledge, some participants reported difficulty obtaining an appointment. Participants living in a rural location noted distance as an additional barrier.

A number of participants also anticipated that their needs would not be acknowledged by health professionals. They reported having specific psychological and sexual health information needs, however they perceived that these needs would be dismissed if they were raised. This resulted in participants keeping these concerns to themselves.

Lack of information led to missed opportunities

Some participants reported experiencing negative consequences as a result of not being made aware of certain information or not receiving information in a timely manner. They expressed that receiving this information could have improved their recovery trajectory.

Frustration at the uncertainty surrounding SCI

A number of participants communicated the need for further information to ease the uncertainty they felt about the origins of pain, the

level of pain that should be tolerated, future pain management plans, infection causes, future care arrangements, and gaining independence. While some participants acknowledged that there was still much unknown about managing spinal cord conditions and that health professionals did not always have the information to provide answers, many reported feelings of frustration.

Discussion

This study highlights the challenges that individuals living with SCI faced when attempting to meet their informational needs in the community. While they received a significant amount of information during rehabilitation, we found that people with SCI experienced difficult transitions back into the community and felt largely left on their own to navigate and integrate information relevant to their current and emerging needs. Furthermore, access to spinal consultants was reportedly limited, as was the knowledge of some GPs. Therefore, learning to integrate, appraise, and personalize information from multiple sources was necessary in order to increase their knowledge and become experts about their condition.

People living with SCI emphasized that when they were experiencing a particular secondary condition, information applicable to it was needed. Information provided initially after SCI does not meet ongoing and long-term informational needs as it can lose relevance and currency over time.^{4,8} Our findings, together with previous research, support the need for a model of care in which the provision of quality and personalized information continues beyond rehabilitation discharge.^{4,6} This involves ongoing relationships with health professionals knowledgeable about SCI, however, consistent with previous studies,^{4,7} participants reported difficulties accessing spinal consultants. Another barrier to obtaining SCI-related health information was the limited knowledge of some GPs, which has also been confirmed in other studies.^{11,15,16} In order to ensure that information provision is ongoing, a range of community-based health professionals need to have SCI-specific knowledge and therefore ready access to accurate SCI information.

Similar to previous studies, we found the Internet was one of the most commonly used

sources of information.^{9,17} However, a notable finding was that individuals living with SCI suggested they were using online information to guide decision making related to the management of secondary conditions and, in some cases, bypassing health professionals in the process. This is likely due to the reported issues with access to knowledgeable health professionals. Matter et al⁹ suggested that in comparison to spinal consultants and community health professionals, the Internet is a readily available source, which may contribute to its popularity. Given that the quality of SCI-related information on the Internet can be variable,^{4,12} information must be appraised for its relevance and accuracy. In line with previous research,^{4,12} people with SCI were aware of the importance of appraising online information, but they emphasized that this was a skill they acquired over time. As many individuals living with SCI in the community are regularly sourcing information from the Internet, it is important that they understand how to critically appraise this information at an early stage. Without this skill, information may not be applied appropriately when making health decisions.¹⁸ These findings reinforce the need for ready access to knowledgeable health professionals prior to making important health-related decisions. Information found on the Internet can be useful for starting conversations with health professionals, and such discussion can support effective decision making about the management of secondary conditions.

Our study demonstrated that health literacy skills (such as the ability to access, use, understand, and apply information) developed and evolved among a number of participants with years of lived experience. Similar to previous studies,^{17,19} participants described the importance of advocating for their needs, which meant that, over time, they became experts about their conditions. In addition, our findings highlighted that some participants trusted their own knowledge over health professionals' advice. While people living with SCI should have an active role in their health-related decision making, engaging qualified health professionals in this process allows them to share health information, maintain a record of health issues, make referrals if needed, and ensure that decision making is informed.²⁰

Consistent with previous research, information received from those living with SCI was appraised as extremely valuable. Manns and May⁶ stated that both casual and formal peer support were sought by individuals living with SCI. Our study extended these findings, with participants who had greater years of lived experience reporting the desire to provide peer support. These reciprocal relationships allowed participants to learn from

others, as well as share knowledge gained from their own lived experience. This supported those with less experience to avoid some preventable problems and learn how to navigate the information available in the community.

