Stanford Chronic Disease Self-Management Program in myotonic dystrophy: New opportunities for occupational therapists

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Stanford Chronic Disease Self-Management Program dans la dystrophie myotonique : De nouvelles opportunités pour les ergothérapeutes

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Key words: Feasibility studies; Intervention studies; Neuromuscular disorder; Occupational therapy; Self-care.

Mots clés : ergothérapie; essais cliniques; études de faisabilité; soins personnels; trouble neuromusculaire.

Abstract

Background. Chronic disease self-management is a priority in health care. Personal and environmental barriers for populations with neuromuscular disorders might diminish the efficacy of self-management programs, although they have been shown to be an effective intervention in many populations. Owing to their occupational expertise, occupational therapists might optimize self-management program interventions. **Purpose.** This study aimed to adapt the Stanford Chronic Disease Self-Management Program (CDSMP) for people with myotonic dystrophy type I (DMI) and assess its acceptability and feasibility in this population. **Method.** Using an adapted version of the Stanford CDSMP, a descriptive pilot study was conducted with 10 participants (five adults with DMI and their caregivers). A semi-structured interview and questionnaires were used. **Findings.** The Stanford CDSMP is acceptable and feasible for individuals with DMI. However, improvements are required, such as the involvement of occupational therapists to help foster concrete utilization of self-management strategies into day-to-day tasks using their expertise in enabling occupation. **Implications.** Although adaptations are needed, the Stanford CDSMP remains a relevant intervention with populations requiring the application of self-management strategies.

Abrégé

Description. L'autogestion des maladies chroniques est une priorité des systèmes de santé. Les facteurs personnels et environnementaux des individus atteints de maladies neuromusculaires peuvent diminuer l'efficacité des programmes d'autogestion, même s'ils présentent des stratégies éprouvées. En raison de son expertise occupationnelle, l'ergothérapeute peut optimiser les interventions des programmes d'autogestion. **But.** Cette étude visait à adapter le programme d'autogestion pour les maladies chroniques de Stanford à une clientèle ayant une dystrophie myotonique de type I (DMI) et évaluer son acceptabilité et sa faisabilité. **Méthodologie.** Une étude pilote descriptive a été réalisée auprès de 10 participants d'une adaptation du programme d'autogestion de Stanford (cinq adultes ayant une DMI et leur proche aidant). Une entrevue semi-dirigée et des questionnaires ont été utilisés. **Résultats.** Le programme de Stanford est acceptable et faisable pour la clientèle ayant une DMI. Des améliorations sont requises, notamment l'inclusion d'un ergothérapeute qui peut favoriser l'utilisation concrète et quotidienne de stratégies d'autogestion puisqu'il possède une expertise pour faciliter l'occupation. **Conséquences.** Bien que des adaptations soient nécessaires, le programme d'autogestion de Stanford est une intervention à privilégier auprès de clientèles nécessitant l'application de stratégies d'autogestion.

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Given the high prevalence and costs associated with long-term conditions (Mirolla, 2004), chronic disease self-management is a priority for the Canadian and Quebec health care systems (Québec Ministry of Health and Social Services, 2010). As advised by the Health Council of Canada, all agencies involved in health care should support self-management more actively and more systematically (Kitt et al., 2012). In recent years, optimization of self-management programs for chronic diseases has become a research priority, especially for nurses (Flannery, 2005; Pierce, Predeger, & Mumma, 2007) and occupational therapists (Hand, Letts, & Von Zweck, 2011). As evidence-based occupational therapy interventions work toward effectiveness (Law, Pollock, & Stewart, 2004), occupational therapists are urged to better support and promote self-management in individuals with chronic medical conditions (Piškur, 2013). To date, occupational therapists are considered to make modest contributions to self-management interventions (Richardson et al., 2014).

Self-management involves the daily tasks that individuals perform to minimize the impact of their health on their lives (Clark et al., 1991). According to Lorig and Holman (2003), self-management comprises three sets of tasks: (a) medical management of the disease, such as taking medicine and maintaining a therapeutic exercise regimen; (b) maintaining, changing, and creating new meaningful behaviours or life roles (i.e., reviewing one's roles and making the necessary adaptations or changes); and (c) dealing with emotional sequelae of having a chronic condition. Despite the lack of a consensual definition, it is usually recognized that chronic diseases involve a prolonged course of illness and a noninfectious origin (Australian Institute of Health and Welfare, 2013; Shah, 2003). Functional impairment is also present to varying degrees and is important to address given the incurability of chronic diseases (Keast et al., 2007). Considering the prolonged course of illness and the presence of functional impairment in individuals with chronic diseases, active client participation in self-management throughout life is needed (Gagnon et al., 2007; Jones, 2006).

