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Complex regional pain syndrome: Facilitating the use of self-management strategies

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ABSTRACT

Aims: While several interventions are used to treat complex regional pain syndrome (CRPS), patient adherence to recommended care including self-management is challenging. To understand the barriers and facilitators to using self-management strategies among CRPS patients; to explore educational tools used to enable self-management; and to develop knowledge translation interventions to address potential barriers using intervention mapping.

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Methods: Semi-structured interviews of patients were conducted to identify the determinants self-management. Findings informed of the development of a tailored theory-based intervention to increase adherence. Result: Theoretical domains identified were: Social influence, Beliefs about capabilities, Beliefs about consequences. Environmental context and resources. Various educational tools were provided by treating clinicians. Interventions should consider increasing knowledge about treatment outcomes, identifying health antecedents and promoting self-monitoring. **Conclusion: Online educational interventions** focusing on patient advice, self-monitoring, and techniques to increase the quality of the clinicianpatient relationship may successfully address patient barriers to using self-management strategies.

Keywords: Complex regional pain syndromes, Interviews, Self-management strategies, Theoretical domain framework

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INTRODUCTION

Complex regional pain syndrome (CRPS) is an uncommon neuropathic pain disorder that can develop after trauma, surgery, and occasionally occurs spontaneously. Studies in the United States and the Netherlands indicate that CRPS is an orphan disease since less than 200,00 people are affected each year [1]. Women are three times more likely to be affected than men [2], and 45% of CRPS cases affect the upper extremities, with fractures being the most common triggering event [3]. CRPS can be divided into two subtypes: CRPSI and CRPSII. While the differentiating factor is the presence of a known nerve injury in CRPSII, the treatments are often similar for both subtypes [4]. While CRPS symptoms subside within 6-13 months for most people, 15–20% will develop long-term disabilities [1]. The Orlando criteria [5] and the Budapest criteria [6] are two internationally acknowledged sets of diagnostic criteria. Further, a standardized core measurement set (core outcome measurement set for complex regional pain syndrome clinical studies) was recently developed to capture the multidimensional nature of CRPS [1]. CRPS has various clinical presentations in which persistent pain in combination with varying maladaptive responses in the sympathetic-mediated vasomotor control, peripheral, and central neuronal plasticity are affected [4]. As such, interventions to manage CRPS symptoms mainly focus on the reorganization of the nervous system. Perhaps due to the wide range of the clinical presentation, the overall quality of supporting therapeutic evidence is low [4].

Current best evidence recommends an interdisciplinary treatment approach to optimize the success of a patient's recovery. The treatment plan generally includes a combination of education to support self-management, physical and vocational rehabilitation, pain relief exercise and medication, and lastly psychological interventions [7]. Furthermore, graded motor imagery and mirror therapy result in clinically meaningful improvements in pain and function [4].

Understandably, patients may have difficulties understanding the nature of the condition itself and recommended interventions, asking questions such as 'Why does the skin color and temperature change?' or 'How can the pain travel to the other limb?' A recent survey administered to patients with CRPS in Switzerland investigated level of knowledge about the condition [8]. Most participants received information related to their condition from their physicians. However, 6% of respondents had only minimal knowledge of the condition as defined by clinical experts. Not surprisingly, such limited understanding can negatively influence patient adherence to recommended care and use of selfmanagement strategies (SMS).

Self-management

Self-management strategies are widely recommended for patients with a chronic disease. Self-management may be defined as actions that an individual should undertake to manage their condition; these actions include medical management, role management and emotional management [9]. Healthcare professionals play a key role in promoting self-management, being responsible for educating their patients and helping make informed decisions to ease their recovery process [10]. A review concluded that shorter duration interventions delivered to groups of patients with chronic musculoskeletal pain, with healthcare professional input, potentially produce better outcomes [10]. Hence, HCPs should have a thorough understanding of the factors influencing patient's use of self-management to provide the best care possible to their patients. A recent study investigated the impact of CRPS patient's activities of daily living in order to provide suggestions on improving their quality of life [11]. Their questionnaire collected general information, however, and the use of self-management was only partly covered. Few studies have explored factors that may increase or decrease the use of SMS. A qualitative phenomenological approach was taken to understand patients' beliefs about and barriers toward using SMS [12]. The current study is part of a larger project aiming to increase the use of evidence-based practice amongst clinicians involved in the CRPS community of practice (CoP) in Quebec, Canada.

