

*iCanCope with Pain*TM: User-centred design of a web- and mobile-based self-management program for youth with chronic pain based on identified health care needs

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BACKGROUND: While there are emerging web-based self-management programs for children and adolescents with chronic pain, there is currently not an integrated web- and smartphone-based app that specifically addresses the needs of adolescents with chronic pain.

OBJECTIVES: To conduct a needs assessment to inform the development of an online chronic pain self-management program for adolescents, called *iCanCope with Pain*TM.

METHODS: A purposive sample of adolescents (n=23; 14 to 18 years of age) was recruited from two pediatric chronic pain clinics in Ontario. Interdisciplinary health care providers were also recruited from these sites. Three focus groups were conducted with adolescents (n=16) and one with pediatric health care providers (n=7). Individual adolescent interviews were also conducted (n=7).

RESULTS: Qualitative analysis uncovered four major themes: pain impact; barriers to care; pain management strategies; and transition to adult care. Pain impacted social, emotional, physical and role functioning, as well as future goals. Barriers to care were revealed at the health care system, patient and societal levels. Pain management strategies included support systems, and pharmacological, physical and psychological approaches. Transition subthemes were: disconnect between pediatric and adult systems; skills development; parental role; and fear/anxiety. Based on these identified needs, the *iCanCope with Pain*TM architecture will include the core theory-based functionalities of: symptom self-monitoring; personalized goal setting; pain coping skills training; peer-based social support; and chronic pain education.

CONCLUSIONS: The proposed *iCanCope with Pain*TM program aims to address the self-management needs of adolescents with chronic pain by improving access to disease information, strategies to manage symptoms and social support.

Key Words: Adolescent; Chronic pain; E-health; Mobile-health; Needs assessment; Self-management

Chronic pain, commonly defined as any prolonged pain that lasts longer than the expected healing time or any recurrent pain that occurs at least three times over a period of three months, is common among adolescents (1). A recent systematic review of

*iCanCope with Pain*TM : la conception centrée sur l'utilisateur d'un programme d'autogestion sur Internet et téléphones intelligents pour les jeunes atteints de douleurs chroniques, conçu d'après leurs besoins de santé

HISTORIQUE : Des programmes d'autogestion émergent sur Internet pour les enfants et les adolescents ayant des maladies chroniques, mais aucune application intégrée pour Internet et téléphones intelligents ne porte expressément sur les besoins des adolescents atteints de maladies chroniques.

OBJECTIFS : Effectuer une évaluation des besoins pour étayer la création d'un programme d'autogestion pour les adolescents, appelé *iCanCope with Pain*TM.

MÉTHODOLOGIE : Les chercheurs ont recruté un échantillon choisi d'adolescents (n=23; 14 à 18 ans) dans deux cliniques pédiatriques de douleur chronique de l'Ontario. Ils y ont également recruté des dispensateurs de soins interdisciplinaires. Trois groupes de travail ont été organisés avec des adolescents (n=16) et un avec des dispensateurs de soins pédiatriques (n=7). Des entrevues individuelles ont également été organisées avec des adolescents (n=7).

RÉSULTATS : L'analyse qualitative a révélé quatre grands thèmes : les répercussions de la douleur, les obstacles à la douleur, les stratégies de gestion de la douleur et une transition vers les soins pour adultes. La douleur influait sur le fonctionnement social, affectif, physique et sur le rôle, ainsi que sur les futurs objectifs. Des obstacles aux soins ont été révélés au sein du système de santé, chez les patients et dans la société. Les stratégies de gestion de la douleur incluaient des systèmes de soutien ainsi que des approches pharmacologiques, physiques et psychologiques. Les sous-thèmes de la transition s'établissaient comme suit : un décalage entre les systèmes pédiatriques et pour adultes, l'acquisition d'habiletés, le rôle des parents et la peur ou l'anxiété. D'après ces besoins, l'architecture du programme *iCanCope with Pain*TM inclura les principales fonctionnalités théoriques suivantes : autogestion des symptômes, établissement personnalisé d'objectifs, formation aux habiletés d'adaptation à la douleur, soutien social auprès des camarades et éducation à la douleur chronique.

CONCLUSIONS : Le programme *iCanCope with Pain*TM proposé vise à répondre aux besoins d'autogestion des adolescents vis-à-vis de la douleur chronique, en améliorant l'accès à l'information sur la maladie, aux stratégies pour gérer les symptômes et au soutien social.

population-based studies reported prevalence rates ranging from 8% to 38% (2). It is estimated that 5% to 8% of these young individuals will develop severe pain-related disability (3), and a significant proportion will continue to experience chronic pain into adulthood (4,5).

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In addition to its high prevalence, chronic pain in adolescents must be considered within the context of a developmental trajectory that is the result of a “dynamic integration of biological processes, psychological factors, and socio-cultural factors” (6). Specifically, as “emerging adults” between childhood and adulthood, adolescents face a challenging transition with respect to developmental tasks (eg, independence from caregivers), social development (eg, peer relationships) and health care systems (eg, transition from pediatric to adult services, a process that usually begins at 15 years of age, with formal transfer typically occurring at 18 years of age) (7-9). Importantly, this developmental period also provides a key window of opportunity for young people to develop and practice positive health behaviours to improve their functioning and prevent future pain-related disability (3-5).

