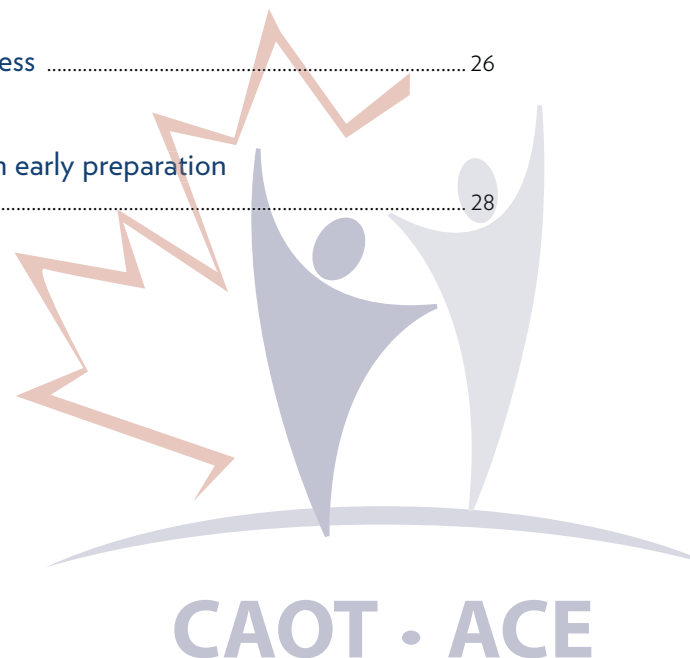


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# An occupation-focused approach to self-management

Tanya Packer

*“It is the looming epidemics of heart disease, stroke, cancer and other chronic diseases that for the foreseeable future will take the greatest toll in deaths and disability. It is vitally important that the impending chronic disease pandemic is recognized, understood and acted on urgently” (World Health Organization, 2005, p. 34).*

The growing incidence and prevalence of chronic disease is fundamentally changing the relationship between ‘patients’ and ‘providers’ in a very exciting way. Creating partnerships of ‘informed, activated patients’ (experts in their own life context and circumstances) and ‘prepared, pro-active practice teams’ (experts in disease) - is at the heart of that change (Barr et al., 2003).

Bodenheimer, Lorig, Holman, and Grumbach (2002), in the *Journal of the American Medical Association* argue that supporting clients to self-manage requires a paradigm shift. Traditional western medicine is based on the assumption that receipt of information from a health care expert results in behaviour change and/or adherence to advice and that this sequence of events results in better health outcomes. The self-management approach, by contrast, assumes that people understand their own life circumstances and take action based on internal motivation and a sense of confidence in their ability to succeed. Knowledge alone does not result in self-management; knowledge accompanied by information, confidence and support does. Professional competencies required to support client self-management are indeed different than those required to manage a chronic condition.

As a student occupational therapist I learned that living with a disability was more than the condition itself with potential impact on all aspects of a person’s daily occupations. This was reinforced when I travelled to Russia with leaders from Disabled Peoples International, when I visited the homes of families in China and when working with people with multiple sclerosis in Canada and Australia. I also learned the power of occupational therapy’s client-centred and occupation-

focused approaches. To see these concepts embedded in wide-sweeping health care reforms brings a sense of awe and excitement, and the realization of responsibility. Awe that occupational therapy theories and practices hold solutions to today’s critical problems, excitement at the opportunity to improve the lives of Canadians, and an overwhelming sense of responsibility. This special issue of *Occupational Therapy Now* demonstrates the profession’s unique successes in the self-management arena and highlights its’ responsibilities – with awe and excitement.

The original qualitative work of Corbin and Strauss (1988) is considered landmark in the understanding of self-management. They identified three forms of ‘work’ involved in living with a chronic condition(s): management of the symptoms and condition, management of the associated emotional consequences, and management of the effect on daily activities and routines. *Working to manage chronic illness in daily life* by Anne Townsend in this issue eloquently articulates the magnitude and extent of this ‘work’.

Self-management programs build self-efficacy (confidence) through problem solving, decision making, action planning and behavior change as strategies to accomplish the ‘work’ of self-management. Ways to successfully navigate the health care system and work in partnership with health providers are typically included. *Listening to clients: Self-management strategies to stay well with bipolar disorder* by Sandra Hale articulates how people find their own self-management strategies and together with Anne’s article reminds us that the relationship between health care professionals and clients with chronic conditions is a partnership, and that professionals must stop and listen in addition to contributing their professional experience.

Occupational therapy’s long standing focus on the ‘work’ of every day occupations is translated into two unique features of occupational therapy self-management programs:

- 1) a deliberate and proactive approach to supporting people

## About the Guest Editor

**Tanya Packer, PhD, OT Reg. (NS)** is Professor and Director at the School of Occupational Therapy at Dalhousie University in Halifax. She holds a cross-appointment in the School of Nursing and is a member of the Brain Repair Centre, also at Dalhousie. Having recently worked in Perth, Australia she continues to hold a position as Adjunct Professor at the Curtin Health Innovation Research Centre. Over the last ten years Tanya and her students have attracted over three million dollars in research funding for self-management research in vision loss, fatigue, and cancer. She authored the Self-Management Strategy for the Western Australian Department of Health, and has served on task forces in Australia and Canada working to develop workforce self-management competencies. Returning home to Canada in 2010 she, Co-principle Investigator Dr. Joan Versnel and their team have been funded to study The Everyday Experience of Living With and Managing Life with Neurological Condition – the LINC study, funded by the Public Health Agency of Canada as part of the National Population Study of Neurological Conditions. Tanya is very keen to meet others working in the area and can be reached at Tanya.Packer@dal.ca.

to self-manage the emotional and daily consequences of life with a chronic condition(s);

- 2) a focus on diverse and often unseen groups within the self-management literature - programs for people whose condition is not significantly modified by management of symptoms, medications or lifestyle factors (diet and exercise).

While working with people with vision and fatigue problems, my research students, colleagues and I coined the term pARTicipation to emphasize that when living with a chronic condition, participation in every-day occupations is an ART; an acronym for self-management of Activities, Relationships and Treatments. Our results show that self-management interventions, focused on activities and relationships do result in improved participation, quality of life and even reduction of some symptoms (Ghahari, Packer, & Passmore, 2010; Girdler, Boldy, Dhaliwal, Crowley & Packer, 2010). The article *Every-day participation: Important outcomes for people with chronic conditions* by Haley Augustine and Jennifer Roberts (two of my current students!) examines participation as an outcome measure in research studies. They emphasize the need to double efforts to ensure that participation is a valued and measured outcome.

Innovative, occupation-focused programs with positive outcomes are featured throughout this issue. *Occupational therapy in migraine headache self-management* by Allison McLean and Kathryn Coutts describes a unique program for people not typically served by self-management programs; the case study included is particularly poignant and illustrates the importance of the focus on everyday occupation. Including new lifestyle patterns into daily routines does not occur automatically for people with cardiac conditions. *Creating Heart-happy occupations in a cardiac rehabilitation circuit* (by Catherine White and Paula Buyting) builds confidence to bridge the gap between hospital and home. Not only are diverse groups the focus of occupational therapy interventions, *Occupational therapists on-line: Equity of access to fatigue self-management*, by Setareh Ghahari, describes positive outcomes of an online fatigue self-management program.