Purpose

The objectives of this study were to:

- understand the barriers and facilitators encountered by CRPS patients to routinely using SMS
- investigate the educational tools used to facilitate patient ability to self-manage their condition
- develop a knowledge translation intervention to address potential barriers to patient adherence to recommended use of SMS using intervention mapping

MATERIALS AND METHODS

We conducted semi-structured interviews with patients with CRPS to inform the design of a tailored knowledge translation intervention to increase the uptake of SMS. Ethics approval was granted by the Centre de Recherche Interdisciplinaire en réadaptation du Montréal Métropolitain (CRIR-1141–0316). All participants signed a consent form prior to the interview.

Theoretical framework

The framework proposed by French et al. [13] was used to develop a knowledge translation (KT) intervention to increase patient adherence with recommended use of SMS. This four-step approach includes:

- problem identification
- selecting a theoretical framework to identify potential barriers and facilitators to behavior change
- elaborating a KT intervention to overcome modifiable barriers and enhance the enablers
- evaluating the impact of the proposed knowledge translation intervention

The focus of our research is to gain a holistic understanding of the experience of using SMS among people living with CRPS. We selected the Theoretical Domain Framework (TDF), which was created by health psychologists and experts in health service research in response to difficulties in understanding the process behind successful and unsuccessful behavior change [14]. The goal of the TDF is to simplify, integrate, and understand domains influencing changes in behavior(s) and ease communication and comprehension between researchers and stakeholders. The TDF has been tested in a wide range of populations, settings, and contexts [15] and has shown to be useful in identifying problems associated with implementing KT interventions [16]. A modified version with 14 domains was later proposed [17].

Participants

A convenience sample of individuals with CRPS was recruited at Constance-Lethbridge Rehabilitation Centre (CLRC) and at the Centre interdisciplinaire en gestion de la douleur (CIGD) of Hôtel-Dieu de Lévis hospital. The participants from the Hôtel-Dieu de Lévis were referred by a member of the CRPS CoP in the province of Quebec. We aimed to include 13 participants to reach data saturation since the stopping criterion is 10 interviews with three further interviews with no new themes appearing [18]. To be eligible, people with CRPS diagnosed by a physician had to be 18-year-old and over, fluent in English or French, and be receiving treatment for their condition by rehabilitation professionals (occupational therapist or physiotherapists) in the province of Quebec. Patients who did not agree to be audio-recorded were excluded from the research.

Interview topic guide

The modified TDF [16] informed the development of the interview topic guide. The TDF interview topic guide included 27 questions (1-4 questions per domain) deemed to be pertinent for gathering the information to fulfill the purpose of this study. Prompts were added for further clarification when needed. Two questions covered two domains (Beliefs about consequences and Reinforcement). Similarly, the domains of Intention, Goals and Optimism were grouped together under three questions. We excluded the domain Social/professional role and identity as we believed relevant information would surface when exploring Social influence and Optimism domains due to overlapping theoretical constructs. An additional question along with a series of prompts asked about the educational tools participants received from their HCP (e.g., pamphlets, PowerPoint presentations, videos, website or books), what they liked most or disliked about the tools, and perceived need for future educational tools. (Supplementary Material 1: Interview Topic Guide).

Procedures

The interview topic guide was initially created in English, and later translated in French by three authors. Formal forward-backward translation was not used due to resource constraint. However, our team of bilingual researchers at the CLRC reviewed the translation. The interview topic guide was piloted with a CRPS patient who had recovered from his condition, but this interview was not added to our results since at that time the study had not received ethics approval. Further modifications were made based on responses received. Face and content validity of the guide were assessed by a researcher and a clinician.

An email and postal mailing were sent to 13 rehabilitation clinicians (physical therapist and occupational therapist) from the neuromusculoskeletal program at CLRC and 60 others from the CRPS CoP, explaining the study objectives and asking them to invite their patients with CRPS to participate in the study. A flyer and letter advertising the study were also mailed to four rehabilitation centres in Quebec: CLRC, Jewish Rehabilitation Hospital, Centre de Réadaptation Lucie-Bruneau and the Institut de Réadaptation Gingras-Lindsay. Potential participants who agreed to be contacted were invited to participate by telephone by members of the research team. During the telephone call a phone script was used to explain the aim of the study and to recruit participants. All of the face-to-face interviews were recorded and transcribed verbatim. A note taker also recorded facial expressions and overall atmosphere.

