Journal of Medical Systems (2019) 43: 145
https://doi.org/10.1007/s10916-019-1273-x

MOBILE & WIRELESS HEALTH

Development of a Self-Management App for People with Spinal Cord Injury

W. Ben Mortenson[1,2,3] · Gurkaran Singh[1,4] · Megan MacGillivray[1,4] · Mahsa Sadeghi[5] · Patricia Mills[2,6] · Jared Adams[7] · Bonita Sawatzky[1,8]

Received: 4 January 2019 / Accepted: 3 April 2019 / Published online: 22 April 2019

Abstract

With decreasing inpatient rehabilitation lengths of stay, there may be a greater risk of spinal cord injury (SCI) populations being discharged into the community without the self-management skills needed to prevent secondary complications. Recent advancements in mobile health has made mobile apps a feasible method of delivering population-based, self-management interventions to address SCI-specific secondary complications. The objective of this study is to describe stakeholder perspectives on the development of a functional mobile app to facilitate self-management skills needed to prevent secondary complications following recent SCI during inpatient rehabilitation. A user-centered design approach was used that involved an evolving mobile app and the collection of prospective qualitative data. Stakeholders from three groups were enrolled in the study: individuals admitted for rehabilitation following SCI ($n = 20$) and informal ($n = 7$) and formal ($n = 48$) caregivers. Iterative feedback was gathered from rehabilitation inpatients during ongoing interactions and via post-discharge exit questionnaires, from informal caregivers via one-on-one interviews, and from formal caregivers via series of focus groups at various phases throughout the design process. Three main themes emerged from the analysis: (1) being individualized and user friendly (i.e., developing an app that is simple and easy to use to facilitate universal uptake), (2) targeting goals to promote self-management (i.e., adopting self-management skills relative to personal goals and confidence), and (3) increasing participation and support-seeking to facilitate lifestyle change (i.e., encouraging leisure activities to facilitate community integration). Key stakeholder perspectives contributed to the development of a self-management mobile app that will be evaluated in future research.

Keywords Mobile apps · eHealth · mHealth · Self-management · Spinal cord injury

Introduction

Inadequate management of secondary complications can lead to adverse physical and psychological outcomes for people living with spinal cord injury (SCI). Some of the most common secondary complications include autonomic dysreflexia, problematic spasticity, genitourinary dysfunction, pressure ulcers, and depression [1]. These secondary complications may require costly interventions, which can lead to reduced quality of life and in extreme cases, may be fatal [2].

This article is part of the Topical Collection on *Mobile & Wireless Health*

✉ W. Ben Mortenson
ben.mortenson@ubc.ca

[1] International Collaboration on Repair Discoveries, Vancouver, Canada

[2] G.F. Strong Rehabilitation Centre, Vancouver, Canada

[3] Department of Occupational Sciences and Occupational Therapy, Faculty of Medicine, University of British Columbia, Vancouver, Canada

[4] Rehabilitation Sciences, Faculty of Medicine, University of British Columbia, Vancouver, Canada

[5] Department of Neurology, Wayne State School of Medicine & Detroit Medical Centre, Detroit, MI, USA

[6] Faculty of Medicine, University of British Columbia, Vancouver, Canada

[7] Self Care Catalysts Inc., Toronto, Canada

[8] Department of Orthopaedics, Faculty of Medicine, University of British Columbia, Vancouver, Canada

Self-management, which has been defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition," has been promoted as a means to reduce the prevalence and severity of secondary complications [3]. Self-management programs emphasize an individual's central role in managing their condition, and are aimed at increasing their problem-solving and decision-making skills to manage their condition [4].

With decreasing lengths of stay in inpatient rehabilitation due to staffing and funding constraints, there may be a higher risk of individuals with SCI entering the community without the self-management skills needed to prevent secondary complications [5]. A recent online survey found that nearly 75% of people with traumatic SCI indicated that the development of self-management programs for use following SCI was "important" or "very important" [6]. Furthermore, there is some evidence that self-management interventions can significantly reduce cost of healthcare utilization in comparison to standard care [7]. For example, a systematic review on the cost-savings in self-management interventions in chronic muscoskeletal pain populations found that 69% of studies (22 out of 32) demonstrated significant cost-savings over standard care [8]. However, there are accessibility barriers to the proper utilization of self-management programs such as transportation issues, lack of insurance coverage, and availability of intervention resources [9].

Over the past decade, consumers have become increasingly engaged with mobile health (mHealth) apps for self-monitoring and self-managing their health [10]. Furthermore, the technological advancement of mobile phones and tablets has made it possible for these technologies to provide population-based, self-management interventions (i.e., reach wide audiences at little cost) [11]. Sixty-three percent of survey respondents with traumatic SCI identified 'internet-based' self-management programs as the best means of delivery (compared to in-person at 30% and a series of DVDs at 7%), and a similar proportion also felt that the program should address the transition from rehabilitation to the community [6]. However, challenges exist with the adoption of mHealth interventions by healthcare professionals and patients [12].

To facilitate the uptake of mHealth interventions, an iterative, user-centered design process has been recommended, which involves key stakeholders at all phases of product development (i.e., prototyping, testing, analyzing and refining a product) [12]. Therefore, a study was undertaken to describe stakeholder perspectives on the development of a functional mobile app to facilitate the self-management skills needed to prevent secondary complications following recent SCI during inpatient rehabilitation.

Methods

This study employed a user-centered design process [13] that involved on-going input and feedback from participants, which was solicited via focus groups, one-on-one interviews, and post-discharge exit questionnaires at three phases throughout the study. Ethical approval was obtained from the University of British Columbia's Behavioral Research Ethics Board and the Vancouver Coastal Health Research Institute. The study is reported according to the Standards for Reporting Qualitative Research guidelines [14].