Self-management has been defined as “the interaction of health behaviours and related processes that patients and families engage in to care for a chronic condition” (10). Self-management interventions for chronic pain that provide individuals with a combination of disease-specific knowledge, strategies to cope with symptoms (eg, cognitive behavioural therapies) and social support have been associated with improvements in pain and functioning (11,12). However, the integration of chronic pain self-management into routine care has been slow, and the majority of adolescents never receive the comprehensive pain education or coping skills training required to promote disease self-management and transition care (13,14). Historically, barriers to accessing self-management therapy have included: poor accessibility (eg, no services available in many geographic areas and/or long wait times); limited availability of trained professionals (eg, psychologists), particularly in nonurban centres; and costs associated with treatment (eg, expense of cognitive behavioural therapies, time off school and work) (13-15). Considerable progress is being made to improve the accessibility and availability of self-management therapies using virtual delivery methods such as web and mobile technologies (16-28). These online interventions are based on effective face-to-face self-management therapies and are usually highly structured, interactive and self-guided. Research indicates that virtual delivery of therapy can dramatically reduce geographical and funding constraints as well as provide 24 h access to disease information and pain coping strategies (17,29). There is also growing evidence that virtually delivered self-management interventions are as effective as face-to-face therapies (22,30).

Until very recently, computers and rudimentary web-enabled cell phones have been the primary means of delivering psychological therapies for pain (22,26,29,31-33). However, the emergence of smartphones has created new opportunities for innovation by increasing point-of-care delivery of health care interventions. Whereas primary and tertiary care for chronic pain was once strictly limited to medical environments and clinician-guided telehealth, smartphones can make health care accessible in almost any setting (34).

Smartphones are particularly valuable for delivering self-management therapy because they can help patients to assume greater responsibility for managing their condition from outside the health care system, at their own convenience. Given that adolescents are among the most active users of this technology, smartphones can also provide a socially acceptable and normalizing medium of delivering care to this population. There are a growing number of smartphone applications (‘apps’) designed to promote pain self-management. However, recent reviews (33,35) have demonstrated that currently available pain apps are characterized by a lack of integrated and comprehensive content; involvement of health care professionals and patients in their development; foundation in current research or behavioural theories; and formal evaluation of impact on health outcomes.

Thus, while there are emerging web-based self-management programs for children and adolescents with chronic pain (36,37), to our knowledge there is not one integrated web- and smartphone-based app that specifically addresses the needs of adolescents with chronic pain.

The purpose of the present study was to conduct a user-centred needs assessment to inform the development of an integrated web- and smartphone-based self-management program for adolescents with chronic pain, called *iCanCope with Pain™*. In the context of this needs assessment, specific objectives included:

- To broadly survey the experiences and health care needs of adolescents with chronic pain from the perspective of adolescents and their health care providers (HCPs) through focus group interviews.
- To design core architecture for *iCanCope with Pain™* based on the user needs identified during initial focus groups as well as current theories for pain self-management.
- To determine acceptability and perceived value of the proposed *iCanCope with Pain™* architecture from the perspective of adolescents with chronic pain through individual semistructured interviews.

METHODS

Study design

The study of adolescents with the experience of living with and managing chronic pain to inform the design of a tailored self-management program lends itself to a qualitative design (38). A descriptive exploratory qualitative design, as described by Sandelowski (39), was implemented from 2010 to 2012. This study design yields a descriptive summary of the informational content of data, which is presented in everyday language (39).

- Separate focus-group interviews were conducted with adolescents as well as HCPs who work in chronic pain to capitalize on shared interaction within each group of participants (eg, building ideas through discussion and communication of personal experiences) (40). Three focus groups were conducted with adolescents and one focus group was conducted with HCPs.
- A proposed architecture for *iCanCope with Pain™* was developed based on the initial interviews as well as current theories for pain self-management. Specifically, a comprehensive wireframe for the program was developed using online software (Cacoo) (41).
- Individual interviews were conducted with a new sample of adolescents to explore emergent themes from the initial focus groups and to collect in-depth data regarding the *iCanCope with Pain™* program. Specifically, the proposed architecture was presented to adolescents to collect feedback on the acceptability and perceived value of the core features.

Participant recruitment strategy

Participants were recruited from two large metropolitan university-affiliated pediatric tertiary care chronic pain clinics in Ontario. Patients referred to these clinics included individuals with chronic pain lasting >3 months that has shown poor clinical response to conventional pain management therapies. Both clinics use a biopsychosocial approach to pain assessment and management, which includes consideration of psychological factors, social factors and biological processes (42). During a typical clinic appointment, the patient met with the entire health team and underwent a comprehensive assessment, including history of the pain problem, pain-related disability (eg, impact on sleep, mood, school), and current pain management strategies (eg, physical, psychological, pharmacological). Convenience sampling was used, which provided information-rich cases and encompassed the varying needs of a heterogeneous sample of adolescents with different types and durations of chronic pain (38,40). The study was approved by the Research Ethics Board of both participating hospitals.