Data analysis

Transcripts were anonymized using numbers and letters to maintain confidentiality. Each transcript was reviewed independently by two investigators to extract meaningful utterances. Those utterances were then placed in an Excel spreadsheet in relevant TDF domains, and then further coded into specific beliefs, and then grouped into themes. Any disagreements occurring

between the two investigators were resolved by a third reviewer. Specific beliefs were then ranked from most to least influential to self-manage using the following three criteria weighted equally:

- relatively high frequency of specific beliefs,
- presence of conflicting beliefs, and
- evidence of strong beliefs that may impact on the behavior [19].

We conducted concurrent data analysis and coding to assess whether or not we had achieved data saturation [18]. Throughout this process, one of the authors with expertise in mixed research methods and the TDF oversaw the analysis and ensured the coded data was robust and defensible.

Intervention mapping

Intervention mapping was used to develop a knowledge translation intervention to increase patient adherence with the recommended use of SMS. Members of the team first prioritized key domains to address. The TDF was used to identify a theory-informed behavior change intervention to ease the implementation of evidence into practice. Three key guiding questions led to the creation of the multifaceted intervention:

- who needs to do what differently?
- which modifiable barriers need to be addressed?
- which intervention can overcome these barriers? [20].

Question (1) "Who needs to do what differently?" was addressed through discussion with clinicians in the CRPS CoP who reported that their patient's compliance with the recommended care at home was suboptimal.

Question (2) was addressed via the semi-structured interview described above.

Question (3) was addressed by linking the key TDF domains to the appropriate 'source of behavior' in the behavior change wheel, and then the 'intervention functions' were identified [20]. For the intervention function, Michie et al.'s [21] matrix was used to map out effective 'behavioral change technique'. Behavioral change techniques (BCTs) are based on expert consensus and aim to target previously identified TDF domains (i.e., barriers). We then specified the exact techniques of the BCT that can be effective in overcoming the sources of the maladaptive behavior [22]. Research team members brainstormed around possible modes of delivery of the interventions. To determine the effectiveness of the proposed interventions, the studies found on the Rx-for-Change database were analyzed to optimize the feasibility of the intervention [23]. As there are no reviews on CRPS available in the database, we considered studies on (i) adult patients, (ii) who had chronic conditions, or painful illnesses, and (iii) with a focus on treatment adherence outside of clinical environments. The team also considered clinician and patient needs, the context and setting (rehabilitation), and the cost of developing and delivering the interventions.

RESULTS

Participants

Eleven individual face-to-face interviews took place in French or English in July and August 2016 at CLRC or at the participant's home (Table 1). Six participants were referred by the CLRC and four participants were referred by a member of the CRPS CoP from the Hôtel-Dieu de Lévis. Six females and four males with a mean age of 46.2 years old took part in this study. The mean duration of symptoms was 2.5 years. One patient with CRPS was excluded because his diagnosis was inconclusive.

Barriers and facilitators

A total of 93 utterances from 10 participants led to 42 specific beliefs and 28 themes (Supplementary Material 2: Elicited Beliefs). Although our interview topic guide covered 11 of the 14 domains, multiple statements addressed two domains (Optimism and Reinforcement). The four most influential domains were social influence, beliefs about consequences, beliefs about capabilities, and environment context and resources. These are discussed in detail below. Social influence may be defined by "those interpersonal processes that can cause an individual to change their thoughts, feelings, or behaviors" [24: p.140].

Table 1: Participants' characteristics

Characteristics	Participants (n = 10)
Sex	
Female	6
Male	4
Age (mean = 46.2)	
≤ 40 years old	2
40–50 years old	4
≥ 50 years old	4
Level of education attained	
High school degree	4
Cégep (College) degree	2
University degree	4
Employment status at the time of the interview	
Employed	5
Unemployed	5
Number of years with CRPS (mean =2.5 years)	
Less than a year	3
Between 1 and 2 years	2
Between 3 and 4 years	5

Twenty-eight meaningful utterances corresponded with this domain. Beliefs expressed as barriers by participants were reflected by statements such as "I lost a lot of friends because they thought I had nothing and I faked" (MPD-03). In contrast, one participant highlighted a facilitator suggesting: "He would say "you're 45, you can't give up on life now, you still have a lot of life left in you [...] get over yourself now" (JD-01).