User-centered design approach

A user-centered design approach to development that followed the International Organization of Standardization's Part 210 of ISO 9241 was implemented in this study (Table 1). Part 210 of ISO 9241 is a four-phase model for iterative, user-centered design [15]. Phase 1 of Part 210 involves understanding and specifying the context of use for our mobile app. During the first focus group session with formal caregivers, a presentation was given that outlined how a mobile app is being developed specifically for rehabilitation inpatients with SCI. Pictures of a mobile app prototype with three examples of general health tools was also presented to give participants a basic understanding of our technology. Phase 2 of Part 210 involves specifying the usage requirements [15]. During each of the three phases of focus groups, formal caregivers provided feedback on the types of general and SCI-specific tools that should be incorporated into the app. Furthermore, needs assessment research conducted by Munce and colleagues on the self-management needs of individuals with SCI was drawn upon at this phase [6]. Phase 3 of Part 210 involves developing design solutions. After each of the three phase of focus groups, SCI-specific health tools were developed based on formal caregivers' feedback and input [15]. Patient and informal caregiver participants were also involved at this stage as they provided additional design recommendations. Phase 4 of Part 210 involves evaluating design solutions against usage requirements [15]. Formal caregivers, informal caregivers, and patients had the opportunity to test the tools they recommended in the app so that they could be further refined during

Table 1 Data collection timeline throughout various phases of iterative development of the mobile self-management app (α = Phases 1/2 of ISO 9241; β = Phases 3/4 of ISO 9241)

Item	2015			2016			
	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Focus Groups	α			β			β
One-on-one Interviews		β	β	β	β	β	β
Exit Questionnaires		β	β	β	β	β	β

development. Since this paper focuses on the development of the mobile app rather than usability testing, usability results are not reported and only the first three phases of Part 210 of ISO 9241 are reported on.

Qualitative approach

A qualitative descriptive approach was taken in this study. This approach seeks to gain a rich description of participant experience about a phenomenon of which little is known [16]. Two key components of the qualitative descriptive approach are (1) learning from participants and their rich descriptions, and (2) applying their knowledge towards an intervention [17]. For this study, a qualitative descriptive approach was used to gain detailed feedback on mobile app design recommendations and apply them towards the iterative development of the mobile self-management app.

Setting

This research was undertaken at a Canadian, in-patient, rehabilitation center. The facility has approximately 68 beds, and provides inpatient and outpatient services to individuals with SCI.

Participants

Three types of participants were recruited for the study: individuals admitted for rehabilitation following traumatic or non-traumatic SCI, informal caregivers, and formal caregivers. To be included in the study, patients needed to be 12 years of age or older, be receiving inpatient rehabilitation for their first SCI, provide their own consent or assent with the consent of a parent or guardian, and communicate in English. Patients who had had a co-morbid diagnosis of traumatic brain injury or other cognitive impairments were excluded from the study.

The unit where the study was conducted had previously admitted adolescents between 12 and 18 years of age; however, none were admitted during the time of the study. As a result, no adolescent participants were recruited in this study. Informal caregivers needed to be friends or family members of patients enrolled in the study, 19 years of age or older, and fluent in English. Formal caregivers (e.g., physiatrists, physiotherapists, occupational therapists, etc.,) were invited to participate if they were employees of the local rehabilitation center, 19 years of age or older, fluent in English, and experienced in providing services to patients with SCI. All participants provided informed consent.

Data collection

Three main methods of data collection were developed by the research team: focus groups, one-on-one interviews, and exit questionnaires (Table 1). The purpose of all three methods of data collection was to gather participants' (stakeholders') thoughts and impressions of the app throughout its development in order to develop a functional mobile self-management app in the inpatient rehabilitation setting (Fig. 1). Rehab inpatients and informal caregiver participants had the opportunity to use the mobile app and shared their experiences and design recommendations for the mobile app throughout the development process. Formal caregivers provided feedback on design changes in the app based on their professional experiences and training. A multi-methods approach to data collection was taken to provide each group of participants (individuals with

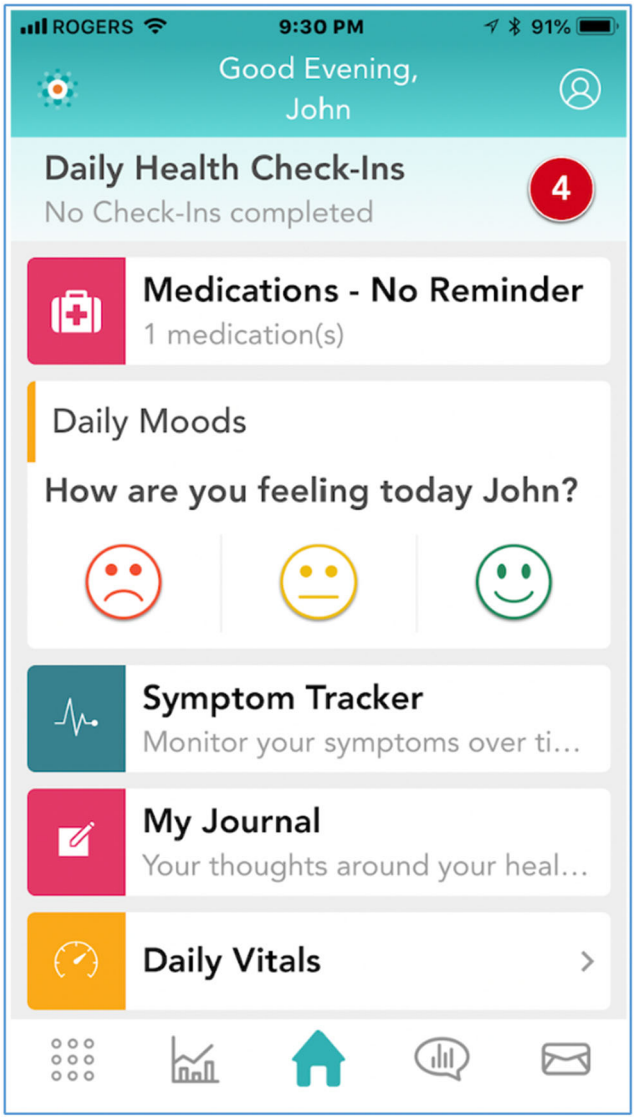

Fig. 1 *SCI Health Storylines*™ mobile self-management app on the Apple iOS© platform. The app was developed based on an existing platform that included a variety of general health tools (e.g., medication tracker, appointment calendar etc.,). To facilitate self-management skill development for patients with SCI, SCI-specific tools were developed (e.g., SCI goal-setting tool, bowel and bladder tracker, spasticity tracker, etc.,). To encourage health lifestyle change, tools such as a nutritional planner and a recreational resources tool were also developed

SCI, formal caregivers, and informal caregivers) with a different medium to provide qualitative feedback on the development of the mobile app.