Site 1: This centre serves metropolitan Toronto and central and northern Ontario. It is staffed by a health team consisting of anesthesiologists, advanced practice nurses, a psychologist, a psychiatrist and physiotherapists.

Site 2: This centre serves regions of Southwestern Ontario. It is staffed by a health team consisting of anesthesiologists, advanced practice nurses, physiotherapists and an occupational therapist.

TABLE 1
Example questions from individual semistructured adolescent interviews

Broad question	Follow-up question(s)
1. What do you think about having a website and smartphone app that could help you to better manage and cope with your chronic pain?	Do you currently use any apps or websites related to chronic pain? If so, what do you find most helpful/least helpful?
2. Do you keep track of your pain symptoms on a regular basis (eg, diary)?	If so, how do you use this information?
3. Would you be interested in tracking your pain symptoms on an app?	What type of information would be most important for you to track and how often? Are there any specific trends that would be important to you?
4. Would you want a function on the app to help you set goals related to your pain?	What sort of goals would you want to make? How could the app help you to reach these goals? Would you want to be able to share your goals with other people, or team up for common goals?
5. Would you be interested in using an online community where you could talk to other young people with chronic pain?	Would you be more or less likely to participate in an online community if it was moderated by a health care professional?
6. Do you ever use your computer, phone, iPod, or other technology to help you deal with pain when it gets really bad? (eg, listening to music, playing games)?	What other coping strategies do you use? What type of resources would you find useful to have in a 'pain coping toolbox'?
7. Are there any important features that are missing from the app or website that could help you to better manage your pain?	Daily tips about how to manage pain as pop-ups?
8. What could motivate or prevent you from using the program on a regular basis?	

Adolescent selection

At Site 1, eligible patients were contacted via telephone and asked to participate in the study. At Site 2, an informational poster in the clinic was used to recruit interested individuals. Adolescents were eligible to participate if they were 14 to 18 years of age, diagnosed with a chronic pain condition by their responsible physician according to their medical chart, undergoing active treatment for their chronic pain, and able to speak and read English. No restrictions were imposed in relation to diagnosis to include a wide range of perspectives from adolescents living with chronic pain. Adolescents were excluded if they had severe cognitive impairments, or major comorbid medical or psychiatric illnesses (eg, severe anxiety disorder) that could preclude their ability to participate in a verbal interview as per their HCP.

HCP selection

HCPs working in the multidisciplinary chronic pain programs at the two pediatric centres were eligible to participate if they had worked in a chronic pain program full-time for at least one year according to self-report, and were able to speak and read English. Trainees were excluded from the study.

Interview protocol

Free and informed written consent was obtained before each interview. Adolescent participants completed brief questionnaires on demographic characteristics, level of use and comfort with computers and the Internet, as well as disease-related information. HCP participants completed a brief questionnaire to document sociodemographic information. Focus groups were scheduled at a mutually convenient time for participants. All interviews (focus groups and individual) were conducted within the hospital sites. The focus groups were facilitated by one team member (MW) who was experienced in conducting focus groups and used interviewing techniques to minimize the power differential between the interviewer and respondents, such as establishing rapport, using developmentally appropriate language, active listening (eg, maintaining eye contact) and relaxed body language (40). The individual interviews were conducted by two team members (CL and LH) who also used the interviewing techniques described above. All interviews (focus group and individual) were audio-recorded and field notes were made during or immediately following the interviews to document the interviewers' impression of participant responses (verbal and nonverbal) to the questions and comfort level with the interviewing process.

A general introductory question was asked followed by broad questions (eg, "What has living with chronic pain been like for you?") and probes (eg, "Can you tell me more about that?") to encourage the

participants to elaborate on their experiences. Interviews were conducted in a semistructured format, following an interview guide created by the research team in which questions were informed by the research literature and clinical experience. The focus group interview guides for adolescents and HCPs were adapted from a previous study conducted by the authors' group (see Stinson et al [43] for full interview guides). Examples of questions used in the individual semistructured adolescent interviews are presented in Table 1.

Statistical analysis

Demographic data were coded and analyzed using SAS version 9.1.3 (SAS Institute, USA) (44) to determine measures of central tendency and the distribution of values for the sample. Interviews were audiotaped and transcribed verbatim. All transcripts were verified against the tapes by one author (MW) and imported into NVivo 8.0 (45), a qualitative software program that helps to organize, code and retrieve data. Field notes taken during the interviews were also transcribed and included in the analytical process. The analysis was conducted independently by four members of the research team (MW, AK, CL, LH). Disagreements (eg, wording of themes) were handled through consensus of all analysts (JS, MW, AK, CL and LH). Qualitative simple content analysis, a dynamic process that summarizes the informational content of data, was used (46,47). Specifically, data for all participants were coded and organized into categories that reflected the emerging themes. The raw data were revisited on a regular basis throughout the analytic process to ensure that the codes and resulting themes were grounded in the data (48). Charts and matrices were used to construct a more unified and integrated understanding of the data as per standard methods (48).

RESULTS

Study participants

Demographic characteristics for the adolescent and HCP sample are summarized in Tables 2 and 3, respectively. All (100%) adolescent participants had a computer at home with Internet access and all reported being 'comfortable' or 'very comfortable' using a computer and the Internet.