Beliefs about consequences are defined by "acceptance of the truth, reality, or validity about outcomes of a behavior in a given situation" [24: p.140]. Participants made 23 meaningful utterances within this domain. Beliefs expressed by participants as barriers are reflected in statements such as "The mirror therapy, this is when it started to go badly. I didn't touch my [affected] hand, I touch the other one [unaffected] that was ok, but the pain in my [affected] hand increased" (RBH-02). One other participant highlighted the following facilitator: "This is maybe one of the only positive points of this bad adventure; I do not feel any guilt about saying no [when people asked for my help]" (LD-02).

Beliefs about capabilities represents "acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use" [24: p.140]. Twenty-one meaningful utterances belonged in this domain. Beliefs expressed by participants as barriers were reflected by statements such as "Self-pacing was very hard to apply; this was the most challenging part of my treatment" (LD-02). In contrast, one other participant highlighted a facilitator suggesting "Even though I always have pain, I am able to do my things" (LD-03).

Environmental context and resources can be defined as "any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities" [24: p.140]. In total, 30 meaningful utterances were coded within this domain. Beliefs expressed by participants as barriers were reflected by statements such as "Everybody [the HCPs] was very sure they can help me. And umm... nobody was really able to help... there were few that were able to" (JD-01). One other participant highlighted the following facilitator: "Flyers and others paper documents helped me understand my condition; there is no doubt about it" (LD-03).

The other domains were felt to be less influential. For some participants, the domain of reinforcement was expressed by statements such as "I adhere to treatments that reduced my symptoms", a specific belief shared by many participants. The domain of Emotions illustrated that anxiety, frustration, and a sense of guilt were the most prevalent emotions. The domain of Goals demonstrated that some patients engaged in their care with the aim of returning to their premorbid state while others aimed to increase their quality of life. Memory, attention and decision processes domains showed that some participants were engaged in the decision process concerning their treatments. Intention domain was influenced by both internal and external motivation. Behavioral regulation showed that most participants integrated SMS in their routine. The domain of knowledge was not found to be a barrier to self-management. In contrast, the domain of skills suggested that being proactive, actively seeking information about their condition, and following through with their home treatment recommendations were essential to self-manage. Optimism domain showed a division between participants as some felt hopeful and others were pessimistic about their future.

Data saturation was achieved for most TDF domains. The four key domains received the highest redundancy in answers provided, and similar statements were made in several other domains, including reinforcement, emotion, goals and knowledge, such that we considered that data saturation was also reached.

Educational tools used by patients with CRPS

Several participants did not specify the types of tools recommended by the HCP. They either alluded to having received "everything" or said that they did not remember. The majority of participants (n = 7) received paper documents discussing their condition and advising how best to manage symptoms. However, six participants felt that they did not receive enough information about their condition. When asked about the content or type of educational tools they felt would be helpful, one of the participants suggested "I would have liked to have explanatory documents that are personalized, like in my case, my syndrome was in my hand" (RBH-01¹). Interestingly, all participants had self-searched the internet to better understand their condition and symptoms. Half reported that looking at the internet for information about their condition was "scary" and/or "overwhelming". For example, participant LD-031 stated that "Because the [vast amount of information found on the] internet sometimes is more 'scary' than anything. People prefer to have more specific information".

Interventions mapped

The behavior of interest or "Who needs to do what differently?" is to increase the adherence of patients with CRPS to SMS, for example engaging in Graded Motor Imagery treatment three times a day at home. The intervention aims to address the four key TDF domains: Social influence, Beliefs about capabilities, Beliefs about consequences, and Environmental context and resources.

Intervention function

The sources of the behavior and corresponding intervention functions (Supplementary Material 3: Intervention Function Definition) are the patient's (i) reflective motivation (education, restriction, and environmental restructuring), and (ii) social and

environmental opportunity (enablement, modeling, and environmental restructuring).

