

# Expectations of a Health-Related Mobile Self-Management App Intervention Among Individuals With Spinal Cord Injury

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Background: Our research team developed a mobile application (app) to facilitate health-related self-management behaviors for secondary conditions among individuals with spinal cord injury (SCI). To facilitate mobile app adoption and ongoing use into the community, it is important to understand potential users' expectations and needs. **Objectives:** The primary objective of this study was to explore user expectations of a mobile app intervention designed to facilitate self-management behavior among individuals with SCI. Methods: Data were collected via one-on-one, semi-structured interviews with a subsample of 20 community-dwelling participants enrolled in a larger, clinical trial. Analysis of the transcripts was undertaken using a sixphase process of thematic analysis. **Results:** Our analysis identified three main themes for expectations of the mobile app intervention. The first theme, desiring better health outcomes, identified participants' expectation of being able to improve their psychological, behavioral, and physical health outcomes and reduce associated secondary conditions. The second theme, wanting to learn about the mobile app's potential, identified participants' interest in exploring the functionality of the app and its ability to promote new experiences in health management. The third theme, desiring greater personal autonomy and social participation, identified participants' desire to improve their understanding of their health and the expectation for the app to facilitate social engagement with others in the community. **Conclusion:** By exploring end-users' expectations, these findings may have short-term effects on improving continued mobile health app use among SCI populations and longterm effects on informing future development of mobile app interventions among chronic disease populations. Key words: eHealth, mobile health, spinal cord injury

#### Introduction

Individuals living with spinal cord injury (SCI) can face multiple health challenges, including a variety of both physical and physiological secondary conditions. The most common secondary conditions resulting from SCI include problematic spasticity, pressure ulcers, autonomic dysreflexia, genitourinary dysfunction, chronic pain, and depression.<sup>1</sup> If not properly managed, these secondary conditions can limit social participation, reduce quality of life, and may prove fatal in severe cases.<sup>1</sup>

An important strategy to reduce the occurrence of SCI-related secondary conditions is through efficient self-management techniques. Selfmanagement refers to "an individual's ability to manage symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with chronic disease."2(p178) Examples of self-management techniques relevant to SCI include pain management, exercise, medication scheduling, and suitable nutrition.<sup>3</sup> Facilitators to adopting health self-management behaviors largely relate to levels of support, acceptance, and independence, whereas common barriers include physical limitations, accessibility, funding policies, and caregiver burnout.<sup>4</sup>

Mobile health applications (apps) are increasingly being used to facilitate self-management behaviors.

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Among individuals with SCI, multiple mobile health apps have been developed and have undergone preliminary testing for the management of various adverse health outcomes (e.g., pressure injuries, bladder dysfunction, and depression).5-8 For example, the app for pressure injuries included features such as skin assessment, pressure injury diary, knowledge repository, and expert consultation.<sup>6</sup> The use of these apps is intended to promote greater independence and reduce burden on health care services.8 A systematic review of randomized control trials of mobile app-based selfmanagement interventions among chronic disease populations (diabetes, chronic lung disease, and cardiovascular disease) found that the primary clinical outcome of interest improved in six out of nine studies.9 However, suboptimal mobile health app engagement is a pervasive challenge that exists across studies, tools, and populations, and it has a detrimental impact on intervention efficacy.<sup>10,11</sup>

This study was conducted as part of a large, multiphase research project to develop an app to facilitate self-management behavior among people with SCI. The first two phases of the project examined the iterative development and usability of the app in the inpatient rehabilitation setting.<sup>12,13</sup> In the first phase, the mobile self-management app was iteratively developed through a usercentered design approach with key stakeholders including clinicians, informal caregivers, and those in inpatient rehabilitation for SCI.12 To facilitate self-management, the app included features such as a pain tracker, bowel and bladder tracker, activity journal, medication reminders, and water intake tracker.12 In the second phase, usability and pilot feasibility testing were conducted on the app's efficacy for promoting self-management behaviors in the inpatient rehabilitation setting.<sup>13</sup>