Focus groups

All three focus groups phases occurred at the rehabilitation center and were audio recorded. Immediately prior to the start of the first focus group phase, formal caregivers were given a 10-min presentation of the overall study, its goals, and were presented with a prototype of the mobile with no SCI-specific health tools developed. During the next two focus-group phases, participants were presented with a demonstration of new and improved features of the app and asked about their impressions and design recommendations. Examples of questions that were asked during focus groups included:

What do you like about the mobile app?

What would you like to have added or changed?

How can we facilitate using this in clinical practice with future patients?

A minimum of two co-investigators (faculty members) and one research coordinator attended each focus group. Upon completion of each focus group, audio recordings were transcribed, and any names or personal identifiers were removed from the transcripts. Focus groups ranged in size from 3 to 12 participants.

One-on-one interviews

One-on-one interviews with informal caregivers took place at the local rehabilitation center. Examples of questions that were asked during one-on-one interviews included:

Did you find the mobile app burdensome to use? Please explain.

Do you feel that your friend or relative has had a positive experience using the mobile app? Why or why not?

Interviews were conducted by a research assistant (fourth author) who wrote detailed notes about participants' responses. No prior interaction existed between the research assistant and participants.

Post-discharge exit questionnaire

Newly-admitted rehabilitation inpatients with SCI were presented with a prototype of a mobile self-management app that they used on their smartphones or tablets. Three months post-discharge from inpatient rehabilitation, participants completed post-discharge exit questionnaires about their overall impressions and thoughts of the app. In keeping with the tenets of iterative design, patients were recruited to use the mobile app as it was being developed. This resulted in some patients having access to the apps during initial phases of development and others having access in later phases. Examples of questions in exit questionnaires included:

Did you find the app burdensome to use? Why?

What was your most/least favorite app tool? Why?

How would you improve the mobile app? What features would you add or remove? Why?

For data collection, qualitative description accommodates the use of a variety of data collection methods, such as semi-structured interviews, focus groups, and questionnaires [18]. In this regard we collected qualitative data during focus groups with formal caregivers, exit questionnaires with rehabilitation inpatients, interviews with informal caregivers, since each of these approaches to data collection is gathering participant experience on the same phenomena (the mobile self-management app) [18].

Recent guidelines for categorizing participant recruitment based on the size of the research project state that for small projects 6 to 10 participants are recommended for one-on-one interviews and groups of 6 to 10 participants are recommended per focus group [19]. Since a series of three focus group phases with two rounds of focus groups in each phase were done with formal caregivers, a greater total number of formal caregivers (n = 48) were recruited in the study (Table 2). A sample size of 7 informal caregivers was achieved for the one-on-one interviews via consecutive sampling. For the post-discharge exit questionnaires, a consecutive sample of patients with SCI was recruited until a desired sample size of 20 was achieved. This sample size was selected in light of the development nature of the study and resources available. Furthermore, previous similar studies employing iterative design in the development of mHealth apps have recruited between 12 and 20 end-users [20–22].

Analysis

Data were analyzed thematically in NVivo 10 (QRS International, Victoria, Australia) according to the five-step inductive process outlined by Braun and Clark [23]. In step one, transcripts were repeatedly read to increase familiarity and to generate initial ideas. In step two, initial codes were developed independently by the second

Table 2 This table includes demographic data of formal caregivers that participated in focus group sessions ($n = 48$), informal caregivers that participated in one-on-one interviews ($n = 7$), and patients with spinal cord injury that completed the post-discharge exit questionnaires ($n = 20$)

Focus Groups with Formal Caregivers (n = 48)		One-on-One Interviews with Informal Caregivers (n = 7)		Exit Questionnaires with Inpatients with SCI (n = 20)	
Age (%)		Age (%)		Age (%)	
19–30	15	19–30	14	19–30	45
31–40	35	31–40	43	31–40	5
41–50	25	41–50	29	41–50	20
51–60	23	51–60	14	51–60	10
61+	2	61+	0	61+	20
Gender (%)		Gender (%)		Gender (%)	
Male	4	Male	14	Male	85
Female	96	Female	86	Female	15
Profession (%)		Relationship to Patient (%)		Injury type (%)	
Physiotherapist	44	Friend	14	Traumatic	75
Occupational Therapist	8	Parent	14	Non-traumatic	25
Social Worker	10	Sibling	29	Para vs. Tetra (%)	
Physician	4	Spouse	43	Paraplegia	25
Registered Nurse	8	Partner	0	Tetraplegia	75
Nurse Aide	2	Other	0	AIS Score (%)	
Personal Care Aide	2			A	40
Rehab Assistant	4			B	25
Educator	6			C	30
Recreational Therapist	8			D	5
Dietician	2			E	0
Use Mobile Health Apps (%)		Use Mobile Health Apps (%)		Level of Injury (%)	
Yes	29	Yes	86	Cervical	75
No	69	No	14	Thoracic	20
No Response	2	No Response	2	Lumbar	5

author by performing preliminary coding of the first six of nine focus group transcripts. Based on discussion among the first three authors, a coding guide was developed, which included twenty-seven unique codes that was applied to all the transcripts. In step three, codes were grouped together to form initial sub-themes, and ultimately, overarching broader themes. A mind-map was used to facilitate this process. In step four, provisional themes were refined by a two-level review process: (1) comparing themes with coded data and (2) checking that themes related to the entire data set. In step five, themes were defined and reflected upon to see the overall story they told about the data.

This study employed a variety of trustworthiness strategies including data triangulation, peer debriefing, and reflexivity. Having multiple investigators independently code the transcripts acted as a form of investigator triangulation. Collecting focus group data in three phases allowed for triangulation of data sources and repeated uses of methods over time. Peer debriefing was carried out by consulting within the research team, which facilitated reflection on the emerging analysis and research results. Interview notes and memos served as tools to detail the analytic process and facilitate reflexivity.

Results

The analysis identified three overarching themes regarding the development of a mobile app to assist self-management following SCI. These themes include: (1) being individualized and user-friendly, (2) targeting goals to promote self-management, and (3) improving participation and gaining support to facilitate lifestyle change. Participants were labelled and identified using a coding system consisting of a sub-group identifier (Formal Caregiver = FC; Informal Caregiver = IC; Patient with SCI = PP) and a participant number (i.e., 1, 2, 3, etc.,).