Youth with chronic conditions who have a lifetime to benefit from self-management receive special attention in this issue. *You're in Charge: Engaging youth in designing and delivering an early preparation self-management program* by Joan Versnel describes benefits for two groups; for youth age 13-15 attending the program and the slightly older youth who designed and delivered this innovative program. Youth transitioning from paediatric services at Holland Bloorview Kids Rehabilitation Hospital to adult services at Toronto Rehabilitation Institute benefit from the myHealth program (*myHealth: Taking charge of your health care*, by Bronwen Moore, Christine Stapleford, & Joanne Maxwell) proving that services can and do work together for the benefit of youth. These two articles demonstrate how young people can become active self-managers and designers of exciting, empowering transition programs. Finally, the importance of families in the lives of people with chronic conditions cannot be overstated. Susan Doble, Susan Hutchinson and Grace

Warner encourage us to take a new view of the family with a client-centred, family-focused lens in the article *Family members as potential support persons: Moving ideas into practice*.

This special issue underscores the unique focus of occupational therapists in supporting people to self-manage life with a chronic condition. I hope you will be awed and excited. Whatever your role or responsibility in health care, I hope you will be a supporter for Canadians living with and self-managing chronic conditions.

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# Occupational therapy: Self-management for people with migraines

Allison McLean and Kathryn Coutts

Approximately 18% of the population has migraine headaches (Lipton et al., 2001). In addition to moderate to severe head pain, associated symptoms can include nausea, vomiting, and sensitivity to light or sound (International Headache Society [IHS], 2004). If left untreated, migraines can last up to several days. The migraine pain may be preceded by an aura (vision changes, numbness, pins and needles, speech problems, and/or dizziness) and followed by a period of excessive fatigue, concentration difficulty, and/or light-headedness (Ng-Mak et al., 2011).

Migraine is most prevalent between the ages of 25 and 55 years (Lipton et al., 2001), generally considered the most productive years of a person's life. Self-reported rates of work absenteeism and presenteeism (decreased performance while at work) have been documented at 31% and 51% respectively (Lipton et al., 2001). Disability in household management, social activities, and family activities has also been reported (Leonardi et al., 2010; Stewart et al., 2003).

## Calgary Headache Assessment and Management Program (CHAMP)

CHAMP is an outpatient headache program within Alberta Health Services. The majority of clients have migraine. The CHAMP team is multidisciplinary, and program components are presented within a self-management model, where the emphasis is on clients taking an active role in their headache management.

All CHAMP team members promote self-management as a means to manage migraine symptoms. However, the occupational therapists add a unique dimension to self-management by utilizing it as a means to (1) restore or maintain engagement in valued tasks (or 'occupations') that have been disrupted by migraine and (2) achieve a satisfying balance amongst self-care, productivity, and leisure occupations. Both occupational engagement and

occupational balance are thought to promote health and well-being (Aegler & Satink, 2009; Backman, 2004). Further, the CHAMP occupational therapists assist with (1) brainstorming creative ways to incorporate self-management strategies into everyday occupations; (2) identifying and eliminating barriers to self-management; and (3) analyzing home and/or work environments to determine potential migraine triggers. Interventions are carried out through a collaborative relationship with the client, and are based upon deficits in occupational performance identified and prioritized by the client. Sometimes the occupational therapy involvement is brief and direct (such as assisting a client to position a computer monitor to minimize awkward neck postures and glare). At other times, the occupational therapy involvement is more in-depth and process-oriented. This includes exploring unhelpful beliefs and self-talk that lead to migraine-triggering approaches to daily occupations, such as over-scheduling or perfectionistic thinking. With the occupational therapist coaching, the client learns how to make adjustments to their self-talk that enhance function and reduce migraine trigger-load. CHAMP occupational therapists are involved in the education session, the self-management workshop, the relaxation workshop, the sleep lecture, the lifestyle assessment and in workplace support.

Interventions that facilitate migraine self-management frequently include behavioural strategies. Many have been associated with reduced headache frequency, intensity, and disability, and are generally long-lasting (Buse & Andrasik, 2009). The behavioural strategies most frequently addressed at CHAMP are trigger identification and management, lifestyle adjustments, relaxation strategies, pacing, and cognitive-behavioural therapy (CBT). Through practice of behavioural strategies, clients begin to develop a sense of confidence that they can take action to help themselves. This sense of confidence, called self-efficacy, has been associated with less migraine-related disability (French et al., 2000).

## About the authors

**Allison McLean, MSc OT**, is employed at CHAMP. She is a University of Alberta graduate (1990 undergraduate and 2001 Master's degree). Allison has worked in Canada and the U.S. in work rehabilitation, ergonomics, chronic pain, and psychiatry. She may be reached at Allison.McLean@albertahealthservices.ca.

**Kathryn Coutts, BSc OT**, is a graduate of the University of Alberta (1990). Kathryn has worked as an occupational therapist in Canada, England and New Zealand. Her areas of specialty include psychiatry, addictions, and chronic pain management. She has been with CHAMP for five years and may be reached at Kathryn.Coutts@albertahealthservices.ca.

Having confidence to help themselves also reinforces to clients that some migraine triggers are within their control, and this knowledge can be empowering (Table 1).

Other migraine triggers are outside a person's control, and

**Table 1. Common migraine triggers within a person's control**

Common Migraine Triggers Within a Person's Control	
• Stress	• Overexertion/over-scheduling
• Skipped meals	• Bright light, fluorescent lights, computer screen glare
• Dehydration	• Prolonged awkward postures
• Dietary	
• Excessive caffeine use	
• Too little/too much sleep; unregulated sleep hours	

by learning to better manage their controllable triggers, clients can reduce their overall trigger load. Consequently, triggers outside of their control (e.g., weather changes) may produce a less severe migraine, or even no migraine at all.

Lifestyle or behavioural treatment recommendations for migraine clients can sound simple enough (e.g., "learn to manage stress better, get more sleep, and start exercising"). However, the implementation of these practices often proves challenging. During a lifestyle assessment, the CHAMP occupational therapist helps the client explore their unique challenges and barriers to incorporating migraine-friendly daily living practices. The client is also introduced to the headache diary, an important self-monitoring tool (Headache Network Canada, 2005). Monitoring and recording various aspects of their migraines reinforces client awareness, choice, and responsibility in better migraine management.

CHAMP clients have reported that activity pacing is a useful self-management tool (Sauro & Becker, 2008). This powerful behavioural approach incorporates prioritizing and planning activities, and balancing activity with rest. Clients report that activity pacing helps them to prevent over-scheduling, a common migraine trigger.

The majority of clients at CHAMP derive greatest benefit from a combination of behavioural interventions and medications. Preventative medications are taken daily, resulting in people being less migraine-prone over time. Symptomatic medications are taken for individual migraine attacks. Balancing medication use with effective behavioural and occupational strategies can help ensure appropriate use and maximum benefit from the medications. For example, excessive daily use of caffeine can raise the client's trigger load, reducing the effect of the preventative medication. As the client develops confidence in self-management strategies, it helps the client to be less reliant on symptomatic medication as a primary coping tool, thereby preventing medication-overuse headaches.

The CHAMP occupational therapist facilitates the self-management workshop, where a small group of clients support each other in practicing new behaviours and migraine self-management skills. These behaviours include relaxation or

meditation practice, activity pacing, positive self-talk, and assertive communication. Debbie, a recent participant, experienced great success through the workshop, and hopes to inspire others by sharing her story.

### Case study



**Kathryn Coutts (L), self-management workshop facilitator and Debbie (R), CHAMP client.**

Debbie is a 47-year-old CHAMP client with a diagnosis of migraine without aura. Her migraines began in her teenage years, but had become more frequent and severe in the past year. When she first presented to CHAMP in 2010, she reported 20-24 migraine days per month. With each migraine attack, she experienced moderate-severe head pain, nausea, dizziness, and sensitivity to light, noise and smell. These symptoms led to fatigue, and impaired focus and concentration, which affected her performance in work, exercise, housework, meal preparation and driving occupations. She hesitated to commit to any social/family plans for fear of having to cancel or be 'trapped' somewhere with a severe migraine. Debbie came to realize that her overall approach to activity was to 'push through' to get to-do lists done and to please others. Debbie wanted to attend the self-management workshop in order to learn how to manage her stress and over-exertion migraine triggers and to improve her quality-of-life with migraines. Figure 1 illustrates Debbie's perceptions regarding her migraine challenges and resources at the outset of the self-management workshop.