As individuals with SCI transition from rehabilitation to the community, their unique needs and approach to self-management care may change. According to Adu and colleagues,<sup>14</sup> mobile selfmanagement app users generally display satisfaction with usability and performance, but continued use remains a key issue. To facilitate mobile health app adoption and ongoing use in the community, potential users' expectations and needs must be understood.<sup>14</sup> According to the Unified Theory of Acceptance and Use of Technology (UTAUT) model, four key aspects of continued use include performance expectancy, social influence, effort expectancy, and facilitating conditions.<sup>15</sup> As part of the third phase of the multiphase project, reported here, we conducted a study to explore preliminary expectations of a mobile self-management app intervention designed to facilitate self-management behavior among individuals with SCI living in the community prior to using the app.

# Methods

Data from this study were collected from a subsample of a larger mixed methods intervention study assessing the efficacy of the mobile self-management app in the community setting.<sup>16</sup> This substudy used a qualitative descriptive approach, which seeks to understand a phenomenon and describe it from the perspective of the people involved. Ethical approval was obtained from the University of British Columbia Behavioral Research Ethics Board and the Vancouver Coastal Health Research Institute. Qualitative findings were reported in accordance with the Standards for Reporting Qualitative Research guidelines.<sup>17</sup>

# Participants

To be included, participants needed to (1) have experienced an SCI, (2) be living in the community at least 1 year post injury, (3) have internet access, (4) be able to communicate in English, and (5) be able to consent. Participants were excluded if they had previously used an SCI-related self-management app to prevent previous preconceived experiences with these types of apps from influencing their expectations. Participants were also excluded if they had cognitive impairments (six-item cognitive impairment test score of 6 or less) that could inhibit their ability to reliably complete required tasks or provide consent.<sup>18</sup>

# Recruitment

Participants were recruited via convenience sampling using five strategies, including social media, putting up posters in local rehabilitation centers, posting the study advertisement on the recruitment page of our research facility's website, reaching out to participants from previous studies, and contacting rehabilitation facilities and SCI support groups across Canada and the United States to share information about our study through their communication channels. Individuals who expressed interest in participating were contacted to confirm eligibility either by phone or email.

# Data collection

Data were collected via 30- to 40-minute semistructured, one-on-one interviews. Most interviews were conducted over the phone; however, there were a few interviews conducted in person for participants who lived in the city where the research study took place and who preferred to meet in person. An interview guide (**Table 1**) was used to explore participants' expectations of the mobile selfmanagement intervention. Using a demographic survey form, demographic data were also collected from participants (e.g., age, sex, employment status, electronic device use). Electronic device use included regular use of smartphone, laptop, tablet, or desktop.

# Data analysis

Analysis of the transcripts was undertaken using the six-phase process of thematic analysis outlined by Braun and Clarke.<sup>19</sup> These include (1) becoming familiarized with the data by reading transcribed interviews multiple times and taking notes on early impressions of the entire body of data; (2) generating initial codes through an open-coding process in which codes were developed and modified throughout the coding process; (3) searching for themes by organizing codes together to form initial subthemes and then broader, overarching themes; (4) reviewing themes to ensure that data within themes are relevant and the themes themselves are inclusive of all the interview transcript datasets; (5) defining and naming themes by identifying the overall message of each theme; and (6) producing the report.<sup>19</sup> Data were analyzed and themes were generated using NVivo 12. We used two main trustworthiness strategies including reflexivity and investigator triangulation. Researchers (G.S. and E.S.) involved in the thematic analysis coded and analyzed transcripts independently along with engaging in regular meetings with the principal investigator (W.B.M.) to debrief, reflect, and reach consensus on the data and study findings. To promote reflexivity, an examination into the impact of one's own beliefs, judgments, and practices on the research process, the interviewers (G.S. and E.S.) recorded notes and memos about the interviews and their interactions with participants.20 Data collection and initial analysis were conducted by the same two coauthors (G.S. and E.S.) who have extensive experience in qualitative data collection and analysis. Whereas G.S. has an academic background that focuses on researching mobile health apps for individuals living with SCI, E.S. has an academic background