Programs have been designed to promote the development of self-management skills based on the belief that the provision of information cannot solely achieve change in behaviour and lifestyle (Packer et al., 2012). Thus, using a systematic provision of education and supportive interventions, such programs have aimed to increase clients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support (Adams, Corrigan, & Institute of Medicine, 2003). To become a "good self-manager," clients have to be "actively engaged in their care" and "able to make decisions that support their health" (Kitt et al., 2012, p. 13). It is important to have a high level of health literacy to know how to manage symptoms and seek effective social and medical support (Kitt et al., 2012). The Stanford Chronic Disease Self-Management Program (CDSMP) is one of the most recognized self-management programs (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001), as it has been shown to be effective in populations living with common

chronic diseases, such as arthritis, chronic obstructive pulmonary disease, and diabetes (see Chodosh et al., 2005; Coster & Norman, 2009; Harvey et al., 2008; Newbould, Taylor, & Bury, 2006). Recently, a meta-analysis of 23 studies that used the Stanford CDSMP showed robust findings of small to moderate improvements in psychological health, self-efficacy, and selected health behaviours (Brady et al., 2013). Improvements were maintained after 1 year in populations with various chronic health conditions (e.g., arthritis, diabetes, chronic obstructive pulmonary disease, heart disease, lung disease, stroke, asthma, and low back pain; Brady et al., 2013). In addition, the Stanford CDSMP is recognized to improve self-management knowledge and skills, improve self-efficacy, and reduce depression symptoms (Packer et al., 2012). Utilized on a national scale, the CDSMP may be an important cost-saving solution for individuals and health care organizations (Ahn et al., 2013).

Although the Stanford CDSMP is recommended for chronic conditions (Brady et al., 2013), little is known about its impact in neuromuscular populations. These populations often face personal (e.g., lower educational level) and environmental (e.g., architectural) barriers that can hinder their ability to self-manage efficiently (Kitt et al., 2012). Among them, myotonic dystrophy type 1 (DM1) is a population demonstrating a high need for self-management education (Chouinard et al., 2009), yet a self-management program has never been assessed with DM1. DM1 is a dominant hereditary disease with multisystemic progressive involvement. A loss of muscle strength with distal to proximal progression and myotonia are the most frequent symptoms (Harper, 2004). Individuals with DM1 present with various impairments requiring close monitoring, including annual cardiac evaluation, vaccination to prevent pneumonia, and assessment of risk of falls (Gagnon et al., 2010). They also demonstrate a high level of lifestyle risk factors, such as being overweight or obese (50%), smoking (23.6%), and being physically inactive (76%) (Gagnon et al., 2013). In addition, several factors need to be considered before providing a self-management program to this population because many programs, such as the Stanford CDSMP, are not designed for them. First, clients with DM1 often have complex situations, with avoidant personality traits, fatigue, and reduced initiative (Gagnon et al., 2007; Yu et al., 2011); these features may limit their health literacy, that is, capacity to actively engage in their care, make health decisions, and navigate the system as they receive services from several partners. Second, most clients with DM1 have a low educational level (Laberge, Veillette, Mathieu, Auclair, & Perron, 2007; Perron, Veillette, & Mathieu, 1989), which can be associated with difficulties understanding their disease (Yu et al., 2011), solving problems, and learning new skills. Third, many clients with DM1 have mild cognitive impairments, lower IQ (Sistiaga et al., 2010), limited selective attention (Malloy, Mishra, & Adler, 1990), and a tendency toward cognitive rigidity (Meola & Sansone, 2007) that may hinder their ability to learn new skills. Fourth, clients with DM1 present with mobility issues (Gagnon et al., 2007) that may influence their capacity to attend the program. Finally, clients with DM1 are often characterized by a low

socioeconomic status and a lack of social support (Laberge et al., 2007; Perron et al., 1989) and access to services (Gagnon et al., 2007), which may influence their ability to implement good practices in their daily lives (e.g., exercising in a gymnasium).