Intervention and behavior change technique

Intervention functions were created after considering BCT definitions (Supplementary Material 4: Behavior Change Technique Definitions), and published articles retrieved from the Rx-for-Change database [25-29]. Team members reached consensus over the following intervention and mode of delivery that may be implemented in future practice: The domains of social influence and beliefs about capabilities should be addressed together using BCTs that included reward, social support (emotional), verbal persuasion about capabilities, and mental rehearsal of successful performance. The team members proposed that these BCT should be delivered by HCP through online educational tools. One of the sessions would advise patients to practice positive self-feedback. Another session would provide education to family and friends on feedback methods (to give empathy and generalized positive feedback) [30]. This strategy is supported by our findings of interviewed participants (n=30 statements) who reported that their HCP, family and friends influence their compliance and use of SMS.

The BCTs that were mapped to the domain of beliefs about consequences include persuasive communication, information regarding behavior (outcome), and selfmonitoring (i.e., feedback). These BCT can also be incorporated into an educational session facilitated by a HCP who is likeable, trustworthy, and influential. The HCP would inform patients about the consequence of not adhering to SMS, provide information about antecedents (e.g. social and environmental situations and events, emotions, cognitions) that predict performance of the maladaptive behavior. Strategies to monitor and record their behavior and process may also be discussed.

Lastly, the BCT related to environmental context and resources likely includes environmental restructuring; restructuring both physical and social environment. To enable the patient to change their environment. HCP can help the patient identify what needs to be modified. Faceto-face discussions with a HCP, clinicians can provide information about antecedents that the patient can encounter during the course of treatment. The patient can record the antecedents so that the patients and HCP can address it at the follow up. To increase the likelihood for the patient to follow through with recommendations, motivational interview skills can be key for patients. Motivational interviewing aims to engage the patient's intrinsic motivation to change behavior, and it is found to have positive intervention effects [29]. This strategy is supported by participants (in 10 statements) who reported that it was hard to find resources to help them manage their condition.

Delivery of the intervention

The team member considered the multiple BCTs identified above and combined them into two live chat group webinars, a mode of delivery that is easily accessible for both patients and HCPs. Based on the best available evidence, the proposed intervention and modes of delivery are as follows:

- (1) A 50-minute webinar targeting patients and facilitated by a likeable and influential HCP containing:
 - Comprehensive information about CRPS and the consequences of not adhering to treatment recommendations, along with advice on self-management and selfmonitoring.
 - Education and recommendations on techniques to self-monitor and record behavior and treatment progress incorporating both explaining and identifying antecedents, illustrated by a few examples.
- (2) A 50-minute webinar targeting HCP facilitated by the aforementioned HCP peer opinion leader teaching on:
 - Motivational interviewing skills, along with demonstrations.
 - Frequent patient visits with a HCP to support them during treatment are recommended.

DISCUSSION

The findings from this study helped clarify potential barriers and facilitators and perceived needs about SMS among patients with CRPS. Four TDF domains (social influences, beliefs about capabilities, beliefs about consequences, and environmental context and resources) appeared to impact on patient's engagement in SMS. In addition, various educational tools provided by HCP may ease patient's use of SMS.

Relationship with HCPs and family members was found to be a pivotal factor ffor patients with CRPS. A strong patient-physician relationship is a positive predictor of treatment outcome [31]. The relational aspects included satisfaction of care, trust in the physician, and patient participation. Furthermore, support from family members increases the likelihood of a positive treatment outcome as family's behavior impacts the daily self-management tasks the person with a chronic illness must undertake [30]. Beliefs about capabilities were also important for self-managing one's condition. A lack of confidence, or a feeling of inadequacy, hinders the person's eagerness to take action [32]. In addition, a person with low confidence is more prone to feel stressed, anxious, and have poor problem-solving capacities [33]. In addition, stronger

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belief in one's capabilities reflects better adhesion to a favorable behavior [34]. Our findings reflect this reality, as higher levels of perceived capabilities positively influenced participants' adherence to SMS. Beliefs about consequences were found to be an important factor to take into consideration when recommending SMS. Based on our results, participants who better understood their condition and the impact of the symptoms though education made greater efforts adhere to SMS. A review of patients with chronic musculoskeletal pain indicates that pain education increases the effectiveness of selfmanagement during the subacute/chronic phase when compared to patients receiving pain education during the acute phase [10]. Furthermore, the participants who develop new psychological competencies (e.g. mindfulness, relaxation, and time management) admit to having greater adherence to recommended SMS. Adding a psychological component boosts the effectiveness of the self-management support strategy [10].