Being individualized and user-friendly

Participants identified the importance of developing a mobile app that had a simple design and was accessible to facilitate universal user uptake. For example, a nurse (FC12) indicated

that the app needed to be "user friendly [and] useful at providing the information in a lot of different ways." Some patients appreciated the variety of tools provided within the app that addressed several patient self-management needs. A young male adult patient with tetraplegia (PP6) stated:

> There [are] enough different tools in [the app] and each person can use related tools for themselves… For example, for me, the spasticity tool was useful [during inpatient rehabilitation] but when I go home now, the medication tool [will be] helpful.

In contrast, other patients felt that tools within the app could be simplified and merged together to reduce clutter and have better visual appeal. For example, a patient with tetraplegia (PP9) stated, "combin[ing] tools related to each other to make [the mobile app] less busy." To provide a simpler design and more user-friendly experience, a scrolling list of tools are displayed on the main user menu of the app (Fig. 2). Formal caregivers discussed the need to provide flexibility in the tools within the app so that they were tailored to patients' individual needs:

> I think [patients should] pick and choose [tools], because if there [are] too many, they could get overwhelmed. Especially the older patients. If the [tools] that they need are there, and nothing else is, then I think they'll use it more. Or they'll be able to track it easier. – Nurse (FC42)

Similar views were also expressed by 4 patients with tetraplegia and 2 patients with paraplegia, who felt that some of the self-management tools provided in the apps "were unnecessary to [their] health needs." As a result, a variety of patient and clinician-recommended SCI-specific tools were incorporated into the app to provide greater accessibility to meet the various different health needs of individuals with SCI (Fig. 2). These tools were iteratively added to the mobile app after each of the three focus group phases with additional input taken from informal caregivers and patients. Examples of SCI-specific tools include a water intake tracker, pain tracker, bowel movement tracker, and a bladder tracker.

Being able to self-monitor changes in health outcomes and observe overall trends was a key educational component to an effective mHealth app identified by formal caregivers.

> I think that being able to see the trends would be [very] educational [for patients…] doing their daily life routine. [For example], it would be interesting [to see] how [emptying of] bowel and bladder relate.
> – Recreational Therapist (FC35)

Formal caregivers indicated it was essential to direct patients towards educational resources as a form of support by making them accessible from within the mobile app rather than overloading them with health information. For example, an occupational therapist (FC10) stated:

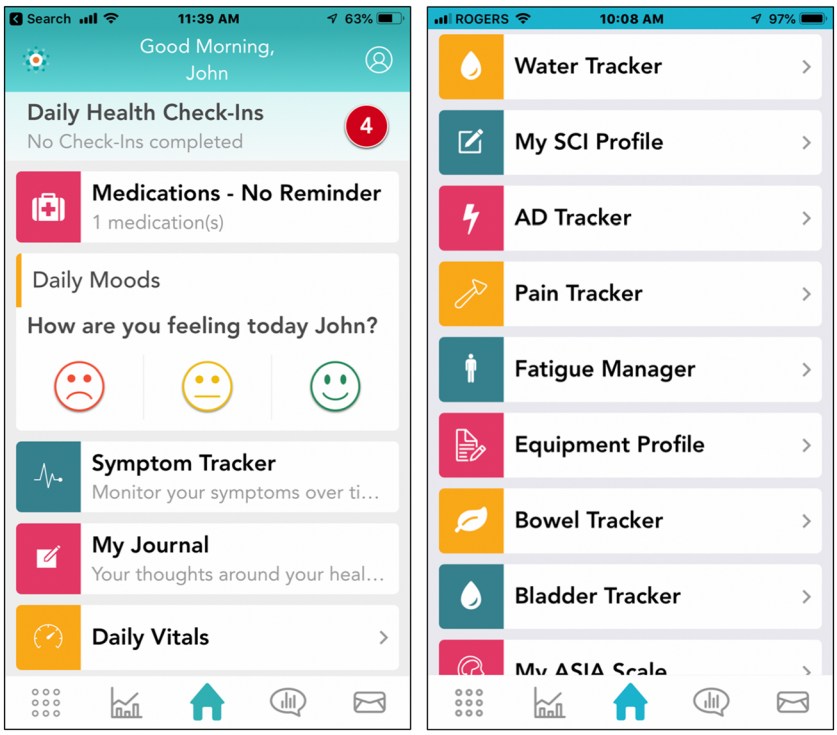

Fig. 2 Changes to the design of the mobile app to include a scrolling list of tools (left) and the inclusion of a variety of SCI-specific tools (right)

> How much is too much information? How do you parse it to give it to people, so… if your routine is taking longer than this amount of time, then maybe you want to seek support in terms of making that or reviewing it rather than "here is all of the information" At least try and give people enough to direct them towards resources and then try to make use of those resources.

Similar views were shared by 3 patients with tetraplegia who felt an information overload would potentially make it difficult to track and understand changes to their health outcomes. To overcome potential barriers related to health literacy and understanding one's personal health data, a health data summary feature was developed for this app (Fig. 3). This feature allows individuals with SCI to monitor and review health status over multiple weeks and outline day-to-day trends between various health outcomes.