As illustrated in Figure 2, Debbie has developed more resources for coping, and is managing her migraine triggers (challenges) with more confidence: "I realize I have choices and I feel more control over my migraines now." She effectively balances her new behavioural strategies with a stable medication regime, and has cut her migraine frequency in half. She has improved confidence to stabilize the intensity of the migraine attacks she still gets. Debbie has also developed a sustainable, migraine-friendly approach to her everyday occupations: "I am living again". For example, she describes a new comfort level with pacing her activities in response to her own needs versus always pleasing others; she now prioritizes engagement in self care and leisure occupations rather than waiting until all of her productivity occupations are completed. Debbie has applied to work with

Figure 1. Debbie's resource-challenge profile prior to the self-management workshop.

<b>Resources</b> (coping skills that give me control over migraines)	<b>Challenges</b> (things that give the migraines power)
<p>Some exercise                      Staying hydrated</p> <p>No caffeine                          Regulated sleep hours</p> <p>Eating Regularly</p>	<p><b>Hormones</b> menstrual period</p> <p><b>Ignoring early symptoms of migraine</b>  <ul style="list-style-type: none"> <li>• pushed through to complete to-do list</li> </ul> </p> <p><b>Limited awareness of early stress symptoms</b>  <ul style="list-style-type: none"> <li>• stress trigger unmanaged</li> </ul> </p> <p><b>Passive style of communication</b>  <ul style="list-style-type: none"> <li>• did not set limits</li> <li>• did not get own needs met</li> </ul> </p> <p><b>Migraine</b></p> <p><b>Pattern of over activity-under activity</b>  <ul style="list-style-type: none"> <li>• frustration due to unpredictable function</li> </ul> </p> <p><b>Distorted thinking</b>  <ul style="list-style-type: none"> <li>• “I’m not working so I should at least keep the house clean and entertain friends”</li> </ul> </p> <p><b>Unhelpful beliefs</b>  <ul style="list-style-type: none"> <li>• Chores must be completed before the reward of leisure</li> </ul> </p>

Figure 2. Debbie's resource-challenge profile following the self-management workshop.

<b>Resources</b> (coping skills that give me control over migraines)	<b>Challenges</b> (things that give the migraines power)
<p>Regular exercise                      Staying hydrated</p> <p>No caffeine                          Regulated sleep hours</p> <p>Eating Regularly                      Diaphragmatic breathing in response to stress</p> <p>Planning &amp; prioritizing to prevent over-scheduling                      Prioritizing leisure  <ul style="list-style-type: none"> <li>• reading</li> <li>• projects</li> <li>• bath time</li> </ul> </p> <p>Coping style self talk “I will do relaxation &amp; stretching, then see how I feel”                      Assertiveness  <ul style="list-style-type: none"> <li>• Asks for help</li> <li>• Re-schedules social time as needed</li> </ul> </p>	<p><b>Hormones</b></p> <p><b>Occasional dehydration</b></p> <p><b>Migraine</b></p> <p><b>Other medical condition can trigger migraines</b></p>

the Federal Census as a way to ease back into a paid work role. If her energy level and migraine management remain stable during that time, she plans to look for part-time work in her own field in September 2011.

Debbie's sense of success is consistent with all four

components of CHAMP's definition of successful migraine self-management (see Table 2).

**Table 2. CHAMP's successful migraine self-management definition**

Successful Migraine Self-Management
Defined at CHAMP as one or more of the following: a) Reduced frequency, intensity and/or duration of migraines b) Improved daily function despite some migraines c) Quality of life improvement/satisfaction d) Sense of control over migraines

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# Everyday participation: Important outcomes for people with chronic conditions

Haley Augustine, Jennifer Roberts and Tanya Packer

According to the World Health Organization (WHO) 35 million people died in 2005 from chronic diseases equating to more than 60% of the deaths worldwide (WHO, 2005). As chronic disease has reached epidemic proportions, the cost to the healthcare system will also continue to grow. Self-management programs will play a critical role in government decisions, the healthcare system, and the public at large (Health Canada, 2007).

The effectiveness of these programs is determined through the outcomes reported. Given that self-management programs are intended to extend beyond medical outcomes, it is important to understand the frequency and type of outcomes being reported. Goals of such programs are to empower the client to manage their disease, relationships, cognitive and emotional reactions, and the impact on everyday life. The role of occupational therapy is well suited to develop and implement self-management programs and to expand the outcome measures to include participation and engagement in everyday life. This review was completed to describe the types of outcomes currently being used to measure chronic disease self-management programs and examine the potential role of occupational therapy in the development and measurement of self-management using client-centred assessment and treatment.

## Design

A 'systematic review of systematic reviews' was used to measure the type and proportion of outcomes reported in systematic reviews on chronic disease self-management. The outcomes of the systematic reviews were categorized into health outcomes, health utilization, participation, or quality of life according to the definitions outlined in Table 1.

## Procedure

The databases Cochrane, CINAHL, Pubmed, OT seeker, and Embase were searched using the terms self care program, self management program, self care strategies, self management strategies, self care intervention and self management intervention.

Systematic reviews were included if they assessed the effectiveness of chronic disease self-management programs in adult populations (>18 years old), examined any chronic disease, were in English, and published between 2008 and 2011. To address inter-rater reliability, five of the articles were first assessed independently by the two authors and then compared. Eighty per cent agreement was set as the acceptable level of agreement. The remaining articles were then divided equally for review. When there were doubts regarding categorization, articles were jointly reviewed and decisions made by consensus.



**Table 1. Definitions**

Health outcomes	Any measurement of health status including both physical and emotional health. (e.g., shortness of breath, pain, range of motion or other biomedical markers).
Participation in everyday activities	Measurement of how chronic disease or disability impacts on occupations of daily living with consideration of the person, environment and their occupations (e.g., activities of daily living, functional assessments, days missed from work, self-efficacy).
Health utilization	Measurement of health care service utilization (e.g., emergency room visits, costs of health care services, medication use).
Quality of life	Measurement of self-reported quality of life (e.g., health related quality of life).

## Data extraction

The outcomes reported in systematic reviews that met the inclusion criteria were classified, recorded and summed. The frequency of the outcomes that fit in each category (health outcomes, health utilization, participation, and quality of life) was recorded. These were expressed as a percentage of the total number of outcomes. The number and percentage of reviews that included each of the four types of outcomes was also calculated.

## Main findings

Thirty-two systematic reviews met the inclusion criteria and were included. There was 90% agreement with respect to inter-rater reliability for the five articles independently reviewed and compared. From the 32 systematic reviews, a total of 190 outcomes were categorized into the four variables (Table 2). The number and percentage of outcomes in each category were health utilization 44(23%), participation 23(12%), health outcomes 105(55%) and quality of life 18(9%).

**Table 2. Systematic review outcomes classified into 4 variables from 32 systematic reviews.**

	Health utilization	Participation	Health outcomes	Quality of life	Total
Total	44	23	105	18	190
Percentage	23.16%	12.11%	55.26%	9.47%	100.00%

Of the 32 reviews 18(56%) reported health utilization outcomes, 17(53%) reported participation outcomes, 27(84%) reported health outcomes and 17(53%) reported quality of life outcomes (Table 3).