In our study, several participants illustrated that accessing services for their CRPS syndrome was challenging. Disparities in services offered to address patient's needs may have far-reaching negative consequences. These consequences can affect their physical and psychological wellbeing, social relations, economic status, independence and quality of life. Onken et al. [35] study also demonstrated that limited services and access hinders patient's recovery. Subsequently, providing access to quality care is important to enable CRPS patients and increase compliance with SMS. Participants in this study indicated that having a safe environment where they could perform their treatment was perceived as beneficial and increased the likelihood of adhering to recommended SMS. Thus, opportunities to perform part of the treatment at home may facilitate compliance.

Resources, such as educational tools, were perceived by most of our participants to be beneficial to managing their condition. According to participants, searching on the internet allowed them to confirm or to complement the information they had already received from their HCPs. This reflects the reality nowadays where the internet is commonly used for self-diagnosis and further clarification of condition, symptoms, and treatments [36]. Unfortunately, we were unable to formulate specific recommendations about types of educational tools to recommend as few participants received the same tools/ documentation from their HCPs.

The four key TDF domains identified in this study support the recommendations to adopt a holistic approach with this population. HCP should aim to increase patients' compliance with SMS. To do so, HCPs must engage with and take notice of the whole person instead of focusing primarily on the physical aspects of CRPS syndrome. Engaging the patient as a whole means considering their mental, emotional and spiritual wellbeing and viewing their environment (e.g., physical, cultural, social, institutional) as equally important during the course of recovery [37]. As suggested by our findings, a change in the person's beliefs, strong social support, a supportive environment and access to appropriate resources are likely to positively influence the person's ability to engage in self-management of the condition.

Study limitations

Very few qualitative studies have attempted to explore the barriers and facilitators that patients with CRPS encounter when managing their condition. Nonetheless, our study has some limitations. First, we did not use formal forward-backward translation for our interview topic guide and coding, which may have been affected the analysis of our study. However, formal translation may have not been required to conduct interviews as interviewers were familiar with the meaning of all questions and could clarify any question for the participants using prompts. Second, as our sample consists of a 'willing' population, selection bias may have occurred. Third, although we aimed to include 13 participants, only 10 participant's data could be analyzed. Thus, it is possible that we did not reach data saturation for all TDF domains, thereby limiting our conclusions. Fourth, as with any interviews, some participants may have been tempted to answer questions to please the interviewer (i.e. social desirability bias) and recall bias may have been an issue for former patients. Fifth, the interview topic guide did not cover the social/ professional role and identity domain which could have provided a more thorough understanding of how one's role, or lack of role, can influence participants behavior and attitude with regards to managing pain. Finally, four different members of the research team conducted the interviews. The delivery of questions across interviews may have lacked consistency as a result. This could have led to a decrease in reliability of our study.

Implications for future research and practice

As the use of the internet was common amongst our participants, we suggest creating an easy-to-use bilingual website with a discussion forum focusing on CRPS which patients and family would be able to access and use. In addition, various educational tools were used by the HCPs. The ease of transmission of knowledge from HCPs to patients can be enhanced by using educational tools. However, it was unclear in the current study what the content should include and what characteristics the education tools should have to be most effective. Future research should focus on developing comprehensive and accessible educational tools for CRPS patients. This could be done in collaboration with HCPs who can suggest current educational tools to evaluate and/or by

forming a focus group to understand the characteristics and most effective content. Finally, the impact of the proposed KT intervention remains untested. A pilot study to determine the feasibility of implementing this intervention to increase patients' adherence to SMS within a rehabilitation setting is needed.

CONCLUSION

Our study contributed new and insightful information about the perceived barriers and facilitators to use of SMS among patients with CRPS in Quebec. Social influences, beliefs about capabilities, beliefs about consequences, and environmental context and resources were found to potentially impact one's ability to adhere to recommended SMS.