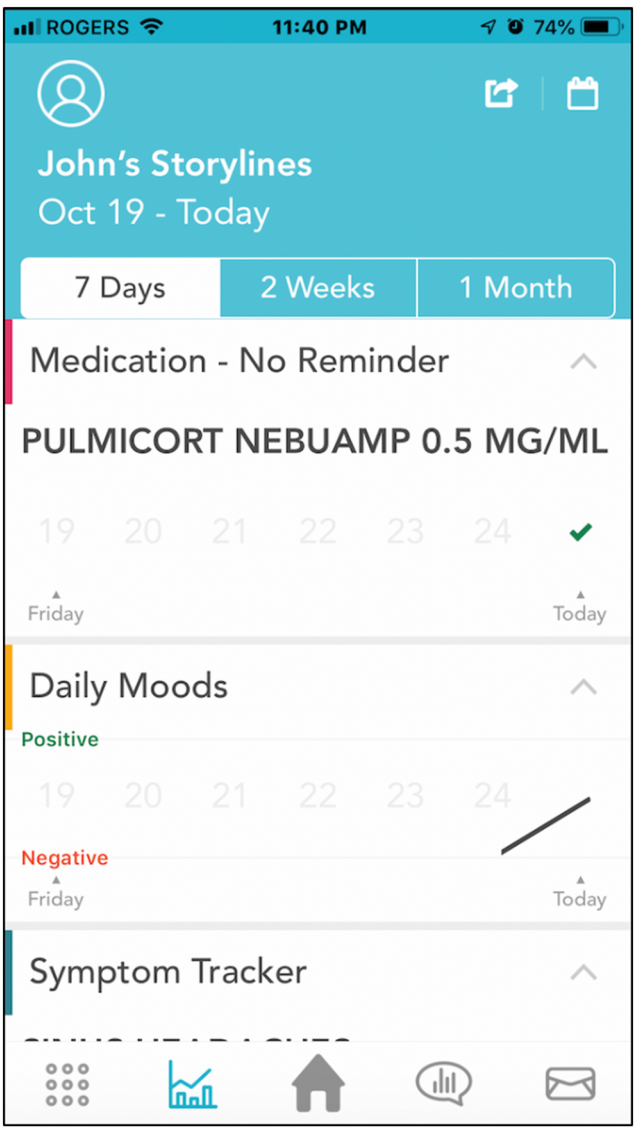

Fig. 3 Inclusion of a health data summary feature

Targeting goals to promote self-management

Participants emphasized goal setting as a key component of self-management. For example, an occupational therapist (FC16) stated, "goals are big here. We are always talking about goals, and this [mobile app] is a way to [encourage] people to define their own goals." Formal caregivers felt it was important to incorporate tools that promote goal-setting:

> Making a goal and [planning is critical…] Getting people to learn to write [a goal] down or put it in their phone … posting it where they can see. Reaching out [to them, they'll say to me, "I'll get to it" or "you know my pain is going to be so bad, I know I am not going to go." But I will say to [them], "make the plan" because if you wake up and you feel crummy, you can change the plan but if you don't ever make the plan, then it is just never going to happen. – Physiatrist (FC19)

In addition, formal caregivers emphasized monitoring was a necessary but not sufficient element of self-management, which was needed to facilitate goal identification: "When you are [monitoring] bowel or bladder, you should actually [choose] some goals relative to that [health outcome] within the app, and then the system could help monitor how that is going." Informal caregivers felt that incorporating tools that promote goal-setting could increase autonomy in patients to become more independent and take control over their health outcomes. For example, the spouse of a rehabilitation inpatient (IC4) stated:

> Especially with the [app] in their hands because they are trained and geared to be independent, that they can be their [case] manager by seeing their bowel and bladder and report[ing] back to their family doctor. It is like they are their own case manager.

Similarly, a patient with tetraplegia (FC12) appreciated having the ability to independently stay on top of his health outcomes.

Participants strongly felt that by engaging in goal-setting and planning, patients could identify health problems proactively, encouraging preventative care over curative care. For example, a physiotherapist (FC9) stated, "It's one thing to track retroactively and then another to make plans for improvement or things to change moving forward. Something like that would be a nice solution." Based on experiences from previous mHealth apps, an educator (FC44) suggested incorporating a tool that provides motivational quotes to encourage patients to take more initiative in self-managing their

secondary complications: "It is a core [tool that] gives motivational quotes, it's really minimal in what it does, but I think [this app] should try to incorporate [it]." Likewise, a patient with tetraplegia (FC16) felt that consistent encouragement from family to use the app motivated him to use the app regularly. As a result, goal-setting and confidence tracking (Fig. 4) tools were developed to motivate patients to set short-term and long-term goals for a variety of health outcomes (e.g., pain management, bladder control, etc.,) and potentially facilitate positive behavioral change.

Improving participation and gaining support to facilitate lifestyle change

Participants felt that increasing community participation and support-seeking was an important focus for an app to promote healthy self-management behaviors. Formal caregivers discussed the importance of incorporating tools that promote leisurely pursuits and how these tools can facilitate lifestyle balance. For example, an occupational therapist (FC4) stated:

> Learning to input some meaningful stuff, you know the physical, creative, the social, the intellectual, the spiritual… they can log themselves and see where they are in the balance and their leisure pursuits marry with their work, school, family life, and chores.

A physiotherapist (FC18) described how a tool focused on promoting leisurely pursuits could be incorporated to provide patients with options on the types of activities they can get involved in relative to their individual needs.

> Think along the lines of exercise. They have an incomplete injury … how far are they going, [or] the kind of distance they are travelling. It is a possibility, just giving people options of what types of activities they [can do] during their day as well as looking at some recreational activities that they [can get] involved in.

Formal caregivers also felt it was important to incorporate tools promoting a variety of extra-curricular activities and programs.

Healthcare providers emphasized the importance of providing social support for clients that were previously discharged from inpatient rehabilitation. For example, a recreational therapist (FC06) stated:

> [Social support] would be really important to track for people or to at least get thinking about and aware of too because there are so many clients that come as outpatients later, 2 years later, and they are socially isolated.

Developing tools that promote socialization and gaining support to reduce social isolation was an important consideration for formal caregivers. For example, a recreational therapist (FC35) stated:

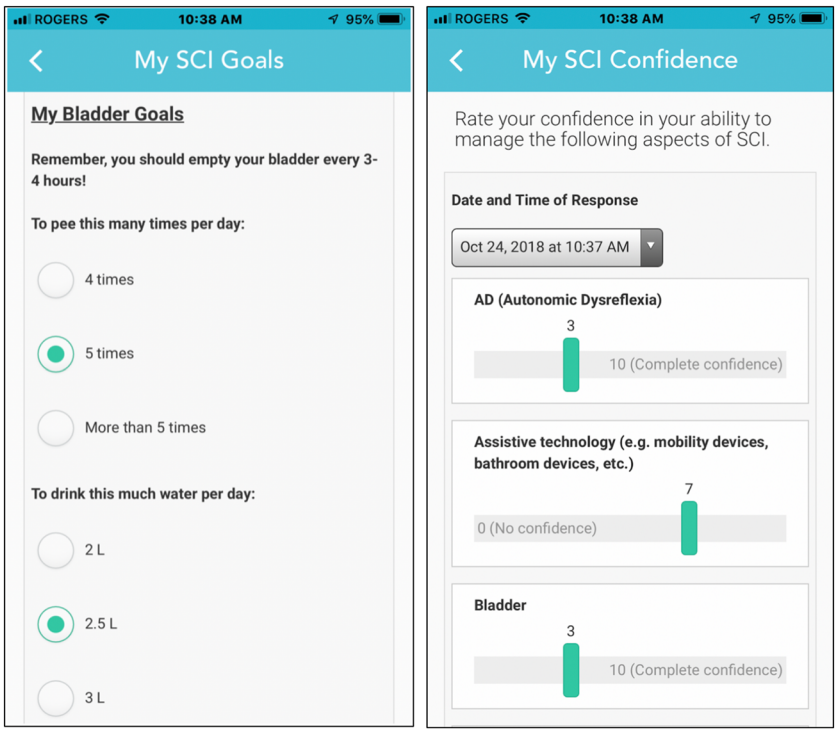

Fig. 4 Inclusion of a goal setting tool (left) a confidence tracking tool (right)

> I think it would be good to have social aspect like how many times have you had social contact in the last week… these are new integrations that are more important for our health, our long-term health.