**Table 3. Number of systematic reviews that had each of the respective outcomes.**

	Health utilization	Participation	Health outcomes	Quality of life
Number of SRs with Variable	18	17	27	17
Percentage	23.16%	12.11%	55.26%	9.47%

## Discussion

Out of 32 reviews, 27 reported on health outcomes. The results demonstrate that the majority (55%) of outcomes reported in systematic reviews were health outcomes, mostly biomedical markers. Participation in everyday activities represented only 12% of the total outcomes with a total of 47% of the systematic reviews making no mention of participation as an outcome following self-management programs. Closer scrutiny revealed that the majority of these were self-efficacy measures which suggests improved activity participation but is not a direct measure of everyday activity. Additionally, the specific outcomes reported in the systematic reviews varied widely, highlighting the inconsistency of the measures used to evaluate self-management programs.

Quality of life as an outcome measure may have been under-represented in the data. While 53% of articles included a quality of life measure, it represented only 9% of the 190 outcomes reported. Systematic reviews often include studies of programs designed for people with different conditions. Quality of life is a singular concept applied to all participants regardless of condition. Conversely, biomedical markers are specific to each condition. For example, if a systematic review is combining information on arthritis and diabetes, the quality of life measurements is the same for both conditions whereas biomedical markers for the two diseases will differ. This may also be true of outcomes related to everyday participation.

## Goals of self-management programs

These results suggest that the outcomes currently used to evaluate self-management programs may need to be expanded. As defined by Effing (2009) self-management programs “teach the skills needed to carry out medical regimes specific to the disease, guide health behaviour change, and provide emotional support for patients to control their disease and live functional lives.” Measuring only health outcomes may be insufficient to demonstrate effectiveness of all self-management program goals. For example, if one were to measure the effectiveness of a self-management program for individuals with arthritis using range of motion (ROM) as the outcome, the program may be reported as ineffective. However, the individual’s participation and quality of life may improve from such an intervention (Iversen, Hammond,

& Betteridge, 2010). Disease specific measurements do not necessarily reflect an individual's participation or quality of life, which may be improved by self-management programs (Ditewig, Blok, Havers, & Veenendaal, 2010). Therefore, the evaluation of self-management programs may be enhanced by consistently including outcomes that match all the program goals, including participation.

The results of this research indicate that there may be a gap between the purpose of self-management programs and what the programs are truly accomplishing, as measured by the outcomes. If the predominant outcomes being measured are health outcomes, this raises the question; are self-management programs truly accomplishing what they claim (i.e., to support people to manage the emotional consequences and the impact on every-day life participation)? It is possible that the outcome measures being used are insufficient to truly capture complete program effectiveness. Alternatively, programs may have focused only on biomedical markers also limiting the content to managing the disease itself. Regardless, if the purpose of self-management programs is indeed to increase every-day participation, the majority of current outcomes are not appropriately assessing the purpose.

### The role of occupational therapy

Occupational therapy is “the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life” (Townsend & Polatajko, 2007, p. 372). Occupational therapy is well suited to play an active role in the development and implementation of self-management programs for persons with chronic disease that are focused on client-centred outcomes such as participation in a chosen lifestyle. Occupational therapists assess engagement in everyday life using client-centred outcomes to evaluate therapeutic interventions. However, self-management programs need to be specifically evaluated with regards to these positive effects in order to justify the need and value of such programs. The current role of occupational therapy with respect to self-management is under-utilized. If occupational therapy is not involved in the design and implementation of these programs the under-representation of participation in the evaluation of self-management programs may continue. The implementation of a reliable and valid measure of participation would shift the focus of outcomes towards the intended goals of self-management programs and ultimately benefit the client. Occupational therapists are encouraged to measure the effectiveness of self-management programs using outcomes that measure participation.

### Future trends in research and practice

A systematic review with participation as the key outcome would further inform our understanding of the effectiveness of self-management programs in this area. It would also inform the apparent scarcity of valid and reliable research tools available to measure this key client outcome. Within the practice arena, a fresh look at the content and focus of programs would ensure that people with chronic conditions are provided with the support needed to manage not just their disease but also the impact on the occupations of everyday life.

This study aimed to provide information on the relative proportion of outcome variables (health outcomes, participation, health utilization, and quality of life) reported in systematic reviews on chronic disease self-management. This information may lead to future research to understand how occupational therapy may improve self-management programs with a client-centred approach and focus on participation and engagement in meaningful occupations. The outcomes used to measure the effectiveness of systematic reviews of chronic disease self-management vary widely with a substantial emphasis on health outcomes, particularly, biomedical markers. The goal of self-management programs is to increase the autonomy and self-efficacy of the client as well as increasing their participation in a chosen lifestyle. Disease specific biomedical markers do not necessarily measure individuals' participation or their confidence to engage in healthy or meaningful behaviours. The outcomes assessed in self-management programs may be more complete if they include participation, an outcome that is also a common goal of occupational therapy.

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## SENSE OF DOING



COLUMN EDITORS:  
HELENE J. POLATAJKO AND JANE A. DAVIS

# Heart-happy occupations in a cardiac rehabilitation circuit

Catherine M. White and Paula L. Buyting

With over 70,000 people experiencing a heart attack each year in Canada, and roughly 54,000 of them now surviving (Heart & Stroke Foundation, 2010), cardiac rehabilitation has become a key need for Canadians. Many survivors leave hospital with sufficient medical advice but limited discussion of when and how to resume previously valued occupations (Parker & Adams, 2008). While limits are initially placed on actions inherent to these occupations, such as lifting, pushing, and pulling, vague directions such as “take it easy” are open to interpretation and are rarely updated throughout recovery, thus limiting a person’s timely return to previous routines (Berman as cited in Parker & Adams, 2008, p. 422). As clients move beyond the shadow of death, their outlook may be inadvertently dampened by inadequately-considered comments from health professionals and others regarding activity restrictions, which may be perceived as unclear and/or highly limiting. Fear, anxiety and depression may accompany persistent physical symptoms and ongoing concerns regarding secondary prevention and management, placing the individual at greater risk for sub-optimal recovery.

Self-management approaches to chronic disease management are garnering increased attention (Gilkey & Garcia, 2010), and are particularly relevant to the ongoing needs of survivors of cardiac disease who may seek to modify the trajectory of their illness by minimizing risk factors (Hawthorne, 1991) and/or live within activity restrictions. Self-management, which highlights the active role of the client, addresses not only the ongoing medical management of the condition, but also acknowledges the emotional impact and the need for the individual to engage in meaningful roles and activities (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003). The emphasis is on self-efficacy, or increasing confidence in problem-solving and decision-making. Clients are encouraged to form key partnerships, access relevant information, and begin to take actions in support of recovery (Lorig & Holman, 2003). In doing so, a range of partnerships may be needed.

As Parker and Adams (2008) suggest, doctors and nurses are experts in such things as wound care and medication management, but may lack the skill set needed to address the overall well-being of the client, which appears to be correlated with the resumption of valued activities (Law, Steinwender, & LeClair, 1998). Vrkljan and Miller-Polgar

(2001) discussed the importance of regaining a sense of health and well-being in the face of life-threatening illness, highlighting that “doing = living” (p. 240). Their study of cancer survivors parallels the experience of heart attack survivors, as both experience a disruption of daily routines and transition toward reconstructing their occupational selves in the face of health changes. Occupational therapists are attuned to such transitions, acknowledging the key role of occupations in successfully navigating them (Blair, 2000; Kerr & Ballinger, 2010; Vrkljan & Miller-Polgar, 2001) and are thus well suited to cardiac rehabilitation teams in support of client self-management.