 Table 1. Qualitative semi-structured interview guide

No.	Interview questions	
1	How would you describe your health currently?	
2	How do you currently manage your health (i.e., living with a spinal cord injury)? PROMPTS: What strategies do you use? Do you use any tools? What health conditions concern you? Do you receive help from a caregiver?	
3	How satisfied are you with the way you currently manage your health?	
4	What, if any, challenges do you currently experience with managing your health?	
5	What are your goals with managing your health?	
6	How do you feel about using a mobile health app to manage your health?	
7	What, if any, worries or concerns do you have about using the app to manage your health?	
8	How do you imagine the app will change your daily life?	
0		

9 What are you hoping to learn from participating in this study?

in kinesiology focusing on means to improve wellbeing and athletic performance. Data were collected until data sufficiency was reached—a point at which themes appear to identify new data without needing to modify established themes.<sup>21</sup> At approximately 15 interviews, the data were consistent at which point any new emerging data did not modify established themes. We conducted an additional five interviews to confirm data sufficiency was reached.

#### Results

**Table 2** presents a description of the participants who were interviewed. A majority of the participants (50%) were between the ages of 50 and 64 years.

The analysis identified three overarching themes regarding the expectations of individuals living with SCI for a mobile self-management app intervention. These themes include (1) desiring better health outcomes, (2) wanting to learn about mobile app's potential, and (3) desiring greater personal autonomy and social participation. **Table 3** presents a selection of quoted examples of participants' expectations of mobile app interventions for health self-management.

#### Desiring better health outcomes

Participants expected that the mobile app intervention would help them improve psychological, physical, and behavioral health outcomes. Psychologically, participants felt the mobile app intervention could help improve their confidence and competency in managing their health while alleviating feelings of anxiety (Table 3; P13, male with paraplegia). Furthermore, participants identified multiple SCI-related secondary conditions impacting their psychological health, including depression, anxiety, and stress.

Physically, many participants felt that the mobile app could promote better physical activity and movement and serve as an escape from a sedentary lifestyle (**Table 3**; P6, female with paraplegia). Similarly, participants felt that utilizing the app to improve physical activity would also provide additional necessary health benefits, such as "losing weight and getting better sleep" (P3, a male with paraplegia). Furthermore, participants felt that the mobile app intervention could help alleviate physical SCI-related secondary conditions such as chronic pain, spasticity, and fatigue. Behaviorally, participants felt that the mobile app intervention could improve overall selfmanagement consistency by providing a system of reminders or alerts for activities such as exercising, taking medications, or visiting health care professionals (**Table 3**; P9, male with paraplegia). Additionally, some participants felt that having a mobile app that reinforces healthy behaviors could provide a valuable "level of accountability" for them to continue practicing self-care.

#### Wanting to learn about the mobile app's potential

Participants described the opportunity to learn about the mobile self-management app's potential as a major expectation from participating in the study. More specifically, participants expressed an interest to explore the functionality of the app to "figure out how it works and see if there are any shortcuts [to navigating the app more efficiently]" (P15). Additionally, some participants described an expectation for the app to be more efficient than devices they currently use, such as a computer (Table 3; P16, female with paraplegia). Participants expressed a desire to learn about how the mobile app intervention could promote new experiences in health management. For example, one participant stated, "Things to learn, yeah the newest way of using an app to try helping me with my health condition" (P16, a male with tetraplegia).

Despite this interest in the app, participants had some reservations. In addition to learning about the app's capabilities, many participants expressed "concern about limitations to the app's privacy" and confidentiality measures (P8). In contrast, some participants did not express concern about the app's privacy and confidentiality measures as they did not feel "uncomfortable about sharing [their] physical abilities and symptoms" (P1). Furthermore, some participants had low expectations about the benefits of the app as a result of their limited or poor experiences with previous health technologies.