Experiences and health care needs of adolescents with chronic pain

Thematic analysis revealed four major themes: pain impact, barriers to care, pain management strategies, and transition from pediatric to adult care. Subthemes were found under each major theme and will be elaborated on below. See Figure 1 for the complete thematic coding scheme.

TABLE 2
Demographic characteristics of the adolescent sample

Characteristic	Adolescents (n=23)
Sex*	
Male	5 (21.7)
Female	17 (73.9)
Current level of education*	
Grade 9	3 (13)
Grade 10	5 (21.7)
Grade 11	4 (17.4)
Grade 12	9 (39.1)
University	1 (4.3)
Type of chronic pain	
Headache	7 (30.4)
Abdominal	5 (21.7)
Widespread	4 (17.4)
Low back	8 (34.8)
Neuropathic	5 (21.7)
Facial	1 (4.3)
Other	11 (47.8)
On medications	19 (82.6)
Type of treatment	
Physiotherapy	13 (56.5)
Psychological therapies	7 (30.4)
Acupuncture	2 (8.7)
Massage	8 (34.8)
Other	4 (17.4)
Duration of pain, months, mean ± SD	49.5±44.5

Data presented as n (%) unless otherwise indicated. *Data for sex and current level of education are missing for one participant

Pain impact:

Physical impact: The physical effects of chronic pain had a major impact according to adolescent and HCP participants, including disruption of sleep and daily activities such as sports and social outings.

Role functioning: Attending school is a developmentally typical and important role for adolescents, and the negative impact of pain on student performance was reported almost unanimously among those interviewed. Participants also described the additional pressures associated with living with pain for a young person. Events such as school tests or having an argument with a parent were described as typical stressors that could negatively impact the ability to cope with chronic pain.

Social and emotional impact: Many adolescents reported the breakdown of peer relationships and the experience of social isolation due to their impaired ability to participate in activities with peers. Another common reason for limited social activity was a perceived lack of peer understanding and empathy. Notably, other adolescents reported the benefits of positive support from peers who wished to help them. The emotional toll of chronic pain was apparent throughout the interviews, with many participants describing the experience of pain-related mood swings and distress. From a HCP perspective, social isolation and a sense of 'being different' were viewed as significant effects of chronic pain. HCP participants also stated that the elusive and long-term nature of chronic pain were additional sources of emotional distress for their patients.

Future: Adolescent participants expressed mixed feelings when asked to think about their future. Some individuals were optimistic and described their "...high hopes for the future". Apprehension and anxiety were also commonly expressed by adolescents, particularly related to how pain would affect their ability to attend postsecondary school, obtain and keep a job, and maintain relationships. Adolescents also expressed concern about the process of disclosing their condition to potential employers. The challenges of securing future employment in the midst of potential absenteeism were echoed by the HCP participants.

TABLE 3
Demographic characteristics of the health care provider sample

Characteristic	Health care provider (n=7)
Type of health care provider	
Physician	2 (28.6)
Registered nurse	2 (28.6)
Physiotherapist	1 (14.3)
Psychologist	1 (14.3)
Psychiatrist	1 (14.3)
Sex	
Female	5 (71.4)
Male	2 (28.6)
Professional experience, years, mean ± SD	26.4±11.3
Chronic pain experience, years, mean ± SD	9.75±7.39
Member of a multidisciplinary team	7 (100)

Data presented as n (%) unless otherwise indicated

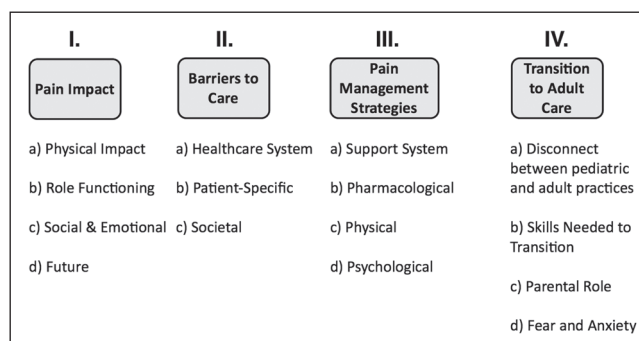


Figure 1) Thematic analysis for adolescent and health care provider interviews

Barriers to care:

Health care system: Although experiences within the health care system varied among adolescents, several common barriers were discussed. Adolescents reported having been "referred around a lot" and going back to the same doctor to obtain referrals. Participants expressed frustration about being referred for psychological care because they perceived their chronic pain to be a physical issue. This mind/body disconnect is a significant barrier to addressing the psychological implications of chronic pain. Adolescents described the challenges of obtaining information from their doctor about what their diagnosis meant, and also highlighted the difficulty of independently finding information about their condition due to outdated and/or unreliable sources on the Internet. HCPs described their own perceived barriers within the health care system, with a particular focus on resource limitations in terms of offering different care options to patients (eg, physical, psychological and peer support therapies).

Patient-specific barriers: Adolescents described the personality and mood changes associated with their pain medications as significant barriers to care. HCPs described the challenges of communicating pain-related education to their patients due to a lack of appropriate written resources as well as the time and energy commitment required by patients to manage their pain.