### An outpatient program

Our newly established cardiac rehabilitation team has created a 12-week out-patient program that adopts a self-management approach. Capitalizing on the skill set of the occupational therapist, physical activity and education components are supplemented with opportunities for supervised occupational engagement. In our original program, as with many cardiac rehabilitation programs, clients engaged in monitored physical activity, such as the use of a treadmill, stationary bike and arm ergometer, and participated in multidisciplinary education sessions focused on such things as improving dietary habits, motivation, reconditioning the cardiovascular system and safely regaining functional recovery. As they moved toward self-management, much of which occurred in the home (Corbin & Strauss, 1991), clients identified a lack of self-efficacy related to the transfer of skills learned in the gym to their day-to-day living, lack of access to the types of exercise equipment available within the program, and concern with their functional recovery (LaPier, 2007). As a result, the occupational therapist, who initially focused on the impact of cardiac restrictions on valued occupations, such as work activities, self-care and leisure participation, realized that clients needed more; more reassurance, guidance and practical options to resume a range of previously valued activities and occupations and to implement their exercise prescriptions at home. A logical next step was to enhance self-efficacy by introducing familiar occupations to supplement the existing exercise program, and bridge the gap between the clinic program and the client’s self-management in every-day life.

As clients expressed concerns regarding a wide range of

occupations, a circuit program was developed as a means of integrating as many of them as possible. By facilitating a problem-solving process with clients and the team, and in consideration of space and budget limitations, a variety of stations were created (see Table 1). Each was designed to address safety concerns, and to allow for grading and modification according to individual need. For each group, various stations are set up according to the activities most relevant to that group, making each circuit as client-centred as possible. Clients integrate the exercise prescriptions previously offered by the physiotherapist as they rotate through the circuit, choosing the easy, medium or hard set-up. To enhance self-efficacy, they are assisted to monitor heart rate (HR) and rate of perceived exertion (RPE) following each task, and record outcomes in a structured activity log which forms the basis for discussion. The program nurse is also present to assist with supervision and provide telemetry which further monitors the heart's response to increased activity. Upon completion of the circuit, which takes about one hour (including warm-up and cool-down periods), the occupational therapist reviews activity logs with group members and discusses how the experience translates to their daily lives.

The circuit program appears to be an effective tool to teach energy conservation, promote self-efficacy, and to provide exercise alternatives as clients prepare to self-manage at home. To teach energy conservation, which is beneficial if clients are experiencing fatigue or pain, they may be instructed on body mechanics and pacing, while monitoring HR and RPE. To promote self-efficacy, the lack of which may limit engagement in the exercise program and daily occupations, activities are graded and monitored, and clients receive immediate feedback on successes. As Fraser and Rodgers (2010) suggest, tangible support and “mastery experiences” may enhance self-efficacy (p. 165), a key component in the success of self-management approaches (Lorig & Holman,



**Figure 1. Occupational therapist, Paula Buyting, monitors the laundry station**

**Table 1: Sample stations in cardiac rehabilitation circuit**

Station	Description/setup	Grading options
Hanging laundry	<ul style="list-style-type: none"> <li>• height-adjustable clothes-line</li> <li>• clothes basket</li> <li>• clothes pins</li> <li>• clothes of various shapes/sizes</li> </ul>	<ul style="list-style-type: none"> <li>• basket placement (on the floor, on a raised surface)</li> <li>• height of the clothes line</li> <li>• number of items to be hung</li> <li>• number of breaks</li> <li>• overall length of time spent on the task</li> </ul>
Playing basketball	<ul style="list-style-type: none"> <li>• height-adjustable net on hard surface</li> <li>• basketball</li> </ul>	<ul style="list-style-type: none"> <li>• style of throw (overhand, underhand, lay-up)</li> <li>• retrieval of the ball (by self or others)</li> <li>• number of breaks</li> <li>• overall length of time spent</li> </ul>
Piling wood	<ul style="list-style-type: none"> <li>• wheel barrow</li> <li>• different sizes and shapes of wood</li> <li>• height-adjustable table</li> </ul>	<ul style="list-style-type: none"> <li>• height of the table</li> <li>• weight of load (size, shape and number of wood pieces)</li> <li>• number of breaks</li> <li>• overall length of time spent</li> </ul>
Lawn-mowing	<ul style="list-style-type: none"> <li>• lawn-mower</li> <li>• various sized weights</li> <li>• long strip of pile carpet</li> </ul>	<ul style="list-style-type: none"> <li>• weight added to the lawn-mower</li> <li>• option of pulling pull cord</li> <li>• length of the mowing strip</li> <li>• opportunity to either push or pull the lawn-mower</li> <li>• number of breaks</li> <li>• overall length of time spent</li> </ul>

2003; Marks, Allegrante, & Lorig, 2005). With increased confidence in what they can safely achieve, clients are supported to set goals and take on the next challenge. To provide exercise alternatives, clients, who have been exercising on the gym equipment to increase strength and endurance, are instructed on how to incorporate physical activity into their daily occupations, and can practice in a controlled setting using the circuit. They are taught how to grade activities, and encouraged to work toward the guidelines outlined in *Canada's Physical Activity Guide to Healthy Active Living* (Public Health Agency of Canada, n.d.). Thus, clients become better equipped to solve problems and make decisions as they carry over the learning from the clinic to their lives at home.

Additional stations which better replicate the clients' home environments, including an outdoor circuit, are being considered. In addition, repeated use of the circuit at various intervals within the program is being explored to offer opportunities for clients to monitor their progress. While more rigorous outcome measures are needed, preliminary feedback

from clients indicates that they find this experience of ‘doing’ valuable as a transitional step toward reclaiming themselves as occupational beings, key to their recovery. As one client mentioned, “[i]t showed us what happened to our heart rates during day-to-day activities,” alleviating concerns about engaging in daily occupations at home. The circuit program, which may lend itself well to other treatment settings, is a small but important step in promoting self-efficacy as clients look to gain proficiency in self-managing their chronic condition.

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# Family members as potential support persons: Moving ideas into practice

Susan E. Doble, Susan L. Hutchinson and Grace Warner

The management of chronic health conditions is enhanced when done within an ‘activated’ community (Barr et al., 2003) that includes family. In this context, family is defined as persons who are related biologically, legally or emotionally, but may also include friends and neighbours (Institute of Patient- and Family-Centered Care [IPFCC], 2011). Within traditional interventions family members are provided with: (a) information about chronic conditions, disease processes, medical treatments, and available resources; (b) information about specific caregiving tasks; and (c) emotional support to enhance their ability to cope with the caregiving role (Rosland, 2009; Rosland & Piette, 2010). These interventions are based

on two assumptions. First, family members do not play a valuable role until persons with chronic conditions require the assistance of a ‘caregiver.’ Second, an ‘activated’ community can be developed through the passive dissemination of information to family members. However, managing health goals is only one component of self-management. In this paper, we argue that family members are important elements of the environments in which persons with chronic conditions engage. As such, they have the potential to influence if and how effectively persons manage their chronic conditions while continuing to live their lives. In other words, family members’ role extends beyond that of caregiver to that of

self-management “coach.” We also argue that the provision of effective support is a skill that family members can acquire and refine with training and practice. In this paper, we provide a specific example of a ‘family-focused’ intervention in which the role of family members as chronic disease self-management “coaches” is highlighted.

### The valuable role of family

The valuable role of family was reinforced during interviews conducted with 19 health providers (i.e., direct service providers, program developers, program managers, and a community health board member) from both urban and rural communities within Cape Breton, Nova Scotia (MacPhee et al., 2010). They unanimously identified that family members need education about relevant chronic conditions and symptom management, followed by information about support groups and respite services. Health providers often used the terms ‘family member’ and ‘caregiver’ interchangeably. Yet these same health providers suggested that if family members did not self-identify as ‘caregivers,’ they may not recognize available services as being relevant.