# Desiring greater personal autonomy and social participation

Participants indicated that an important expectation from participation in the mobile app intervention is the promotion of a greater sense of self-reliance and social engagement. In terms of

Demographic		Mean (SD)
Age, years		47.5 (13.2)
Time since injury, years		20.8 (14.8)
		n (%)
Age	18-34	4 (20)
	35-49	4 (20)
	50-64 > 65	10(50)
Sex	Female	2 (10) 14 (70)
	Traumatic	
Injury cause (traumatic/non-traumatic)		13 (65)
Injury type (paraplegia/tetraplegia)	Paraplegia	10 (50)
International Standards for Neurological Classification of Spinal Cord Injury score	A	6 (30)
Chassification of Spinar Coru fijur y scole	B	6 (30)
	C	8 (40)
Level of injury	Cervical	10 (50)
	Thoracic	6 (30)
	Lumbar	4 (20)
Employment	Full-time	7 (35)
	Part-time	4 (20)
	Unemployed	9 (45)
Education	Less than high school	1 (5)
	High school	4 (20)
	Post-secondary	15 (75)
Marital status	Single/never married	7 (35)
	Married	5 (20)
	Common law	3 (15)
	Separated	2 (10)
	Divorced	3 (15)
Income	< \$15,000	5 (25)
	\$15,000-29,999	2 (10)
	\$30,000-44,999	1 (5)
	\$45,000-59,999	2 (10)
	\$60,000-74,999	3 (15)
	> \$75,000	3 (15)
	Prefer not to say	4 (20)
Electronic device use	Smartphone	15 (65)
	Tablet	8 (40)
	Laptop	7 (35)
	Desktop	10 (50)

**Table 2.** Participant demographic data (N = 20)

Theme	Participant code	Quote
Desiring better health outcomes	P13	"[The app] might be able to make me feel more competent or confident in myself or knowing that things are not abnormal. Knowing it's normal to have these symptoms might be able to make me feel less anxious"
	Р6	"I guess better health wise. I think I want better endurance because I'm sitting a lot. And then I was doing that before too but I'm more active now because of the chair. And I found sports. So more physical endurance I guess."
	Р9	" that was part of my goal. Trying to exercise [laugh] I don't really do anything so it would be nice to have a reminder or be able to set up a schedule and keep to it. But there's other things that go on. Like appointments for physio or whatever. Doctor's appointments stuff like that that I'm just like oh oh yeah, I didn't do my stretches for the day."
Wanting to learn about the mobile app's potential	P19	"If an app is more efficient, then another way, then I need to use that, but if, but that's what it comes down to, it's back to the point system, if it takes less points that means I have more points to do something else."
Desiring greater personal and social autonomy	Р5	"Well I think it would, I mean when you can see the data, exactly what you are doing, if you are making sure to record things you can see okay I'm not drinking enough water, I'm not being active enough, you know like, these specific days I was in way more pain, why was that. It can help figure things out with yourself, why it's happening."
	P10	"Spend more time doing things that I know will be there long-term for me as I get older. And that is to practice, uh, drawing and, uh, artwork. Which I've totally neglected for way too long."

Table 3. Selection of quotes of participants' expectations of the app intervention

personal autonomy, participants expressed a desire for the mobile app intervention to improve their understanding of their health. More specifically, participants felt that the mobile app intervention could allow them to better understand changes in normal daily health and the secondary conditions they experience (**Table 3**; P5, female with paraplegia). In gaining a greater sense of personal autonomy, participants expected that the mobile app intervention would teach them "a more holistic health approach" (P3). In terms of social participation, participants wanted the mobile app intervention to provide a means to promote social participation. Participants felt that one way the mobile app intervention could promote social participation is by increasing engagement in recreational activities (**Table 3**; P10, female with paraplegia). Another means to promote social participation that participants shared was an expectation for the app to facilitate social engagement with others in the community. One participant felt that the intervention could help

them "exercise a little bit more, and also try to go out to the community to different places" (P6).

#### Discussion

This discussion is organized into the three themes that were identified by study participants on their expectations of the mobile app intervention. These themes include (1) desiring better health outcomes, (2) wanting to learn about the mobile app's potential, and (3) desiring greater personal autonomy and social participation.