A first webinar targeting CRPS patients delivered by a patient advocate will provide information on the condition, the consequences of not adhering to treatment recommendation, and advice on self-management and self-monitoring. A second webinar targeting clinicians delivered by a peer opinion leader teaching motivational interviewing skills will aim to ease increase the use of SMS by CRPS patients. Clinical encounters with a HCP should aim to support patients during treatment interventions. Clinicians' use of tools and strategies to increase patient's adherence to SMS should be further explored. The impact and feasibility the proposed KT intervention in a rehabilitation centre remains to be tested.

Key Messages

- Increasing patient adherence to self-management may require addressing barriers such as social influences, beliefs about capabilities, beliefs about consequences, and environmental context and resources;
- Interventions aiming to increase knowledge about treatment outcomes, identifying antecedents and promoting self-monitoring should be considered when managing CRPS patients;
- The use of motivational interviewing during patient clinical encounters can maximize support.

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Author Contributions

Xuan Chi Julia Dao – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published Rosalie Blais-Hébert – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

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André E. Bussières – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Guarantor

The corresponding author is the guarantor of submission.

Conflict of Interest

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REFERENCES

1. Grieve S, Perez RS, Birklein F, et al. Recommendations for a first Core outcome measurement set for complex regional PAin syndrome clinical sTudies (COMPACT). Pain 2017 Feb 4.

- de Mos M, de Bruijn AG, Huygen FJ, et al. The incidence of complex regional pain syndrome: A population-based study. Pain 2007 May;129(1-2):12-20.
- Packham TL. Outcome measurement in complex regional pain syndrome. (Master's thesis, McMaster University, Canada). [Available at: https:// macsphere.mcmaster.ca/bitstream/11375/10502/1/ fulltext.pdf]
- 4. Smart KM, Wand BM, O'Connell NE. Physiotherapy for pain and disability in adults with complex regional pain syndrome (CRPS) types I and II. Cochrane Database Syst Rev 2016 Feb 24;2:CD010853.
- 5. Reinders MF, Geertzen JH, Dijkstra PU. Complex regional pain syndrome type I: Use of the International Association for the Study of Pain diagnostic criteria defined in 1994. Clin J Pain 2002 Jul–Aug;18(4):207–15.
- 6. Harden RN, Bruehl S, Perez RS, et al. Validation of proposed diagnostic criteria (the "Budapest Criteria") for Complex Regional Pain Syndrome. Pain 2010 Aug;150(2):268–74.
- Turner-Stokes L, Goebel A; Guideline development group. Complex regional pain syndrome in adults: Concise guidance. Clin Med (Lond) 2011 Dec;11(6):596-600.
- Brunner F, Gymesi A, Kissling R, Bachmann LM. Disease-related knowledge of patients with chronic regional pain syndrome. J Rehabil Med 2010 May;42(5):458–62.
- 9. Bodenheimer T, MacGregor K, Sharifi C. Helping patients manage their chronic conditions. California Health Care Foundation; 2005.
- Carnes D, Homer KE, Miles CL, et al. Effective delivery styles and content for self-management interventions for chronic musculoskeletal pain: A systematic literature review. Clin J Pain 2012 May;28(4):344– 54.
- 11. Schneider MA, Smith CE, Pomidor MA. Compassionate Care for Patients With Complex Regional Pain Syndrome. J Neurosci Nurs 2015 Aug;47(4):204–10.
- 12. Creswell JW. Qualitative inquiry and research design. Choosing among five approaches. 2ed. London: Sage Publications; 2007. p. 147–76.
- 13. French SD, Green SE, O'Connor DA, et al. Developing theory-informed behaviour change interventions to implement evidence into practice: A systematic approach using the Theoretical Domains Framework. Implement Sci 2012 Apr 24;7:38.
- 14. Michie S, Johnston M, Abraham C, et al. Making psychological theory useful for implementing evidence based practice: A consensus approach. Qual Saf Health Care 2005 Feb;14(1):26–33.
- 15. Francis JJ, O'Connor D, Curran J. Theories of behaviour change synthesised into a set of theoretical groupings: Introducing a thematic series on the theoretical domains framework. Implement Sci 2012 Apr 24;7:35.
- 16. McCullough AR, Ryan C, O'Neill B, Bradley JM, Elborn JS, Hughes CM. Defining the content and delivery of an intervention to Change AdhereNce to treatment in BonchiEctasis (CAN-BE): A qualitative approach incorporating the Theoretical Domains

Framework, behavioural change techniques and stakeholder expert panels. BMC Health Serv Res 2015 Aug 22;15:342.