Formal caregivers felt that incorporating tools that focus on leisure pursuits should strike a balance between patients being able to get out of the house and into the community and connecting socially. Recreational activity journaling and planning (Fig. 5) tools were incorporated into the mobile app to help individuals to identify and target activities within the community that they can engage in.

Discussion

Building on recommendations to develop an internet-based self-management program for individuals with SCI [6], this study used an iterative design approach to develop a novel self-management app. The discussion that follows has been organized based on the three themes that were identified by key stakeholders as important to the development of the app. Visual design changes to the app are also provided based on each theme identified by key stakeholders.

Being individualized and user-friendly

The emphasis on simplicity and flexibility resonates with findings from previous research. For example, a previous study suggested that problems with adoption of mHealth apps are primarily related to poor app architecture and tool design that does not meet the requirements of patients [24]. To facilitate mHealth uptake, it is recommended to develop tools that are perceived as user-friendly and useful to patients' individual health needs [25]. Involvement of stakeholders via iterative design has also been suggested as a way of increasing commitment, trust, and a positive attitude towards eHealth technologies [12]. A recent qualitative study exploring the use of a user-centered model in designing mHealth apps found that identifying users' health needs can lead to the development of a more functional and accessible mobile app [25]. Furthermore, a study on the development of an mHealth app promoting self-management behavior among cancer patients outlined the importance of taking into consideration the perceptions of users throughout the development process as they are most aware of their own condition [26].

A variety of challenges exists for people to use mHealth data to make health behavior changes. Providing a visual representation or trend of their personal health outcomes may be important for patients to be able to attribute meaning to data entered into a mobile app and, if necessary, become aware of the need to make health behavior changes. According to a recent survey, only 12% of US adults demonstrate proficient

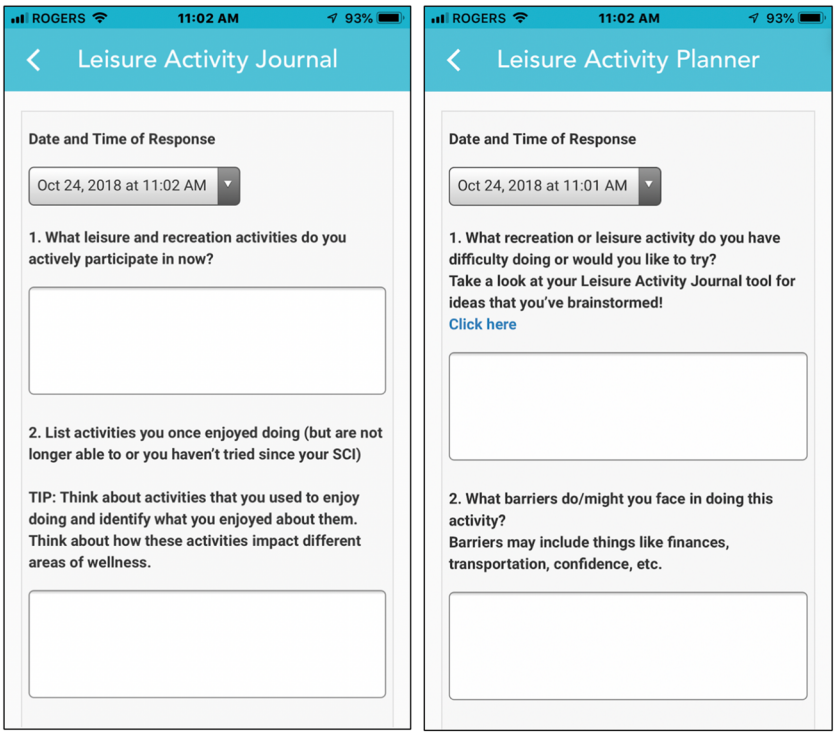

Fig. 5 Development of a recreational activity planning tool (left) and a recreational activity journaling tool (right)

health literacy–one's capacity to obtain, process, and understand basic health information required to make important health decisions [27]. Issues with health literacy may make it difficult for patients to interpret data that are not provided in an easy-to-read format. A lack of proficient health literacy in adult populations can be further exacerbated by incompetent digital literacy skills, or inability to properly utilize internet and mobile devices [28]. These barriers can make it difficult for patients with SCI to understand personal health data and be in a position to effectively self-manage their health, highlighting the importance of having a user interface that facilitates the intuitive display of behavior tracking data.

Targeting goals to promote self-management

The importance of goal setting in terms of health and wellness tracking, as emphasized by participants, is congruent with findings from previous studies. Setting daily and weekly goals in order to increase discipline and facilitate behavior change was recommended by participants in a study of users' perceptions of mHealth apps [29]. In order to encourage patients to develop a habit of setting weekly and monthly goals, a goal setting tool was incorporated into the app. Goal specificity has been identified as a strong predictor of goal achievement in asthma self-management [30]. Identifying specific goals may provide individuals with a clear target to strive towards, whereas general goals that are poorly described are unlikely to motivate or self-encourage behavioral change [31]. It has been found that when individuals are engaged in a behavior that provides a just-right challenge, they are more likely to repeat that behavior [32].

Bandura's self-efficacy theory, which indicates successful behavioral change is predicated on one's self-confidence in carrying out an action and desire to achieve a particular goal, supports the importance of goal setting in promoting self-management behavior [33]. Participants in this study shared the view that confidence and motivation are important facilitators to successful behavioral change. In a recent study exploring the views of people with traumatic SCI on the components of a self-management program, approximately 40% of participants indicated that a tool on increasing confidence was "extremely important" [6]. Furthermore, it has been found that maintaining control over one's care is an important facilitator to self-management among individuals with SCI [6].