Self-management programs have to be adapted to the needs of individuals with cognitive impairments (Jones, 2006) and target underserved populations affected by personal and environmental barriers (Kitt et al., 2012). In the past, the Stanford CDSMP had been adapted for specific diseases, such as diabetes or arthritis, with specific content for the disease and, at times, advocating health professionals as leaders (Lorig et al., 2001). More recently, it was adapted for cancer survivors, mostly by adding content to the program, including specific examples for the disease and simplifying the terminology (Risendal et al., 2014). The participation of caregivers might be a potential adaptation for the Stanford CDSMP for DM1, as it was successful in another type of program and with other types of clients. According to health care professionals, caregivers can support the client by providing emotional support and helping to implement the recommendations and strategies at home (Rees, Saw, Larizza, Lamoureux, & Keeffe, 2007). In addition, the exploration of involving caregivers in self-management programs with populations with cognitive impairments has been recommended (Satink, Cup, de Swart, & Nijhuis-van der Sanden, 2015). However, acceptability and feasibility of self-management programs for people with DM1 who have both mobility and cognitive impairments have never been assessed. With the agreement of the authors of the Stanford CDSMP, this study aimed to optimize this program for the population with DM1. The objectives of this study were to (a) adapt the Stanford CDSMP, (b) assess its acceptability and feasibility, and (c) propose further adaptations, including from an occupational therapy perspective.

Method

Study Design

A single-group prospective design was used to examine the feasibility and acceptability of the program based on Sidani and Braden's (2011) conceptualization and operationalization of intervention evaluations and as recommended by Bowen et al. (2009). Acceptability was described as the client's general view, continued use, and satisfaction with an intervention. The criteria used to address acceptability were the client's judgment regarding appropriateness, effectiveness, convenience, adherence, and perception of intervention risk. Feasibility was described as the adequacy of the logistics to implement an intervention with enough resources and good procedures. Feasibility was assessed by looking at the leaders' availability and quality, training, material resources, context, and fidelity to the intervention implementation. The study was approved by the Chicoutimi Health and Social Services Centre (Centre de santé et de services sociaux de Chicoutimi, Québec, Canada) Internal Review Board.

Participants

Participants were recruited from among the 500 clients with DM1 attending the regional neuromuscular clinic, Centre de santé et de services sociaux de Jonquière. Ambulatory clinics, such as neuromuscular clinics, have been recommended for self-management education (Lorig & Holman, 2003). A group of 10 to 15 participants including family members was usually targeted when implementing the Stanford CDSMP (Lorig et al., 1999). A total of 10 participants (five adults with DM1 and their caregivers) were selected by the neuromuscular nurse case managers following their annual evaluation based on (a) self-management needs and (b) motivation to change behaviours. The self-management needs were based mainly on the identification of at-risk behaviours, such as smoking, inactivity, or poor compliance with medication regimens. The willingness to change such behaviours was then considered by asking motivational interviewing questions, such as "What would you like to see different about your current situation?" (Miller & Rollnick, 2014). If the client was willing to change behaviours, he or she was offered the self-management program. Other inclusion criteria were (a) having a DM1 diagnosis (adult phenotype) confirmed by molecular analysis, (b) willingness to attend the program once a week for 6 consecutive weeks, and (c) having a caregiver willing to participate in the study. People were excluded if they presented with another condition with acute symptoms that might affect their capacity to attend a self-management program (e.g., nonstabilized mental health issue, recent stroke).

Intervention

Developed by Lorig and colleagues, the Stanford CDSMP is a 2.5-hr workshop given once a week for 6 consecutive weeks. Generally, two non-health professional leaders with a chronic disease facilitate the workshop; however, both leaders may also be health professionals or a mixed pair of leaders (Lorig et al., 2001). The sessions have a high level of participation. Mutual support and success are used to build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives. At the end of each session, participants make an action plan to implement strategies by setting short-term goals. The only document provided in the CDSMP program, *Living a Healthy Life*, covers ways to learn about one's health condition and how to adopt healthy lifestyles. Unfortunately, as it has not been translated into French, the book was not given to participants. Leaders received the certification course given by Stanford University trainers. With the consent of Lorig and colleagues, the leaders used a French translation of the Stanford CDSMP leader manual that had been translated by two native French speakers (fluent in English) and reviewed by a French-speaking reviewer from our research team and a professional editor. The program was given at the Jonquière Rehabilitation Centre, Le Parcours, in an ambulatory care setting.