- 17. Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. Implement Sci 2012 Apr 24;7:37.
- 18. Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. Psychol Health 2010 Dec;25(100):1229–45.
- 19. Francis JJ, Stockton C, Eccles MP, et al. Evidencebased selection of theories for designing behaviour change interventions: Using methods based on theoretical construct domains to understand clinicians' blood transfusion behaviour. Br J Health Psychol 2009 Nov;14(Pt 4):625–46.
- 20. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr 23;6:42.
- 21. Michie S, Johnston M, Francis J, Hardeman W, Eccles M. From theory to intervention: Mapping theoretically derived behavioural determinants to behaviour change techniques. Applied Psychology 2008;57(4):660–80.
- 22. Michie S, Wood CE, Johnston M, Abraham C, Francis JJ, Hardeman W. Behaviour change techniques: The development and evaluation of a taxonomic method for reporting and describing behaviour change interventions (a suite of five studies involving consensus methods, randomised controlled trials and analysis of qualitative data). Health Technol Assess 2015 Nov;19(99):1–188.
- 23. The canadian agency for drugs and technologies in health. Reaction for change database. [Available at: https://www.cadth.ca/rx-change]
- 24. Phillips CJ, Marshall AP, Chaves NJ, et al. Experiences of using the Theoretical Domains Framework across diverse clinical environments: A qualitative study. J Multidiscip Healthc 2015 Mar 18;8:139–46.
- 25. Bennett MI, Bagnall AM, José Closs S. How effective are patient-based educational interventions in the management of cancer pain? Systematic review and meta-analysis. Pain 2009 Jun;143(3):192–9.
- Kivelä K, Elo S, Kyngäs H, Kääriäinen M. The effects of health coaching on adult patients with chronic diseases: A systematic review. Patient Educ Couns 2014 Nov;97(2):147–57.
- 27. Eland-de Kok P, van Os-Medendorp H, Vergouwe-Meijer A, Bruijnzeel-Koomen C, Ros W. A systematic review of the effects of e-health on chronically ill patients. J Clin Nurs 2011 Nov;20(21–22):2997–3010.
- 28. Berman RL, Iris MA, Bode R, Drengenberg C. The effectiveness of an online mind-body intervention for older adults with chronic pain. J Pain 2009 Jan;10(1):68–79.
- 29. Hill B, Richardson B, Skouteris H. Do we know how to design effective health coaching interventions: A systematic review of the state of the literature. Am J Health Promot 2015 May-Jun;29(5):e158–68.

- Rosland AM, Heisler M, Piette JD. The impact of family behaviors and communication patterns on chronic illness outcomes: A systematic review. J Behav Med 2012 Apr;35(2):221–39.
- 31. Farin E, Gramm L, Schmidt E. The patient-physician relationship in patients with chronic low back pain as a predictor of outcomes after rehabilitation. J Behav Med 2013 Jun;36(3):246–58.
- 32. Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors?. Health Serv Res 2007 Aug;42(4):1443–63.
- 33. Torsi S. The Self-Management of Chronic Conditions. Germany: Lap Lambert Academic Publishing GmbH & Co. KG; 2012. p. 34.
- 34. Wallin L, Boström AM, Gustavsson JP. Capability beliefs regarding evidence-based practice are associated with application of EBP and research use:

validation of a new measure. Worldviews Evid Based Nurs 2012 Aug;9(3):139-48.

- 35. Onken SJ, Craig CM, Ridgway P, Ralph RO, Cook JA. An analysis of the definitions and elements of recovery: A review of the literature. Psychiatr Rehabil J 2007;31(1):9–22.
- 36. White RW, Horvitz E. Web to world: Predicting transitions from self-diagnosis to the pursuit of local medical assistance in web search. AMIA Annu Symp Proc 2010 Nov 13;2010:882–6.
- 37. Polatajko HJ, Townsend EA, Craik J. Canadian model of occupational performance and engagement (CMOP-E). In: Townsend HJ, Polatajko EA, editor. Enabling occupation II: Advancing an occupational therapy vision of health, well-being and justice through occupation. Ottawa: CAOT Publication ACE; 2007. p. 23.