A simple solution would be to describe the targeted audience for interventions as family, broadly defined, rather than caregivers. However, there is more than semantics at stake here. When family are viewed only as caregivers or potential caregivers, we may fail to recognize their potential roles as support providers and coaches. This is particularly true for persons without advanced disability.

### A client-centred, family-focused approach

The question then becomes how do we do this? Within some family-centred care settings, health providers provide families with opportunities to be involved in the decisions made on their family member’s behalf (IPFCC, 2011). While this approach may be appropriate when persons with chronic health conditions are minors and/or unable to independently make decisions about their own care, the majority of adults with chronic health conditions are capable of being active participants in decisions related to their health care, as well as decisions that affect their daily lives. So rather than advocating a family-centred approach, we advocate for a client-centred, family-focused approach that acknowledges the effect of the environment on persons’ self-management efforts. Within this approach, efforts are made to enable family members to effectively support those with chronic health conditions in two ways. First, family members are guided to support persons’ efforts to self-manage their lives despite having chronic

conditions. Secondly, family members are guided to help those with chronic conditions integrate ‘illness care’ into their daily lives without compromising opportunities to experience meaning and satisfaction.

When adopting a family-focused approach, we recognize that family members may need to learn how to help persons manage their chronic health conditions and achieve their goals. Thus, family-focused interventions are designed specifically to provide family members with opportunities to develop the required skills and recognize when the strategies they are using are and are not effective. This can be accomplished, in part, by including family members in self-management programs for persons with chronic health conditions. However, to become effective self-management coaches, family members must recognize the importance of working in collaboration with persons with chronic health conditions, and then develop and refine these skills through practice. To

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*“they not only enrich their own occupational lives and better tolerate the stresses associated with living with a family member with a chronic health condition, but recognize how they can be positive role models”*

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accomplish this, interventions must provide family members with opportunities to develop and master the skills needed to coach persons with chronic health conditions. This entails providing opportunities to practice and implement skills

related to setting goals, solving problems, making decisions, taking action, and evaluating their experiences.

There is some evidence that interventions that are specifically identified as being ‘family-focused’ (as opposed to being targeted for ‘caregivers’) are being developed and evaluated. For example, Martire and colleagues (2003) developed an add-on program to a six session Arthritis Self-Help Course (ASHC; Lorig, 1995). Each session was supplemented by a twenty minute segment designed to address the effects of persons’ symptoms and negative



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emotions on family members, and help family members learn how to provide effective assistance and support to help persons manage their arthritis. The Family to Partnership Intervention (Clark & Dunbar, 2003; Dunbar et al., 2005) is a nurse-led four-hour program offered over two sessions for persons with heart failure and their families. Program goals included increasing family members' use of autonomy supportive behaviours, enhancing the ability of persons with heart failure to effectively elicit support, and reminding family members to address their own needs.

Recently, we developed the *Take Care* program (Doble & Hutchinson, 2011), a brief intervention that introduces family members and friends to the roles of support provider and coach. The *Take Care* program, like the Family Partnership Intervention described above, is a four hour intervention offered over two sessions specifically for family members and friends of persons with chronic health conditions. The importance of engaging in meaningful activities (occupations) is highlighted. Participants learn strategies they can use to ensure they address their own occupational needs, particularly their needs for pleasure and renewal (Doble & Santha, 2008). The group format offers opportunities to learn from peers, reinterpret their experiences, and receive support and encouragement from peers (Bandura, 1977). Participants implement their knowledge and skills by setting and acting on goals they set to address their needs for pleasure and renewal. By doing so, they not only enrich their own occupational lives and better tolerate the stresses associated with living with a family member with a chronic health condition, but recognize how they can be positive role models. In other words, through their actions, family members and friends can embody the message that 'if I can use this set of skills to enrich my own occupational life, so can you.' Participants are also provided with opportunities to learn to effectively support or 'coach' family members with chronic health conditions to set and achieve meaningful, enjoyable, and do-able personal goals while minimizing the likelihood of providing ineffective support.

Preliminary evidence to support the effectiveness of a three-hour single session *Take Care* program was promising (Hutchinson, Doble, & Warner, under review). Based on findings of the initial evaluation, the *Take Care* program was revised and is now being offered over two sessions (each two hours long). This change is providing participants with an opportunity to implement their action plan between sessions, and review their progress during the second session. We are currently undertaking research to examine the effectiveness of this unique family-focused intervention.

Occupational therapists are beginning to recognize family as "important allies" (Rosland & Piette, 2010, p. 8). By adopting a family-focused approach when working with adults with chronic conditions, occupational therapists can "harness the power and resources of the family to optimize care" (Fisher & Weihs, 2000, p. 565). The *Take Care* program is just one of the many interventions occupational therapists can provide to enhance persons' and family's efforts to manage their chronic conditions and enrich their occupational lives.

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# myHealth: Taking charge of your health care

Bronwen Moore, Christine Stapleford and Joanne Maxwell

The transition from the paediatric healthcare system to the adult healthcare system can be fraught with challenges for young people living with a disability. Youth living with chronic disabilities often make this transition without understanding how to manage in the adult system (Canadian Paediatric Society, 2007). There is a clear, demonstrated cultural difference between the paediatric and adult healthcare systems that requires a different level of involvement for both client and family, the acquisition of new skills and more independent management (Canadian Paediatric Society, 2007). As a result, youth with disabilities are often unprepared, overwhelmed and lack the skills necessary to effectively navigate the adult system and properly address their needs. The consequences can be potentially devastating to their health and quality of life (Reider-Demer et al., 2008).

A new group-based intervention was developed as part of the LIFEspan Service - a partnership between Toronto Rehabilitation Institute (TRI), an adult healthcare service provider, and Holland Bloorview Kids Rehabilitation Hospital (HBKRH), a paediatric service provider, to address these challenges. The LIFEspan team at HBKRH works with young adults, aged 16-18, with neurological disabilities to prepare them for the transition to adult healthcare services. The LIFEspan team at TRI receives clients at age 18, orients them to adult services, and provides ongoing care throughout adulthood. The new group-based intervention, called myHealth: Taking Charge of Your Healthcare, aims to increase participants' skills in managing their own healthcare (such as keeping track of appointments, expressing goals, and following through on recommendations) and to de-mystify the transition process and the adult healthcare system.

## Development of the myHealth group

The myHealth group is based on information gathered through consultation with clients and team members, a review of the literature, and an environmental scan. It is aligned with the best practice recommendations from CanChild Centre for Childhood Disability Research, a research and educational centre that provides evidence-based information to improve the lives of children and youth with disabilities and their families (Stewart & Antle, 2008) and with the Toronto Central Local Health Integration Network's (TCLHIN) focus on self-management of chronic illness.

The myHealth group program consists of seven weekly evening sessions (see Table 1 for session outlines), each two hours in duration. A group-based approach was selected as group self-management programs have been shown to be an effective medium for building coping skills (Hindmarsh, 2008), lowering distress related to health concerns, reducing utilization of healthcare services, and improving client self-efficacy (Lorig et al.,

2001a; Lorig et al., 2001b). The group's content and structure were drawn from the literature and related programs (Clarke & Snicer, 2008; Cromwell & Usher, 2008; Law et al., 2005; Roebroek et al., 2008; White, 2008). The group made use of multiple media and experiential activities to enhance clients' learning and engagement.