Improving participation and gaining support to facilitate lifestyle change

Participants' emphasis on incorporating tools that promote engagement in leisurely pursuits and social support are not surprising considering they are essential to increasing community participation and facilitating lifestyle change. Beyond focusing on reducing medical secondary complications, positive self-management behavior can be important for facilitating social participation and improving overall wellbeing as individuals transition from rehabilitation into the community [34]. Challenges experienced by individuals with SCI reintegrating back into the community are partly attributable to limited opportunities for meaningful social participation, including leisure pursuits [35]. A study found that for individuals with SCI, injured at least 10 years prior, participation in sport and recreational activities decreases from 84% pre-injury to 47% post-injury [36]. The most frequently reported reasons for poor participation reported in a recent study, evaluating a community reintegration outpatient program for community-dwelling individuals with SCI, included the lack of opportunity to engage in several indoor and outdoor recreational activities (e.g., sailing, hand cycling, strength training, etc.,) [37]. Findings from the study show that engagement in recreational activities elevates both mood and self-efficacy in people with SCI, underlying the importance of developing tools that promote engagement in leisurely pursuits [38]. There is also evidence that social support (the supportive relationships built around an individual including the support of family, friends, community peers, and formal caregivers) is a key facilitator to the long-term adoption of an mHealth app [39]. Thus, tools that facilitate socialization and support seeking may have the potential to reduce an individual's sense of isolation.

Strengths and limitations

A key strength to this study is that it involved ongoing involvement from a variety of key stakeholders through-out the development process. There are also several limitations to this study. Although efforts were made to probe for negative cases, a social desirability bias may have encouraged participants to focus on more positive experiences with the app. Furthermore, the exploratory nature of the study (e.g., only including participants in inpatient rehabilitation) may limit the transferability of findings. In light of budgetary constraints, we were unable to achieve saturation. Additionally, since interactions with rehabilitation inpatients and informal caregivers were not audio-recorded, limited direct quotes could be reported. Future projects could be pursued to explore the perspectives of community-dwelling individuals with SCI in the iterative development of the app. Furthermore, a similar study including participants from a variety of cities, provinces, and countries could provide a broader perspective.

Conclusion

To the authors' knowledge, this is the first in-depth study on the iterative development of a functional mobile app to assist self-management following SCI during inpatient rehabilitation. Involving key stakeholders into the iterative design

process resulted in the emergence of three central themes important to the mobile app's functionality, which include offering a user-friendly app experience, including tools with a goal-setting focus, and encouraging user engagement towards leisure activities. Future research is needed to evaluate the effectiveness of this mobile app in SCI populations. These findings may have long-term implications on the manner in which mHealth self-management interventions are delivered within the inpatient rehabilitation and community settings.

Funding Funding for the research study was provided by the Rick Hansen Institute's 'Emerging Interventions & Innovative Technologies' grant (Grant No. G2015–11). Dr. Mortenson's work was supported by a New Investigator Award from the Canadian Institutes of Health Research.

Compliance with ethical standards

Conflict of interest The authors WBM, GS, MKM, MS, PBM, BJS report no real or perceived conflicts of interest. JA has a conflict of interest as he 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 JA) having no access to any research data, which remained on the University of British Columbia premises. JA was not involved in the analysis of the data, but was involved in reviewing the final draft of the paper.

References

1. Adriaansen JJ, Rujis L, van Koppenhagen C, van Asbeck F, Snoek G, van Kuppevelet D et al (2016) Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. J Rehabil Med 48(10):853–860. https://doi.org/10.2340/16501977-2166
2. Savic G, Charlifue S, Glass C, Soni BM, Gerhart KA, Jamous MA (2010) British ageing with SCI study: changes in physical and psychosocial outcomes over time. Top Spinal Cord Inj Rehabil 15(3):41–53. https://doi.org/10.1310/sci1503-41
3. Barlow J, Wright C, Sheasby J, Tuner A, Hainsworth J (2002) Self-management approaches for people with chronic conditions: a review. Patient Educ Couns 48(1):177–187. https://doi.org/10.1016/S0738-3991(02)00032-0
4. Hirsche RC, Williams B, Jones A, Manns P (2011) Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. Disabil Rehabil 33:1136–1146. https://doi.org/10.3109/09638288.2010.523103
5. McColl MA, Aiken A, McColl A, Sakakibara B, Smith K (2012) Primary care for people with spinal cord injury. Can Fam Physcian 58(11):1207–1216. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3498012/pdf/0581207.pdf. Accessed 10 June 2018
6. Munce SEP, Fehlings MG, Straus SE, Nugaeva N, Jang E, Webster F, Jaglal SB (2014) Views of people with traumatic spinal cord injury about the components of self-management programs and program delivery: a Canadian pilot study. BMC Neurol 14:209. https://doi.org/10.1186/s12883-014-0209-9
7. Cline CM, Israelsson BY, Willenheimer RB, Broms K, Erhardt LR (1998) Cost effective management program for heart failure reduces hospitalization. Heart 80(5):442–446. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1728835/pdf/v080p00442.pdf. Accessed 12 June 2018
8. Hernon MJ, Hall AM, O'Mahony JF, Normand C, Hurley DA (2017) Systematic review of costs and effects of self-management interventions for chronic musculoskeletal pain: spotlight on analytic perspective and outcomes assessment. Phys Ther 97(10):998–1019. https://doi.org/10.1093/ptj/pzx073
9. Jerant AF, von Frieerichs-Fitzwater MM, Moore M (2005) Patients' perceived barriers to active self-management of chronic conditions. Patient Educ Couns 57(3):300–307. https://doi.org/10.1016/j.pec.2004.08.004
10. Gill PS, Kamath A, Gill TS (2012) Distraction: an assessment of smartphone usage in health care work settings. Risk Manag Healthc Policy 5:105–114. https://doi.org/10.2147/rhmp.s34813
11. Lewis TL, Boissaud-Cooke MA, Aungst TD, Eysenbach G (2014) Consensus on use of the term "app" versus "application" for reporting of mHealth research. J Med Internet Res 16(7):e174. https://doi.org/10.2196/jmir.3460
12. van Gemert-Pignen J, Nijland N, van Limburg M, Ossebaard H, Kelders S, Eysenbach G et al (2011) A holistic framework to improve the uptake and impact of eHealth technologies. J Med Internet Res 13(4):1–19. https://doi.org/10.2196/jmir.1672
13. Sanchez J, Canton MP (2012). Embedded systems circuits and programming. Boca Raton: Taylor & Francis Group
14. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA (2014) Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 89(9):1245–1251. https://doi.org/10.1097/acm.0000000000000388
15. ISO FDIS 9241-10 (2009) Ergonomics of human system interaction – Part 210: Human-centered design for interactive systems. Geneva: International Organization for Standardization
16. Sandelowski M (2000) Whatever happened to qualitative description? Res Nurs Health 23:334–340. https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
17. Sullivan-Bolyai S, Bova C, Harper D (2005) Developing and refining interventions in persons with health disparities: the use of qualitative description. Nurs Outlook 53(3):127–133. https://doi.org/10.1016/j.outlook.2005.03.005
18. Colorafi KJ, Evans B (2016) Qualitative description methods in health science research. HERD 9(4):16–25. https://doi.org/10.1177/1937586715614171
19. Braun V, Clarke V (2013) Successful qualitative research: a practical guide for beginners. London: Sage
20. Gabrielli S, Dianti M, Maimone R, Betta M, Filippi L, Ghezzi M, Forti S (2017) Design of a mobile app for nutrition education (TreC-LifeStyle) and formative evaluation wiith families of overweight children. JMIR Mhealth Uhealth 5(4):e48. https://doi.org/10.2196/mhealth.7080
21. Lyles CR, Altschuler A, Chawla N, Kowalski C, McQuillan D, Bayliss E, Heisler M, Grant RW (2016) User-centered design of a tablet waiting room tool for complex patients to prioritize discussion topics for primary care visits. JMIR Mhealth Uhealth 4(3):e108. https://doi.org/10.2196/mhealth.6187
22. Castensøe-Seidenfaden P, Reventlov Husted G, Teilmann G, Hommel E, Olsen BS, Kensing F (2017) Designing a self-management app for young people with type 1 diabetes: methodological challenges, experiences, and recommendations. JMIR Mhealth Uhealth 5(10):e124. https://doi.org/10.2196/mhealth.8137
23. Braun V, Clarke V (2006) Using thematic analysis in psychology. Qual Res Psychol 3(2):77–101. https://doi.org/10.1191/1478088706qp063oa
24. Davis FD (1989) Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Quarterly 13(3):319–340. https://doi.org/10.2307/249008