Societal barriers: A prominent societal barrier was the perceived stigma and discrimination experienced from peers and teachers due to the invisible nature of chronic pain. Others described their experiences of being denied accommodations at school, such as getting into trouble for using the elevator or being penalized for requiring extensions on schoolwork. HCPs echoed these perceived societal barriers.

Pain management strategies:

Support system: Adolescent participants described the value of friendship as a support system to help manage pain. HCP participants also recognized the importance of peer support for their young patients in relation to the need for connection and encouragement.

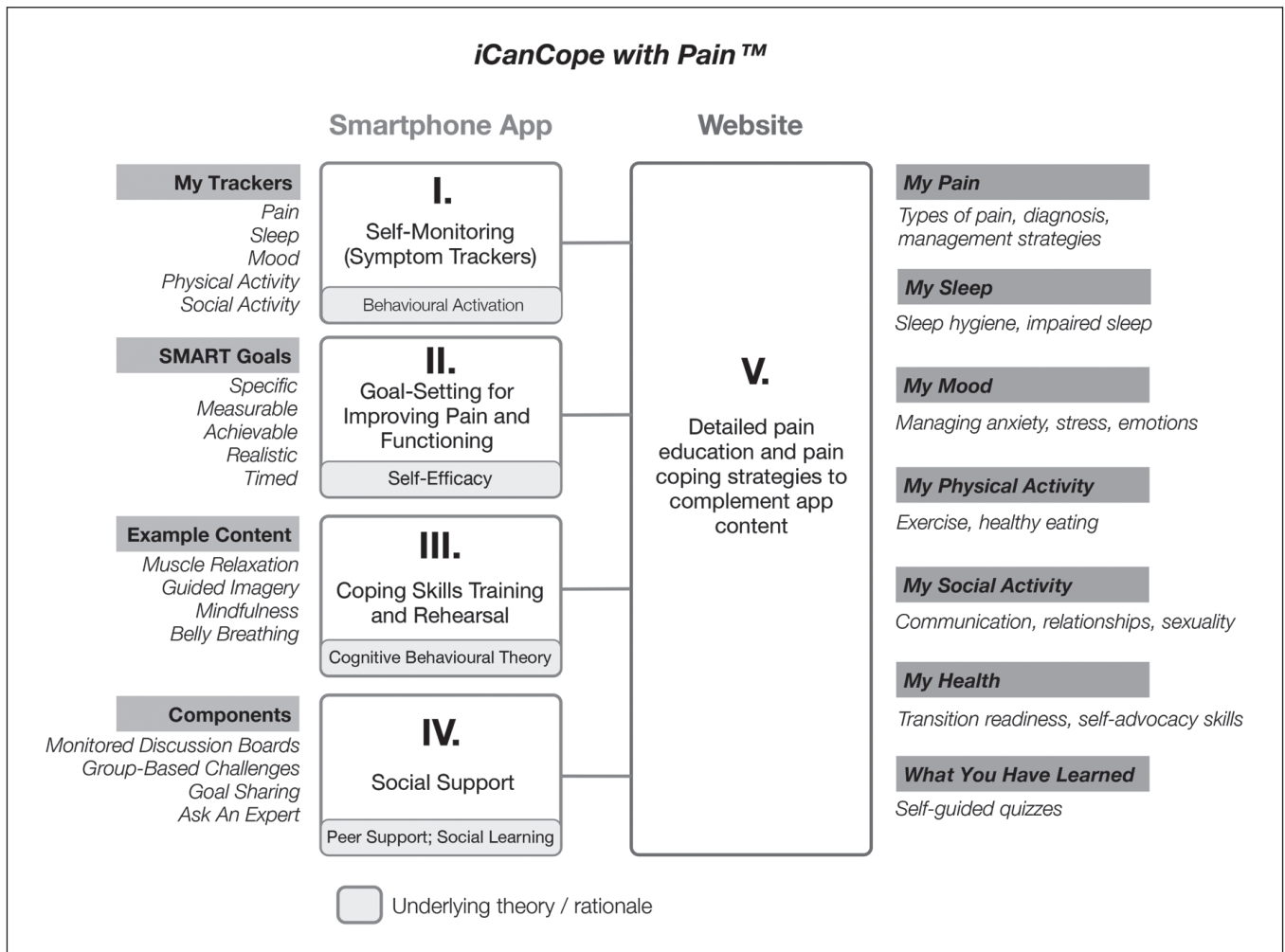


Figure 2) Proposed architecture and underlying theory for iCanCope with Pain™ integrated smartphone and web-based self-management program for youth with chronic pain

Pharmacological strategies: When asked about their experience with pharmacological therapy, adolescents described a need for additional knowledge about their medications. HCP participants described the importance of involving their young patients in the decision-making process regarding their treatment to promote adherence.

Physical strategies: Adolescent participants described the use of physical therapies as a pillar of their chronic pain management, and HCPs discussed the necessity of earning acceptance from patients when recommending physical strategies.

Psychological strategies: Adolescent participants recognized the value of certain psychological strategies such as distraction. Adolescents also used the strategy of focusing their energy on positive aspects of their life such as hobbies or involvement in extracurricular activities. HCP participants described the challenge of dealing with the social stigma associated with psychotherapy.