The myHealth group aims to benefit both youth in transition and the healthcare system. For participants, myHealth provides knowledge and skills important for managing their healthcare in the adult system. Participants learn about their health condition and history, and discuss ways to track and prepare for appointments. Participants learn strategies to communicate assertively with health providers, problem-solve and self-manage their health concerns. For service providers, the group supports clients to use health services in a more appropriate, effective way. The program also works in a resource efficient manner by serving multiple clients in a group setting.

## A pilot myHealth group

*"Before the group, I thought I knew about healthcare, but there was a lot to learn. It was very useful. I enjoyed coming here."*

Participant in pilot group.

A pilot group was run in 2009 and feedback and experience from this trial was used to further refine the protocol. Inclusion criteria for the pilot group included young adults 16-25 years of age living with cerebral palsy or acquired brain injury who had goals suited to the program and who were able to participate in discussions and activities. Sessions were co-facilitated by a social worker and an occupational therapist. Both facilitators were highly experienced in the provision of group-based programming with strong communication skills and an understanding of different adult learning styles. Each participant was provided with a resource binder and weekly handouts. Participants were also given a weekly challenge to do at home that built upon what had been discussed at the session. A separate session was offered for parents of the participants to develop familiarity with the program and facilitate support for their child's participation. Snacks were provided for all sessions and a small user fee was requested to cover the cost of the binder and snacks. This fee was waived for clients in cases of limited financial resources.

Participants provided positive feedback on the use of existing technologies, and visuals/multi-modalities to facilitate their learning.

The facilitators identified the following recommendations to enhance future offerings of myHealth:

1. Have a more 'youth-friendly' room to enhance the comfort level of the participants.



**Table 1: Weekly session outline**

Week	Title	Topics Discussed
1	Getting to know each other	<ul style="list-style-type: none"> <li>• Introductions to group members and facilitators (an occupational therapist and a social worker)</li> <li>• Creation of guidelines with the group</li> <li>• Goal setting</li> <li>• Outcome measurement (initial assessment)</li> </ul>
2	What can I expect of my healthcare provider? What do they expect of me?	<ul style="list-style-type: none"> <li>• Knowing your rights and responsibilities as a consumer of healthcare services</li> <li>• Finding the right 'fit' with a healthcare provider</li> </ul>
3	Making choices	<ul style="list-style-type: none"> <li>• Helpful ways to approach choice making</li> <li>• Goal / Plan / Do / Check process for decision-making</li> </ul>
4	Let's get organized!	<ul style="list-style-type: none"> <li>• Managing medical appointments through effective communication</li> <li>• Planning to bring the right things and information to appointments</li> </ul>
5	Keeping track of healthcare information – Where to begin?	<ul style="list-style-type: none"> <li>• How to compile a health history</li> <li>• How to track and describe new symptoms</li> </ul>
6	When things are not going the way you planned...	<ul style="list-style-type: none"> <li>• Advocacy and negotiation skills</li> <li>• Assertive communication tips</li> </ul>
7	Wrap-up and looking forward!	<ul style="list-style-type: none"> <li>• Outcome measure re-assessment</li> <li>• Review of goals and progress</li> <li>• Celebration and certificate of completion</li> </ul>

2. Enhance the outcome measures for the group to include more rigorous measures.
3. Provide attendant care.
4. Offer the group at different times during the year.
5. Offer the parent group concurrently to enhance engagement as this was key in supporting the participants with their learning.

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### Summary

The introduction of the myHealth group into the LIFEspan service was well received by clients, families and clinicians. Initial evaluations from participants demonstrated a positive change in their knowledge, confidence and comfort level of the adult healthcare system. The facilitators played a key role in tailoring the group content to the goals and learning styles of diverse group members. The facilitators supported the participants in developing the necessary skills and a sense of empowerment in navigating the adult healthcare system. Through role modelling, interactive games and demonstrations, the facilitators aimed to introduce participants to their future role as managers of their own health care. The skills of occupational therapy and social work were ideally suited for this self-management educational experience because of the focus on practical skills, problem solving and generalizing learning into real life contexts.

Overall, the myHealth group holds applicability over a wide range of diagnostic populations and materials could easily be adapted for other groups. Future plans include more active dissemination of the myHealth group to interested families, providers and community facilitators, possibly using Internet-based resources.

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# Listening to clients: Self-management strategies to stay well with bipolar disorder

Sandra Hale

Diagnosis of a potentially chronic, recurring illness, such as bipolar disorder (BD) can seem daunting. BD is an illness of mood; symptoms range from the lows of depression to the highs of mania sometimes veering into psychosis (a break from reality). It can be a confusing, scary ride (Jamison, 2006). Some medications work extremely well for people with BD. Psychological treatments like cognitive behavioural therapy and social factors such as supportive family and friends help people to manage their illness (Miklowitz, 2007b).

The growing body of evidence for psychosocial treatment specific to BD (Miklowitz, 2007a) supports the individual and group interventions commonly used by occupational therapists. The emerging understanding of client self-management as a critical contributor to positive health outcomes is highly compatible with existing occupational therapy interventions. Client-centred enablement is a core competency for occupational therapists (Townsend & Polatajko, 2007) who recognize that clients are the experts in their own lives (Clark, 2000; Murray et al., 2010).

The following self-management strategies are drawn from interviews with 33 people living with BD participating in a research project at the University of British Columbia. Interviews focused on strategies each person found helpful in order to live full and productive lives. Self-management strategies are first presented in the voice of people living with BD and then discussed.

## Sleep, diet and exercise

*"I make sure I have a waking rest every day."*

*"If my sleep is off then I know I need to watch myself."*

*"Walking by the sea is the best thing I do."*

Participants identified that staying well begins with a strong foundation: eating a balanced diet, regular exercise, and healthy sleep. This link between sleep disturbance and mood relapses is well established (Murray & Harvey, 2010). Addressing sleep patterns is part of the consensus treatment guidelines for BD (Yatham et al., 2006). Participants identified that maintaining a healthy diet taking vitamin supplements, regular eating patterns and limiting the intake of sugar, food high in fat, and caffeine) helped to build a strong foundation. Finding manageable exercise was aided by the questions "What suits me?" and "What can I do regularly?" Walking outdoors and enjoying nature were reported as inexpensive

and easily adopted. Occupational therapists, with knowledge of daily occupations are in an excellent position to support these strategies.

## Watching for signs and taking action

*"You learn to watch for your warning signs."*

*"With depression, my husband often notices it before I will."*

People identify sleep, mood and energy changes as common signs of impending illness often recognized when daily activities are affected. Learning the unique triggers for people living with BD and making the changes needed to address impending problems is crucial. Strategies reported include adjusting medications, getting more sleep, or seeking advice from a supportive friend or healthcare professional. As with all self-management, triggers and solutions are unique for each person. Occupational therapists can support the development of self-management strategies that may include the development of self-monitoring strategies to identify triggers and crisis action plans to respond to impending relapse. When clients agree, including family should be common practice.

## Reflection

*"I keep a journal and reading it later...I could see, oh, I was really out of whack."*

Some of the participants found that reflective, meditative practices were effective in learning self-management strategies. One participant described how reading her journal after a period of mania promoted self-awareness and understanding. Others reported that yoga, tai chi and Buddhist-type meditation, when used regularly, were beneficial practices. For others, drawing, painting or sculpting activities provided a way to focus attention, yet clear the mind. Introducing and/or reinforcing activities, or occupations as deliberate self-management strategies that encourage growth and wellness is supported theoretically in most occupational therapy literature.