The recommendations provided in **Table 3** may assist to address many of the issues raised by facilitating multiple points of access to high quality information in the community.

Table 3. Recommendations

Issue identified	Recommendation
Difficulties with access to information through health professionals	<ul style="list-style-type: none"> • Online resources, such as The Spinal Cord Injury Research Evidence (SCIRE) Project developed in Canada, could be adapted for the Australian context in order to support community health professionals to access reliable SCI information.²¹ <ul style="list-style-type: none"> ◦ Resources such as this one could reduce the need for health professionals to conduct extensive SCI research, as it synthesizes up-to-date best clinical practice information on a range of topics and is formatted to inform decision making in SCI rehabilitation and community reintegration settings. ◦ Eng et al²¹ found that SCIRE increased health care providers' access to and improved their knowledge of SCI evidence, as well as impacting on their clinical practice and increasing their confidence to treat people with SCI. • To develop specific and targeted strategies to assist general practitioners (GPs) to effectively guide people living with SCI, research into the level of GP knowledge is needed to determine how this differs from the informational needs of people with SCI. • Upon discharge from rehabilitation, it is important that individuals are linked with resources through which they can access information that may become applicable in the future. <ul style="list-style-type: none"> ◦ Rehabilitation offers an opportune time in which to link people with SCI with community health professionals, such as GPs, who specialize in treating individuals with SCIs. ◦ A statewide or national database could facilitate this linkage process, while also factoring in distance from residential locations. • Regular appointments, potentially via phone or email, could also be scheduled with spinal consultants to provide communication opportunities with SCI informational experts. • Telehealth is an established technology that could be used to overcome geographical barriers to accessing specialist SCI health professionals.²²
Need for education about critical appraisal	<ul style="list-style-type: none"> • Education about how to critically appraise information in the rehabilitation setting could assist newly injured individuals to develop this skill and access reliable and useful information after discharge.²³ <ul style="list-style-type: none"> ◦ For example, the DISCERN tool provides validated criteria (ie, sources of information used to compile the resource, date of publication, inclusion of risks and benefits) for appraising the quality of health information used to make treatment choices.²⁴
Bypassing health professionals to make health-related decisions	<ul style="list-style-type: none"> • While those who have experience and well-developed health literacy skills may be able to effectively access and understand information, it is important to share responsibility for SCI health care and maintain open communication with trusted health professionals. • Although they do have the opportunity to use their credibility to pass on good health messages, people living with SCI and acting in peer mentoring roles also need to ensure that health information gained through experience is used to complement information provided by SCI specialist health professionals.
Need for individualized information	<ul style="list-style-type: none"> • Collaboration between previously injured individuals and rehabilitation health professionals may assist to tailor appropriate and relevant content for education in the rehabilitation setting, as well as post discharge. <ul style="list-style-type: none"> ◦ This could help to reduce concerns held by people with SCI about particular information, including sexual function and psychological issues needs not being addressed, as the findings from our study and others confirm.^{11,25} • Dissemination of information could be tailored to individuals' needs by screening for comprehension, willingness to receive information, and learning style.

Limitations

People with an interest in sharing their experiences with managing information about secondary conditions in the community may have been more likely to participate in this study. We only interviewed English-speaking people and therefore the views of those who speak a language other than English may not be represented. We recruited participants through AQA Victoria who largely relied on the electronic distribution of information, thus those not connected to AQA or its linked partners or those without an Internet connection are unlikely to have had the opportunity to participate. Although our findings highlighted that the Internet was one of the most commonly used sources of information, it should be noted that the participants were an information technology savvy group, given that the majority responded to an electronic invitation.

Conclusion

The findings from this study highlight the difficulties people living with SCI face when

attempting to meet their information-related needs in the community. There is a need to provide greater support to people with SCI early after injury to navigate and manage information. Education to improve health literacy and greater linkage with community health professionals prior to discharge from rehabilitation may facilitate ongoing access to high-quality SCI information that is relevant to individuals' needs.

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