Transition:

Disconnect between pediatric and adult health services: In speaking about their upcoming transition at age 18, adolescents expressed apprehension about the perceived disconnect between pediatric and adult health care cultures in terms of receiving personalized care. This sentiment of disconnect and attitudinal shift between pediatric and adult was echoed by the HCPs.

Skills needed to transition: Adolescents displayed awareness of skills that would help them to successfully transition and thrive in the adult system such as self-advocacy in communicating with their HCPs and taking responsibility for their health. The HCP participants also stressed the importance of helping young patients to accept

responsibility for their care in the adult system, which is very inflexible compared with the pediatric system.

Parental role: When asked about the role of their parents in supporting transition, adolescents described a spectrum of involvement in their disease management. The topic of parental involvement in transition readiness was also discussed by HCPs, who identified a need to help parents to better prepare their adolescent for moving forward to the adult setting.

Fear and anxiety: Dialogue about transition revealed fears and anxieties among the adolescents related to the accurate transfer of their health information to new providers. Transition-related fears were also recognized by the HCP participants, who described the challenges of sending patients to a new and unfamiliar adult hospital where they may not feel a sense of belonging.

Overall, all HCP and adolescent participants in the focus groups endorsed the idea of a technology-based program (iCanCope with Pain™) as an acceptable means of meeting the need for comprehensive chronic pain education, strategies to manage symptoms, and social support.

Overview of program architecture

Based on the identified health care needs (by the first focus groups) as well as current best practices for pain self-management, a core iCanCope with Pain™ architecture was generated. As illustrated in Figure 2, the proposed architecture consisted of five theory-based components, integrated across smartphone and web-based platforms: self-monitoring; smart goal setting; personalized self-management instruction and rehearsal; peer-based social support; and detailed pain education. The first four components would be delivered via the iCanCope with Pain™

TABLE 4
Overview of functionality and perceived value of iCanCope with Pain™ self-management program

Program feature	Description of functionality	Participant feedback on perceived value of proposed feature
I. Self-monitoring via symptom trackers for pain, sleep, mood, physical activity and social activity	<ul style="list-style-type: none"> • Real-time symptom tracking via patient self-report • Customizable graphs and reports • Aim to help patients recognize patterns in their pain and functioning 	"I'd have it written down...how I was one day compared to the next and what affected me from one day to the next. So, that could be good and that could also help me [to] do more with my life...to manage it myself."
II. Personalized goal-setting with respect to improving pain and functioning	<ul style="list-style-type: none"> • Set goals related to improving pain, sleep, mood, physical activity and social activity • Adherence to SMART* framework 	"...remember when you set your goals to make sure that they're realistic for you. So it could be goals [for] social interaction, it could be goals for sports or physical activity, or it could be school related, or it could be family related, getting your family to understand it more...or moving forward with the doctors, trying to find some balance between everything."
III. Pain coping skills training and rehearsal	<ul style="list-style-type: none"> • In-the-moment access to pain coping strategies • Personalized instruction based on goals • Aim to help patients develop and practice healthy self-management skills 	"It's more a regular thing to practice so then you have the skill when you need it."
IV. Peer-based social support	<ul style="list-style-type: none"> • Opportunity to interact with other young people with chronic pain via monitored discussion boards • Share pain coping strategies and receive motivation toward reaching goals 	"I think just like moral support knowing that you're not alone in this... there's other people and you might not know them personally but at least you know if you do something, if you achieve one of your goals for example ... people who are experiencing it [can say], 'I'm so proud of you because...you've inspired me to make sure I achieve my goals'. Um I think that would be really useful for people and just bring up your moral support and your confidence to say, you know, I can do this type of thing."
V. Website containing detailed pain education and coping skills training to complement the content of the app	<ul style="list-style-type: none"> • Provide information on types of pain, strategies for maintaining physical activity and strategies for managing anxiety, stress and emotions 	"I think what they need is access to information particularly independent from the clinic. So online stuff is probably much more believable for them and allows them time to sort of get into it, look at it, think about it in a less pressured situation"

*SMART (specific, measurable, achievable, realistic, and timed) framework described by Bovend'Eerd et al (51)

app, which would be accessible to users on their smartphone and provide in-the-moment access to content. All of these app functionalities would be integrated with the *iCanCope with Pain™* website (the detailed pain education component)

Theoretical rationale

The self-monitoring component is based on the theory of behavioural activation, which purports that engagement in meaningful activity reinforces future engagement (49). This function will enable adolescents to track their symptoms in real time and generate customized reports and graphs from their data. The parameters that will be tracked by the app will be pain, sleep, mood, physical activity and social activity, because these were identified as important in the initial interviews. This function will aim to help adolescents to recognize and understand patterns in their pain and functioning, and better communicate their symptoms.

The goal-setting component is designed to enhance self-efficacy, defined as perception of one's ability to successfully produce a desired effect in a task or behaviour affecting their life (50). This app component will guide adolescents in setting structured goals aimed at improving their pain and functioning (sleep, mood, physical and social activities, and navigating health care). The app will guide adolescents in developing goals that adhere to the SMART framework – specific, measurable, achievable, realistic and timed (51). The app will also provide users with reminders and positive feedback on their progress in reaching their goals. Adolescents will have the option of sharing their goals for motivation and encouragement.