To respond to the specific challenges associated with DM1 discussed above, adaptations were made according to the characteristics of clients with DM1 and discussions between

research and clinical team members (nurses, neurologist, neuropsychologist, occupational therapist). Focus groups were also used to discuss all adaptations. Lorig and colleagues consented to these adaptations.

Measures

Interview. To explore participants' perception of whole program acceptability, a semi-structured interview was conducted with each participant following the last session of the program. Topics discussed were perceptions of (a) appropriateness, (b) effectiveness, (c) possible risks and benefits associated with interventions, (d) caregivers' participation in the program, (e) program uptake and adherence, and (f) suggestions to improve the program. The interview guide was based on a previous study using the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) Framework to develop the questionnaire to assess the Stanford CDSMP (McGowan, 2007). The interview consisted of open-ended questions and was audiotaped and transcribed to minimize biases in interpreting interview responses and to provide more detail and subjective insight.

Questionnaire. A brief feasibility questionnaire with a 4-point Likert scale from 0 (*poor*) to 3 (*very good*) was completed after each session to explore participants' perception of program feasibility for each session as different topics were addressed; the topics addressed were (a) leaders' availability and quality, (b) leaders' training, (c) material resources, (d) context, and (e) fidelity to the intervention implementation. A section asking for comments about how to improve the program was provided at the end of the questionnaire to allow participants to freely express their opinion or concerns about the intervention.

Nonparticipant observations. Nonparticipant observations were made by two researchers (a nurse and an occupational therapist), who were present at every session and acted as overt observers. As recommended by Sidani and Braden (2011), the observers' role was to document how the sessions were carried out and to identify issues encountered to improve the sessions progressively during the program and provide further adaptations. Based on the criteria of feasibility and acceptability, the observers wrote their observational notes using free writing on a blank page during or immediately after each session. Occupational therapists involved in this study reviewed the participants' comments retrospectively from an occupational perspective. This review allowed the exploration, from a second viewpoint, of the opportunities for occupational therapists to better support and foster self-management without influencing the participants' and observers' responses.

Data Analysis

Using interview transcripts, a thematic content analysis was performed using a code frame to assess the acceptability of the

Stanford CDSMP. The code frame was based on the conceptualization of acceptability proposed by Sidani and Braden (2011) with the five categories of acceptability (appropriateness, effectiveness, convenience, adherence, and perception of intervention risk). As themes emerged from the interviews with participants, they were categorized and revised iteratively. We used the term *majority* when a theme recurred with more than five participants. Qualitative analyses provided more in-depth primary data. Rigorous coding was performed by the first author and reviewed by second, third, and last authors to achieve internal validity. Feasibility data were analyzed using frequency and percentage of responses to the feasibility's questionnaire. As no variation in the responses was found between sessions, all six sessions were pooled with the exception of the first one as an adaptation was made after it. Nonparticipant observers' comments were combined with participants' opinions from the comments section of the feasibility questionnaire to extract further program adaptations. Extraction was done by carefully reading comments, identifying suggestions or barriers to acceptability and feasibility topics, and discussions among researchers and observers. Then the occupational therapist researchers considered further adaptations and benefits that could result from the involvement of occupational therapists through such a program. Occupational therapists' role and competences were based on Canadian Association of Occupational Therapists guidelines described by Townsend and colleagues (2013).

Findings

Adaptations to the Program

Adaptations to the Stanford CDSMP were made considering the barriers specific to individuals with DM1, which may hinder their ability to self-manage efficiently, as identified in the literature review: (a) complex disease, (b) low educational level, (c) mild cognitive impairments, (d) mobility issues, and (e) low socioeconomic status (see Table 1). Contrary to what is customary for the Stanford CDSMP, the program was facilitated by two health professionals, a neuromuscular nurse specialist and a neuropsychologist, to ensure better comprehension of self-management strategies considering the barriers specific to the disease identified above. Nevertheless, there is no evidence that CDSMP outcomes were different whether the leaders are peers or professionals (Lorig et al., 2001). Caregivers were invited to participate in the program to support retention of information and application of strategies in daily life. All the content in the original Stanford CDSMP was given to the participants. As the book was not available in French at the moment of the program, written materials of main recommendations (e.g., on exercise or diets) were added. Throughout the workshop, the leaders used plain language to facilitate comprehension of the content. Three activities were used to engage participants and their caregivers in the program: a brainstorming session, elaboration of the action plan, and the creation of short term goals. Written materials based on the brainstorming session were also provided to