# Desiring better health outcomes

This theme highlighted participants' expectations for improving their psychological, behavioral, and physical health outcomes by participating in the mobile app intervention. Similar to our findings, previous studies have emphasized the importance of addressing mental health concerns among individuals living with SCI.22,23 For example, a cross-sectional study on 443 individuals living with SCI found that 48.5% of individuals live with at least one mental health issue, including depression (37%), anxiety (30%), and posttraumatic stress disorder (8.4%).<sup>22</sup> Furthermore, a longitudinal study on 3556 patients with traumatic SCI found that, postdischarge from rehabilitation, patients had a significant 29% increase in risk of anxiety and depression compared to a non-SCI control group.<sup>23</sup>

Congruent with our findings, multiple qualitative studies have reported an expressed interest among individuals living with SCI to become more physically active and maintain an active lifestyle.<sup>24</sup> Unfortunately, a study found that leisure time physical activity is generally low among people with SCI and that specific subgroups such as older adults, women, and individuals with older injuries require specific attention and resources to overcome barriers to poor engagement with physical activities.<sup>25</sup> Similarly, a large proportion of our study participants were older adults, female, and living with SCI for over 20 years on average.

Having a variety of psychological and physical secondary conditions can impact self-management confidence and self-efficacy for individuals with SCI.<sup>16</sup> To improve behavioral outcomes, such as selfmanagement consistency, Bandura's<sup>26</sup> self-efficacy

theory indicates that successful behavioral change requires individuals to be confident taking action to achieve a desired goal. A recent study exploring the views of individuals with SCI on self-management programs found that 40% indicated it was "extremely important" that a program or intervention would increase their confidence.<sup>27</sup> Furthermore, qualitative studies exploring users' perspectives of mobile health apps designed to promote self-management behavior have found that daily task reminders and alerts are important factors in driving behavioral change that can promote users' willingness to adopt and continue to use mobile health apps.13 This supports the facilitating conditions component of the UTAUT model (i.e., if users perceive that the technical infrastructure needed to use an intended system such as app reminders and alerts are present, continued app use can be fostered).<sup>15</sup> Studies have found the repeated daily tasks reminders can result in adverse outcomes, including habituation (i.e., ignoring reminders), negative emotions (i.e., anger and frustration), and intervention fatigue.28 As a result, novel approaches to implementing mobile health app reminders have been developed included the just-in-time adaptive intervention (JITAI) approach.<sup>28</sup> In the context of app reminders, this approach involves adapting the type, timing, and intensity of reminders based on the users' internal and contextual state.29

#### Wanting to learn about the mobile app's potential

Similar to the perceptions of our study participants, an earlier study on the perceptions of individuals with SCI on a mobile health app found that app functionality is a heavily emphasized component to user adoption.13 Another study found that for individuals with disabilities, the overall interface of a mobile health app should address the unique needs of users to promote equitable access and adoption.<sup>30</sup> To address the unique needs of individuals with SCI, a mobile app was developed based on interactive feedback from patients, health care providers, and informal caregivers.<sup>12</sup> This study identified several SCI-specific tools that were important for facilitating self-management skill development among individuals with SCI, such as a bowel and bladder tracking, spasticity tracking, and

water intake tracking.<sup>12</sup> Furthermore, in accordance with the effort expectancy component of the UTAUT model, continued app use can be expected if participants are provided with a system that is easy to use and addresses their unique needs.<sup>15</sup>

Some of our study participants' attribution of their poor expectations of the mobile app's benefits to their limited knowledge of mobile apps can be explained by the concept of eHealth literacy, which is defined as "the ability to seek, fund, understand, and appraise health information from electronic sources and apply knowledge to addressing or solving a health problem."<sup>31(p2)</sup> Even though studies have shown that eHealth technologies, such as mobile health apps, are beneficial to promoting self-management, the barrier of insufficient eHealth literacy can negatively impact adoption.<sup>32</sup> In fact, serious concerns have been raised about poor eHealth literacy in vulnerable populations, such as individuals with severe chronic conditions and people with lower levels of education.<sup>33</sup> Furthermore, a recent study exploring technology use among 290 United States veterans with SCI found individuals who reported fair or poor health had significantly lower eHealth literacy than individuals who reported having excellent or good health.<sup>34</sup> That said, one study found moderate levels of eHealth literacy and general health literacy among the broader community-dwelling SCI population.35