The personalized self-management instruction and rehearsal component will provide in-the-moment access to pain coping strategies to promote positive changes in mood, behaviour and, ultimately, the pain itself. The content will be based on the theoretical underpinnings of cognitive behavioural therapy (52), and will include self-management strategies such as muscle relaxation, guided imagery, mindfulness and belly breathing, as well as problem-solving and communication skills training. This training will be personalized based on each user's goals.

The social support component will be based upon social learning theory, which describes how individuals learn from one another through direct experience, observation and social feedback (53). This component will provide an opportunity for adolescents to interact and share coping strategies with other young people via monitored discussion boards. The app will also allow adolescents to enter group-based team challenges related to improving pain and functioning, and will include an 'Ask the Expert' feature where adolescents can seek input from HCPs.

Finally, the website-delivered pain education and coping skills training component will aim to provide comprehensive disease-specific education to increase adolescent knowledge and complement the app content. Given the large screen size and increased memory available on a computer-based versus mobile platform, the *iCanCope with Pain™* website will deliver detailed education and skills training in a multimedia format (eg, animations, videos, audio).

Adolescent feedback on *iCanCope with Pain™* core functionalities

During the individual interviews, the majority of adolescents (six of seven [86%]) endorsed the proposed *iCanCope with Pain™* architecture as acceptable for meeting their pain self-management needs. For instance, one adolescent stated, "I don't think that there would be anything to push me to use the app cause this is something that I see myself using on a day-to-day basis...even more than once per day". One adolescent indicated that they were not interested in learning how to self-manage their pain through goal setting, symptom tracking, peer support or pain management strategies. The individual interviews also elicited specific feedback from adolescents regarding the perceived value of each proposed core feature of the app and website. These data are summarized in Table 4.

DISCUSSION

To our knowledge, the present study was the first to explore the experiences and health care needs of adolescents with chronic pain

with the goal of informing development of a smartphone and web-based self-management program for this population. Youth in the present study clearly articulated the significant physical, role functioning, social, emotional and future impact that chronic pain had on their lives. They also identified barriers that impeded optimal pain management at the health care system, patient and societal level. They identified strategies that help them to cope with pain such as finding meaningful social support, and using pharmacological, physical and psychological strategies. Participants described the challenges associated with transition and provided recommendations for promoting successful transfer to adult health care services, such as skills development and rehearsal. Nearly all participants felt that the *iCanCope with Pain™* program would improve access to and meet the need for more chronic pain information, ways to manage symptoms and social support provided in a context that is developmentally appropriate for adolescents. They also endorsed the proposed program architecture (Figure 2) and provided guidance on the value associated with each core functionality of the program.

Outcome data for technology-based disease self-management interventions for adult (17-19,21-23) and pediatric (20,24,27,28) populations have rapidly increased over the past decade. Results from systematic and meta-analytic reviews suggest consistent efficacy for symptom reduction, knowledge attainment and improved health behaviours in chronic pain and across a wide range of chronic health conditions. In the field of chronic pain, there is good evidence from two recent systematic reviews in adults (26,28) and one in children/adolescents (27) that self-guided treatments delivered over the Internet can reduce pain intensity.

The use of information and communication technologies (ICTs) in the assessment and treatment of chronic pain is especially relevant for youth. First, if youth in the early stages of chronic pain are taught to use effective patterns of coping strategies, this practice may prevent future costly pain-related disability (physical and psychological morbidity) (3-5). Second, ICT-based therapies are likely to be readily accepted and adopted by youth because they represent one of the most active and fastest-growing users of this technology (eg, in 2011, 29.5% of 12- to 17-year-olds and 54.5% of 18- to 24-year-olds had smartphones; in 2016, it is projected that these numbers will rise to 65.4% among 12- to 17-year-olds and 87.3% among 18- to 24-year-olds) (54-56). Similarly, in 2010, 96% of Canadian households had Internet access, with 92% having high-speed access (57). Third, using ICT-based interventions dramatically reduces geographical and funding constraints as well as providing 24 h access to information and pain coping strategies (17,29). Furthermore, for many youth living in rural and particularly remote areas, an online intervention may be the only treatment available to meet their needs on an ongoing basis. Finally, adding human support via brief telephone/e-mail contact with a therapist, or lay peers, and/or including social networking opportunities has improved motivation and adherence to e-health care services, thereby optimizing achievement of desired outcomes (17,22,24,58,59).

Some adolescents in our study described psychological therapy as 'inappropriate' for the treatment of their chronic pain. This perceived stigma associated with psychotherapy has been documented in previous studies (60,61), and further highlights the need for integration of physical and behavioural supports for these patients. Importantly, given that youth represent one of the fastest growing users of mobile and web-based technology, these online delivery methods for psychotherapy provide a more private, socially acceptable and normalizing method of obtaining treatment in a less-stigmatizing manner (60,62). However, it is important to recognize that an app cannot replace a trained therapist and the intent of *iCanCope* is to provide self-management support and basic psychological techniques for pain management.