Table 1
Summary of Adaptations to and Justifications for the Stanford Chronic Disease Self-Management Program to Address Challenges Associated With Myotonic Dystrophy Type 1

Adaptation	Justification					
	Complex disease	Lower education	Cognitive impairments	Transportation issues	Lower income	No documentation
Two trained health care professionals as leaders	x	x	x			
Caregiver involvement in sessions and action plan	x	x	x	x	x	
Written materials summarizing the main recommendations		x	x			x
Inclusion of examples specific to the population with myotonic dystrophy type 1 (e.g., modification of the sleep section to include information on hypersomnolence)	x	x	x			
Translation of important concepts using plain language or visual material		x	x			

participants to promote higher retention of information by taking into consideration limited selective attention and mild cognitive impairment often present in individuals with DM1.

Description of Participants

All clients to whom the program was offered agreed to participate in the study. The participants with DM1, three women and two men, were between 42 and 53 years old (see Table 2). Four of the five participants with DM1 had an educational level of 12 years or less and were currently working. The age of the caregivers was not collected for administrative reasons. There were no dropouts, but not all participants completed the six-session program. One client and his caregiver were unable to attend one session because of an acute medical condition.

Acceptability

Appropriateness. All participants reported having learned at least one significant aspect from the program, including strategies to manage or solve physical or emotional problems. Particularly, one participant reported that he had adopted some self-management strategies. He stated, “[I have learned] breathing techniques, [have been given a] pamphlet containing exercises to do, [and have learned] distraction and emotion management strategies.” Also, one caregiver stated, “It’s really good; we become aware of many things that we can pay close attention to after implementing them.”

Effectiveness. A majority of participants perceived the program as effective for managing symptoms. One participant mentioned that “it [the program] gave me the tools to better manage them [the symptoms],” and the caregiver specified that “she [the client] is often alone. Relaxation, food programs, these are subjects that may have helped her.” Only one client with DM1 reported having no symptoms and did not find the program useful for this purpose.

Possible risks and benefits associated with interventions. The advantages or benefits perceived by a majority of participants mainly concerned the information received, discussion among participants during focus group sessions, and use of action plans. For example, a participant viewed the interactions with others and information received as benefits, and his caregiver added that the action plan was a benefit. With regard to disadvantages, emerging themes related more to feasibility than acceptability. Three participants considered some explanations to be too long (“too much talking about experience, it was not going anywhere”) and one too short (“sharing was not long enough, not enough time”). Four participants reported seeing no disadvantages. However, two believed that there could have been more demonstrations illustrating physical exercises and practical strategies.

Participation of caregivers in the program. The inclusion of a caregiver was received positively by participants.

Table 2
Participant Characteristics (n = 10)

Characteristic	Participant									
	CL1	CL2	CL3	CL4	CL5	CG1	CG2	CG3	CG4	CG5
Gender	M	F	M	F	F	M	M	F	M	F
Age in years	42	47	53	42	51	n/c	n/c	n/c	n/c	n/c
Marital status	Single	Single	Single	Married	Married	n/c	Single	Married	Married	Married
Educational level	12 years	<12 years	College	12 years	<12 years	University	12 years	College	College	12 years
Employment	Part-time job	Part-time job	Part-time job	Unemployed	Full-time job	Retired	Part-time job	Full-time job	Unemployed	Unemployed
Walking ability	Walk without AD	Walk without AD	Walk without AD	Walk without AD	Walk without AD	Walk without AD	Walk without AD	Walk without AD	Walk without AD	Walk without AD
Living situation	Living alone	Living alone	Living alone	Not living alone	Not living alone	Not living alone	Not living alone	Not living alone	Not living alone	Not living alone
Self-rated general health	Good	Poor	Very good	Good	Good	n/a	n/a	n/a	n/a	n/a
Relationship with patient	n/a	n/a	n/a	n/a	n/a	Father	Former boyfriend	Sister	Husband	Sister-in-law

Note. AD = assistive device; CG = caregiver; CL = client; n/a = not applicable; n/c = data not collected.