# Desiring greater personal autonomy and social participation

The importance of personal autonomy is often emphasized in Western cultures to the point where those deemed independent are preferentially enabled.<sup>36</sup> This perspective can result in a lack of funding and services for those with disabilities and creates an imperative desire among those with SCI, for example, for a higher level of independence.<sup>37</sup> These services are offered primarily to individuals who have the possibility of aging in place.<sup>37</sup> Along with the cultural drive, greater self-management of ones' health also removes some of the dependency on health professionals. A reliance on health care professionals causes a greater imbalance in the power dynamics between patient and professional.<sup>38</sup> Independence when managing their health will collectively reduce the power imbalance and

also empower the individuals.<sup>39</sup> By aiding the expectation of greater self-management, the app intervention can help to improve independence and empowerment and increase app use.<sup>15</sup>

personal autonomy, Along with social participation has strong links to improved physical and psychological health outcomes. More specifically, social participation is thought to contribute to greater health-related quality of life, reduced depressive symptoms, increased physical activity, lower risk of cancers, lower risk of heart disease, and lower risk of all-cause mortality.40 Unfortunately, some studies indicate a dramatic decrease in social participation from pre to post SCI,<sup>41</sup> which suggests why our findings illustrated a desire for greater social participation. Other apps that have promoted social participation while reducing social isolation and increasing physical activity include the OnRoule app, which provides information about the physical accessibility and availability of adaptive equipment at various public locations across Quebec. Similarly, the GBER app connects older people in Japan to activities, jobs, and events in their community.42,43 According to the UTAUT model, if the app can contribute to greater social participation, it would be more likely to be adopted as a social norm and become more readily used.14 Greater use of the app could help the app intervention potentially meet other expectations, including facilitating health-related self-management behavior to cope with or prevent the development of secondary conditions.

# Strengths and Limitations

The study had several strengths and limitations. Twenty participants represented a relatively large sample, which allowed us to achieve data sufficiency. In terms of sampling, participants demonstrated extensive variability across most demographic items such as age, level of injury, and income. There are three main limitations with the study. First, because of confidentiality, we were restricted in terms of how much information we provide about specific participants, which may affect transferability. Second, we only spoke to those who had access to technology. As many individuals who have experienced SCI may not use a computer, we may have missed out on the perceptions and expectations from that subgroup of the population. Finally, the omission of data on race and ethnicity of study participants was a limitation.

# Conclusion

We conducted this study to explore user expectations of a mobile self-management app intervention designed to facilitate self-management behavior among individuals with SCI. Three central themes important to users' expectations emerged: desiring better health outcomes, wanting to learn about the mobile app's potential, and desiring greater personal and social autonomy. As part of a larger program of research, for the final phase of the project, plans are underway to examine community experiences with our mobile self-management app and to evaluate the efficacy of the app at helping community-dwelling individuals with SCI achieve self-selected, self-management goals.16 Future ethnographic research could explore how individuals with SCI use mobile health apps in real life and help identify potential barriers to continued use. Furthermore, future studies could examine the implementation of JITAI to examine the benefits of this approach in promoting app adherence. Finally, future research could examine how to make mobile health apps more accessible for people with very low eHealth literacy levels to improve mobile health app accessibility. This research emphasizes the importance of exploring end-users' expectations to improve mobile app uptake and continued use and informs the development of other mobile health app interventions for people with SCI.

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#### **Conflicts of Interest**

Dr. Adams works as a research and development officer for Self-Care Catalysts, a company that may benefit from the development of the mobile app. Conflict of interest was mitigated by Self-Catalysts (including Dr. Adams) having no access to any research data or involvement in data analysis.

#### Statement of Ethics

Ethical approval was obtained from the Vancouver Coastal Health Research Institute and the University of British Columbia's Behavioral Research Ethics Board.

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