Seeking understanding through social (or peer) support was an important way that respondents managed their chronic pain. Social support is a multifaceted concept that can be defined as the formal and informal relationships that provide for the needs of individuals in their everyday environments (63). Youth with chronic pain have been

found to have fewer friends and be perceived as more isolated and less likeable than peers without pain (64). This lack of social support further underscores the need for intervention in this population, given that strong peer relationships are predictive of positive judgments of independence, emotional adjustment and identity formation (64-66). Polomano et al (67) reviewed social support web-based resources for patients with chronic pain and concluded that the Internet can empower patients to self-manage pain and seek effective social support venues for improving their lives. Thus, online and mobile chronic pain self-management programs should provide a variety of opportunities for social support (eg, discussion boards, video clips modelling successful self-management behaviours and problem solving). It should be noted that while peer support is a key component of a comprehensive online self-management program for youth with chronic pain, there are unique challenges with implementing such a program with respect to user privacy, and appropriateness of peer feedback. Specific considerations must be made regarding the benefits versus limitations of having professional oversight of the channels of communication between users of the program.

Rosser and Eccleston (33) recently reviewed the smartphone apps available for pain management. Of the 111 apps identified, the majority were designed for the iPhone (79%) whereas fewer were available for Android (16%) or BlackBerry (5%). Only two (1.8%) apps were designed for use across multiple platforms. The apps were intended for a variety of pain conditions including general pain, headache, migraine, back pain, fibromyalgia, arthritis and degenerative disc disease. The primary app functions included self-management components such as education skills training (54%), self-monitoring (24%) and relaxation training (22%). More recently, Wallace (35) completed an updated review of 222 pain-related apps across mobile platforms and found that 30% of identified apps had no involvement of health care professionals in their development. Furthermore, three recent systematic reviews failed to identify any large-scale randomized controlled trials that evaluated the effectiveness of pain apps on health outcomes (31,68,69). Thus, while this is a burgeoning field, formal evaluations of ICT-based (especially smartphone) intervention impact, level of resource utilization and user satisfaction have lagged far behind their development (17,27,33,70).

Our group has previously explored the information and service needs of young adults with chronic pain through semistructured focus group interviews (43). A convenience sample of n=17 young adults 18 to 29 years of age were recruited from two adult tertiary care multidisciplinary chronic pain clinics in Ontario. Interdisciplinary health care professionals (n=17) were also recruited from these sites. Thematic analysis revealed similar themes to the current study in adolescents; namely, pain impact, pain management strategies, barriers to care and service delivery recommendations. The only major difference in thematic structure was that the young adults did not discuss 'transition' as a significant theme. Similar to the current data, all of the young adult and adult health care professional participants believed that a web-based program would be an acceptable means of meeting the self-management needs of young people with chronic pain. Based on these findings, the needs of both adolescents and young adults living with chronic pain could be met through the use of *iCanCope with Pain™* and, therefore, the program should be targeted to young people included in both of these age groups.

While there are clear benefits of making health care accessible through ICT-based programs, it should be noted that these programs are not intended to replace the care provided by professionals. This concern is inherent with the use of any self-management program, and steps must be taken to promote the program as a complement to professionally delivered health care when possible. Indeed, it is designed to empower the user to better understand their condition and, as a result, to better communicate their needs with their health care professionals. Furthermore, we recognize that this means of self-management health care delivery may not appeal to all youth with chronic pain; however, in our sample, there was sufficient enthusiasm to suggest that the

majority of youth with chronic pain may incorporate *iCanCope with Pain™* into their ongoing self-management practice.

The rigor of the current study was enhanced by using analyst triangulation (ie, using multiple analysts to understand different ways of viewing the data) to reduce the likelihood of bias (38). Study limitations included that our sample was obtained from two urban, primarily English-speaking centres in southwestern Ontario in Canada, and did not include a community-based sample. Further research would be needed to confirm the self-management needs of a community-based sample of adolescents. However, it is reassuring to note that Dewar et al (71) found similar findings to our study using a community-based sample of individuals 15 to 80 years of age with chronic pain. In the Dewar study, 53 participants participated in 10 focus groups, but only five participants were younger than 30 years of age. The top identified service priorities included: medical treatments, problems with daily living, emotional distress, social issues, sleep disturbances and financial issues. Participants indicated that they had difficulty finding accessible, effective and acceptable care. Similar to our study, the participants in the Dewar study believed that alternative measures were needed to improve self-management and accessibility of treatment (71). Furthermore, we have confidence in our reported adolescent themes because the same ones were endorsed from the HCP focus groups. Finally, we were only able to interview each participant once and were not able to perform member checking to verify the themes.

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CONCLUSIONS

Exploring the perceptions of youth with chronic pain was crucial in laying the foundation for development of the *iCanCope with Pain™* self-management intervention. This early involvement of youth with chronic pain will help to ensure that the content and format of the intervention is relevant and acceptable, and meets the developmental needs of this at-risk group. The next step will be to develop a prototype of the *iCanCope with Pain™* integrated smartphone and web-based program in accordance with the patient-endorsed architecture, and to rigorously evaluate its impact on clinical health outcomes through a randomized controlled trial.

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