Table 3
Participant Perspectives Regarding Program Feasibility

Aspects	Participant perspective <i>n</i> _{pooled} ^a (%)			
	Poor	Fair	Good	Very good
Leaders' availability and quality	0 (0)	0 (0)	3 (5.2)	55 (94.8)
Leaders' training	0 (0)	0 (0)	11 (19.0)	47 (81.0)
Material resources	3 (5.2) ^b	3 (5.2) ^b	8 (13.8)	44 (75.8)
Context				
Session ambience	0 (0)	0 (0)	5 (8.6)	53 (91.4)
Contact among participants	0 (0)	2 (3.4) ^b	6 (10.4)	50 (86.2)
Physical organization	0 (0)	0 (0)	9 (15.5)	49 (84.5)
Intervention implementation				
Topics covered	0 (0)	0 (0)	10 (17.2)	48 (82.8)
Clarity of information	0 (0)	0 (0)	9 (15.5)	49 (84.5)

^aEach participant (n = 10) completed a questionnaire after each session: 10 participants × 6 sessions = 60 responses for each question; however, two participants missed one session each, resulting in n = 58 responses.

^bFirst session.

A majority of them saw a benefit in being together to discuss, share information following sessions, and learn more about what other people experience. One participant with DM1 said, "We encouraged one another, we can discuss it together afterwards, we exchanged our notes." The caregiver stated, "I really appreciated hearing the experiences of others like my brother. I learned about their worries, their problems, what they experience."

Program uptake and adherence. During the final session, the majority of participants reported daily use of self-management strategies learned during the program. For example, one participant reported, "[I have used] relaxation, breathing techniques, watched less TV and it seems like I need less sleep than before." Another participant acquired a new set of physical activity habits: "[I do] more exercises than usual. I used to do less exercises, it helped me to do more."

Feasibility

Results revealed that feasibility was perceived to be "very good" by the majority of the participants for each aspect over the six sessions (see Table 3 above). Among feasibility topics, the leader's competency was the most appreciated aspect for each session, followed by the session atmosphere. The first session was perceived by some as poor and fair in terms of content and contact between the participants, respectively. In the comments section, participants mentioned having felt that visual support was insufficient. Written material was provided to the group from the second session onward. After this material was added, neither comments nor challenges in the adequacy of the logistics to implement the program reported by participants could be adjusted.

Table 4

Observer and Participant Suggestions for Improvement Regarding Further Adaptations Associated With Reflections on Opportunities for Occupational Therapists to Better Support and Promote Self-Management

Topics	Suggested improvement	Opportunities for occupational therapists
Acceptability		
Effectiveness	Provide demonstrations for both the proposed exercises and self-management strategies to improve efficacy of teaching.	By identifying significant activities of participants and using occupational analysis, occupational therapists can better adapt exercises to this population and use exercise simulation to provide demonstrations and give client-centred feedback.
Possible risks and benefits associated with interventions	Ensure supervision during discussion session to prevent them from being too long or too short.	Being skilled in group dynamics and able to handle diverse communications, occupational therapists might optimize discussion sessions.
Caregivers' participation in the program	Include a specific session on the role of caregiver as "coach" in self-management process.	Occupational therapists could support caregivers in developing the role of coach, as they possess knowledge on coaching, mentoring, and training.
Program uptake and adherence	Involve an occupational therapist to help facilitate transition of skills learned to daily life.	By using knowledge of occupation and occupational analysis, they might give specific cues regarding problem solving and action plans. They also might help to anchor self-management strategies with concrete day-to-day aspects as they possess expertise in enabling occupation.
Feasibility		
Material resources	Prepare a participant notebook to facilitate the collection and classification of documents. Use technological support (e.g., slide show) to facilitate visual support used.	As occupational therapists are able to adapt their communication approach, they can help create notebooks and slide shows adapted to specific barriers known for this population.
Context	Create a more conducive learning environment (e.g., in a smaller room).	By using analysis of person-occupation-environment, occupational therapists might propose physical design options to improve the learning environment.

Further Program Adaptations

The observers as well as four out of 10 participants, including one person with DM1, made suggestions for improving the program in terms of acceptability and feasibility (see Table 4). Occupational therapists may also be involved to better support and promote self-management. Five participants reported having no comments to make, while one participant did not mention anything. The observers suggested that the program could benefit from some modifications. They noted that participants with DM1 asked questions, and the role of the caregivers was not clear. Therefore, they proposed adaptations in response to these observations. The involvement of an occupational therapist was suggested to help facilitate program uptake and adherence. Nevertheless, occupational therapists might support and promote self-management in many ways. Suggestions provided by observers and participants represented opportunities for occupational therapists to make contributions to self-management interventions. Indeed, by having a central expert role in enabling occupation, supported by six complementary roles (communicator, collaborator, practice manager, change agent, scholarly practitioner, and professional; Canadian Association of Occupational Therapists, 2012), occupational therapists might develop creative or novel ways of doing things to support self-management in programs, such as CDSMP, and with complex diseases, such as DM1. For example, an occupational therapist could help to anchor self-management

strategies in daily occupations by identifying participants' significant activities and analyzing them, simulating practice of self-management skills, and giving immediate feedback.