25. Schnall R, Rojas M, Bakken S, Brown W, Carballo-Dieguez A, CarryM et al (2016) A user-centered model for designing consumer mobile health (mHealth) applications (apps). J Biomed Inform 60: 243–251. https://doi.org/10.1016/j.jbi.2016.02.002
26. Gibson F, Aldiss S, Taylor RM, Maguire R, Kearney N (2009) Involving health professionals in the development of an advanced symptom management system for young people: the ASyMS©-YG study. Eur J Oncol Nurs 13(3):187–192. https://doi.org/10.1016/j.ejon.2009.03.004
27. Kutner M, Greenberg E, Jin Y, Boyle B, Hsu YC, Dunleavy E (2007) Literacy in everyday life: results from the 2003 national assessment of adult literacy. Available from: http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2007480. Accessed 19 Oct 2018
28. Morris L, Bower K (2016) Digital literacy is health literacy. Leeds: Leeds Beckett University. Available from: https://ojs.leedsbeckett.ac.uk/index.php/COL/article/view/4419/4264. Accessed 21 October 2018
29. Peng W, Kanthawala S, Yuan S, Hussain SA (2016) A qualitative study of user perceptions of mobile health apps. BMC Public Health 16(1158):1–11. https://doi.org/10.1186/s12889-016-3808-0
30. Smith L, Alles C, Lemay K, Reddel H, Saini B, Bosnic-Anticevich S, Emmerton L, Stewart K, Burton D, Krass I, Armour C (2013) The contribution of goal specificity to goal achievement in collaborative goal setting for the management of asthma. Res Soc Adm Pharm 9(6):918–929. https://doi.org/10.1016/j.sapharm.2013.02.002
31. Walker ER, Wexler B, Dilorio C, Escoffery C, McCarty F, Yeager KA (2009) Content and characteristics of goals created during a self-management intervention for people with epilepsy. J Neurosci Nurs 41:312–321. https://doi.org/10.1097/JNN.0b013e3181b6bec5
32. Robeiro KL, Polgar JM (1999) Enabling occupational performance: optimal experiences in therapy. Can J Occup Ther 66(1):14–22. https://doi.org/10.1177/000841749906600102
33. Bandura A (2004) Health promotion by social cognitive means. Health Educ Behab 31(2):142–164. https://doi.org/10.1177/1090198104263660
34. Tonack M, Hitzig SL, Craven BC, Campbell KA, Boschen KA, McGillivray CF (2008) Predicting life satisfaction after spinal cord injury in a Canadian sample. Spinal Cord 46(5):380–385. https://doi.org/10.1038/sj.sc.3102088
35. Corrigan JD (1994) Community integration following traumatic brain injury. NeuroRehabil 4(2):109–121. https://doi.org/10.3233/NRE-1994-4207
36. Tasiemski T, Bergstrom E, Savic G, Gardner BP (2000) Sports, recreation and employment following spinal cord injury – a pilot study. Spinal Cord 38:173–184. https://doi.org/10.1038/sj.sc.3100981
37. Zinman A, Digout N, Bain P, Haycock S, Hebert D, Hitzig S (2014) Evaluation of a community reintegration outpatient program service for community-dwelling persons with spinal cord injury. Rehabil Res Pract 2014:1–14. https://doi.org/10.1155/2014/989025
38. Ong WM, Chua SS, Ng CJ (2014) Barriers and facilitators to self-monitoring of blood glucose in people with type 2 diabetes using insulin: a qualitative study. Patient Prefer Adherence 8:237–246. https://doi.org/10.2147/ppa.S57567
39. Bair MJ, Matthias MS, Nyland KA, Huffman MA, Stubbs DL, Kroenke K et al (2009) Barriers and facilitators to chronic pain self-management: a qualitative study of primary care patients with comorbid musculoskeletal pain and depression. Pain Med 10(7): 1280–1290. https://doi.org/10.1111/j.1526-4637.2009.00707