Discussion

To the best of our knowledge, this is the first study to assess the acceptability and feasibility of a self-management program in individuals with DM1. In addition, this study focused on clients' needs as adaptations to the program were made prior to implementation. Participants' perception of program effectiveness was acceptable, although they saw the need for some improvements. In general, the adapted Stanford CDSMP is feasible in the context of ambulatory care in health care institutions, such as rehabilitation centres or neuromuscular disease clinics (Lorig & Holman, 2003). According to participants, the program had certain disadvantages related to its feasibility rather than its acceptability. A majority of participants found that there was a benefit from the inclusion of the family caregiver, a finding that concurred with a study by Rees et al. (2007) examining the efficacy of group-based rehabilitation programs for adults with low vision. This latter study noted that caregivers can help retain information while being sensitized to other participants' experiences. In the present study, though, contrary to Rees et al., participants raised no points regarding the implementation of strategies at home and mobility problems. In a study of

clients with common chronic conditions (e.g., diabetes) enrolled in an occupation-based self-management program, partially based on the Stanford CDSMP and the Lifestyle Matters program, participants had positive views concerning peer learning, the group atmosphere, social interaction, goal setting, and the participant workbook (O'Toole, Connolly, & Smith, 2013). Although the content and outcomes of the interventions were focused mainly on occupation in the occupation-based self-management program, in the present study, similar views emerged with respect to acceptability and feasibility, with the participants' perception that peer learning is beneficial and that the group atmosphere was "very good" after the first session. In a study aiming to determine the acceptability of peer- and health professional-led self-management education using the Stanford CDSMP with Australian veterans and their partners, it was found that information provided on self-management was helpful and relevant (Beattie, Battersby, & Pols, 2013). As in our study, this study by Beattie et al. (2013) also identified obstacles to effective learning (e.g., very large space where voices had to be raised because of ambient noise or distance between speakers).

As the study by Beattie and colleagues (2013) mainly focused on veterans (e.g., content on alcohol problems was added), few of the recommendations made to improve their program were comparable to those formulated in the present study. Their suggestions mainly focused on increasing the duration of the program, including partner-specific issues and content, embedding alcohol-related issues into the content, or adding content specific to the veteran community. In our study, the main elements identified for improvement were (a) clarifying the role of the caregiver, (b) rethinking certain elements regarding how meetings are conducted (e.g., material resources, demonstrations, physical environment), and (c) involving an occupational therapist to help facilitate the transition of skills learned to daily life. To follow the example in the study by O'Toole et al. (2013), we believe that the involvement of an occupational therapist could help improve the acceptability and feasibility of the Stanford CDSMP for clients with DM1. Eight weeks following the conclusion of an occupation-based self-management program, this latter study showed benefits with respect to self-esteem and participation in productive and leisure activities. In fact, possessing expertise focusing on enabling occupation with supporting roles, such as scholarly practitioner and change agent (Canadian Association of Occupational Therapists, 2012), occupational therapists might be key in creating, modifying, and delivering self-management programs for persons with neuromuscular diseases and/or a certain degree of cognitive impairment. According to Piškur (2013), the contribution of occupational therapy is essential to self-management to provide people with information on chronic conditions and support with decision making related to their meaningful activities. As stated by Packer (2013), "self-management is gained through conscious and planned engagement in specifically structured occupation" (p. 2). To foster generalization of increased

skills, practical implementation of the concepts, and participants' active commitment, it is important to give more support to clients with DM1 with respect to the adoption of strategies, especially by anchoring the self-management program to concrete day-to-day aspects of clients' lives. These improvements aim to increase the acceptability and feasibility of the Stanford CDSMP in clients living with DM1.

Study Limitations

The convenience sample for this study was based on the judgment of nurses concerning the clients' willingness to attend a self-management program; thus selection bias cannot be completely excluded. In addition, most participants were employed, which may imply high potential for self-management skills. Even though participants were asked to complete the questionnaires and interview with the answers they considered correct, a potential social desirability bias could have resulted in overestimating the acceptability and feasibility of the program. Although this limited the fidelity of the evaluation of the intervention implementation as a feasibility criterion, the nonparticipant observers helped by reflecting on whether the content was covered adequately. In addition, as is often the case with individuals with cognitive limitations, superficial responses were provided by clients, especially on questions with a more abstract focus. Finally, as the book *Living a Healthy Life* was not provided to the participants, possible complementary information may not have been available to participants.

Future Research

The role of an occupational therapist in delivering and adapting the program should be explored, in particular with respect to facilitating the efficient transfer of the skills learned to daily life. Further studies using the Stanford CDSMP with the population with DM1 should also be done to evaluate effects and improvements in a larger sample and with a control group.

Conclusion

This pilot study provided an overview of the acceptability and feasibility of the Stanford CDSMP for a specific population, people living with neuromuscular disorders. The program is acceptable and feasible for this population, although it requires improvements to address gaps identified by participants and observers.

Key Messages

- The Stanford Chronic Disease Self-Management Program is acceptable and feasible for use with individuals with myotonic dystrophy type 1.

- Some improvements related to the conduct of the sessions and the caregiver's role during the program are needed to increase its feasibility and acceptability.
- Because of its occupational perspective, the inclusion of occupational therapists is a potential solution for improving this self-management program.

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Book Review

Block, Pamela, Kasnitz, Devva, Nishida, Akemi, and Pollard, Nick. (Eds.). (2016). *Occupying disability: Critical approaches to community, justice, and decolonizing disability*. New York, NY: Springer. 394 pp. US\$139.00. ISBN: 978-94-017-9983-6

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Claiming to build on “politically engaged critical approaches to disability that intersect ... occupational therapy, disability studies and anthropology” (p. 3), this book “explores the concept of ‘occupation’” and aims to “give occupational therapy scholars, students, and practitioners more complex theoretical approaches to disability using anthropology and disability studies” (p. 6). These are worthy goals, although the choice to include these particular perspectives and not, for example, those also of political science, sociology, education, law, literature, geography, history, and philosophy (that have all contributed valuable, critical work addressing disability in the context of colonialism, community, and justice) is not explicated. In reality, many of the chapters do not employ theoretical insights from anthropology or disability studies, and few address the relevance of their material to occupational therapy. The various authors address disablement in Australia, Brazil, India, Jamaica, Japan, Palestine, and the United Kingdom. Sadly, because most of the chapters derive from the United States, so does most of the cited scholarly literature, and the book largely disregards the wealth of critical disability scholarship that has arisen, for example, in England, India, the Middle East, and France during the past four decades. It also ignores most of the important and critical work published in the journal *Disability and Society*.

The aim of this book is tremendously important, and it is regrettable that so few occupational therapy scholars have engaged with the vast and valuable literatures generated by disability activists and critical (postcolonial, queer, critical race, and critical feminist) disability scholars. But a few *have* done

so. It is therefore both regrettable and bewildering that this book references very little of the published work of those occupational therapists who have already contributed “to push the boundaries of how occupational therapy/science approaches disability” (p. 4) as this book purports to be the first to do.

As with all edited books, the quality of the chapters is uneven, with a few truly critical, insightful, and thought-provoking contributions (most notable is chapter 11, by Mansha Mirza et al.) mixed in with some that would have been better suited to online blogs. The book is expensive (although individual chapters are available for purchase in electronic format), so the decisions underpinning the inclusion of chapters were important. Thus the choices to include, for example, a chapter focused on police violence at an “Occupy” protest in 2011 and one on Israel’s occupation of Palestine are puzzling. While I wish neither to negate the importance of these injustices nor to overlook the play on the ambiguous English word *occupation* that they underline, their importance in broadening occupational therapists’ understanding of critical disability perspectives is minimal. Further, many of the chapters take an atheoretical approach, favouring personal anecdotes of individual struggles or poetry over critical analysis. This is not to deny the value of individual narratives or creative expressions but, rather, to argue that these ought not to be misconstrued as constituting the “complex theoretical approaches” that the book promised. Moreover, because occupational therapists are already attuned to hearing individual life stories, the contributors’ valuable opportunity—to identify, explore, and theorize those structural and ideological forces that create and perpetuate inequities and injustices for so many disabled people—was often squandered. While I believe passionately in the stated intent of the book, there is a great wealth of published scholarly, artistic, and activist work that provides more insight into critical and complex theoretical approaches to disability, decolonization, and justice than has been accomplished by *Occupying Disability*.

Karen Whalley Hammell

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