## Understanding the illness and educating others.

*"... educating others really helps...because when you have an episode and you need a hand they are there for you."*

For effective self-management, people living with BD need to understand the unique feature of the illness and its' impact

on their daily lives. Reading self-help books, newsletters, and books like *An Unquiet Mind*, written by someone who lives with BD (Jamison, 1996), were all suggested by participants. The use of Internet sites to locate information, attending education groups offered at clinics, hospitals or mood disorders agencies were reported as important ways to gain an understanding of BD. Being able to then educate others promoted ways of accessing support. When people are involved in occupational therapy group treatment, mutual support can promote further understanding and support for therapeutic benefit (Cowsls & Hale, 2005).

### Staying connected to the world

*"I have this group of people to draw support from...they give me power."*

Nearly all participants spoke of the importance of having friends, family and mental health professionals in their lives. Positive, relaxing people who can help "put things in perspective" gives a strong base of support when you live with a condition that can disrupt mood and emotions. The message "do not go it alone" echoed throughout the study. Having supportive relationships, including with mental health professionals, made it easier to deal with BD.

### Keeping well but planning for "just in case"

*"I work at being well."*

Staying well takes planning and regular use of self-management strategies. Even with strong supports and well-tested strategies periods of illness from BD may still occur so it makes sense to have a plan in place. Occupational therapists, through collaborative planning and decision making can assist people to develop action plans that include self-monitoring for the signs of depression or mania, names and contact information of people they believe could help if there is an emergency, and a planned recovery strategy including their own part in that process.

Can people stay well with BD? Yes, people can and do live well with this condition. As one participant said, "it is like a ship that is always righting itself". Little changes to daily life can make all the difference and occupational therapists can

provide the right tools at the right time to enable clients to keep their ship upright.

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# Working to manage chronic illness in daily life

Anne Townsend

*"It is impossible not to manage ones health, the only question is how one manages." (Lorig & Holman, 2003, p. 1).*

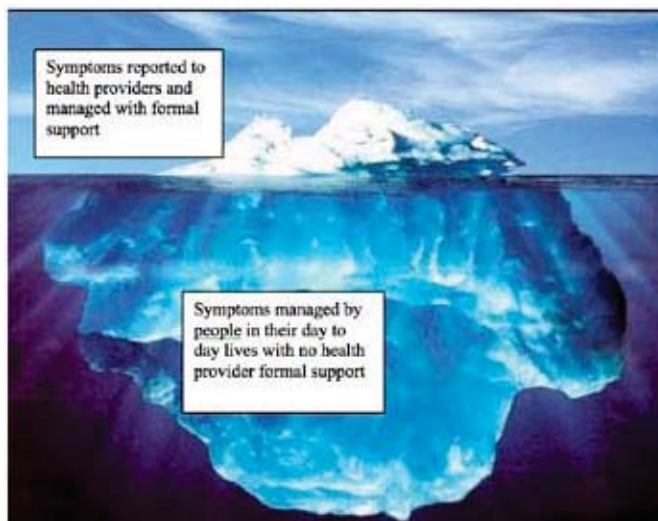
Self-management of chronic illness extends beyond managing disease to managing the impact of symptoms on everything we do (our occupations) and daily life. Self-management has become a cornerstone of public health strategy due to the rising rates of chronic illness. Programs and initiatives flourish and there is an increasing demand for allied health professionals to support individuals in their response to chronic illness (Health Council of Canada, 2010). Because of their understanding of the relationship between functional ability, illness, the environment, and personhood, occupational therapists can play a key role in providing such support.

It is well documented that those who seek care only represent the tip of the iceberg and health professionals see only a small proportion of the symptoms and illness people experience. Evidence from the United Kingdom (UK) shows that people with chronic conditions actively engage in complex and varied self-management strategies and use the family physician consultation as a last resort (Townsend, Wyke, & Hunt, 2008). In short, people use skills and resources to manage as best they can without using health services:

*...the universal experience of symptoms of illness does not translate automatically into demand for care. Only a small proportion of symptoms which people experience are presented to the general practitioner. The large number of symptoms dealt with, without medical care has been termed "the illness iceberg" or the "symptom iceberg" (Campbell & Roland, 1996, p. 75)*

Research shows that people with chronic conditions do different types of work: work to manage the symptoms, the medicines, the treatments; work to manage occupation and continue 'normal' daily life; and work to maintain their familiar identities (Corbin & Strauss, 1988; Townsend, Wyke, & Hunt 2006). This self-management 'work' occurs in the context of health system transformation. Health policy now recognises people's existing skills, practices and tendencies to self-manage (Wyke, 2006). There has been a shift from the notion of a passive patient to a more active partner in healthcare, working alongside the healthcare team to enhance the experience of chronic illness (Wyke, 2006). It is also hoped that increasing patient self-management can ease the economic burden imposed on health systems by the rising rates of chronic illness.

This article draws on a qualitative study about help-seeking in early rheumatoid arthritis (RA), a debilitating chronic condition. I report on individuals' accounts of self-management activities, in pre- and early post-diagnostic stages of RA. Aspects of their experiences have been reported elsewhere (Townsend et al., 2010).



## Interviews

The Early Rheumatoid Arthritis Help Seeking Experience (ERAHSE) study examined the help-seeking process from symptom onset to one year after diagnosis of RA. Thirty-eight adults were recruited through medical offices and arthritis web-sites. Participants had all been diagnosed with RA in the previous twelve months, resided in British Columbia, were English speakers and were aged in their 30s to 70s. They came from a mix of household compositions and diverse employment circumstances; homemakers, retirees, those in employment (full- or part-time), or receiving sickness or disability payments. A topic guide was used to elicit detailed responses through in-depth interviews. Constant comparisons guided the thematic approach to analysis. Ethics approval was secured and informed consent obtained.

## Findings

Participants described multiple and independent (unsupported by a health professional) management strategies to alleviate symptoms as they attempted to limit impact of illness on their daily occupations and lives. They were concerned to fulfill social roles and maintain favored identities. Themes generated from the interviews included self-management as: a) illness work; b) daily life work; c) identity work.

## Illness work: Managing symptoms with no support

People undertook varied strategies to ease symptoms in their attempts to limit the impact of pain on daily life. Often they were averse to relying on medications. They sought information about alternative medications and treatments as

they faced debilitating pain, which impacted negatively on function. They expressed a stoic approach, and determination to 'push through' the pain or fatigue and 'carry on' or 'keep going' with occupations in order to avoid disruption of daily life and continue in their roles and with leisure activities. However they were frustrated at their attempts and typically they had no formal guidance or support (beyond prescribed medication) prior to getting a diagnosis, and often subsequent to receiving a diagnosis. One participant, Rain, noted how he was unsupported while waiting nearly a year to see a specialist, while another, Nora, lacked support post diagnosis:

*The GP he... hasn't directed me in something else I could do in the meanwhile other than just taking medication; so that I am not too happy. I have been doing a lot of walking. That's about it. ... Someone mentioned swimming. I should get into that. The problem is you're kind of in the middle waiting, you know. (Rain)*

*I had researched... the medication and I just didn't want it.... So I went to a naturopath, I went to acupuncture, I did lots of diets and you hear from people you... should take this kind of pill... So I tried everything... everybody said. But... nothing really helped.... I thought: "I need help... somebody has to do something." (Nora)*

### Everyday life work: Bad days, worse days

In order to function in their day-to-day lives participants 'worked hard at self-management'. They undertook multiple combinations of strategies and a range of diverse management techniques in order to continue familiar occupations. They described the importance of: a positive attitude, over the counter medications, pacing, resting, reorganizing tasks and having family support. Often participants expressed having to scale back or stop activities or 'push through' pain in order to 'keep going'. Such activities included personal care (e.g., getting dressed, continuing in employment, parenting tasks or leisure activities). One participant described how she self-managed in multiple ways, with no professional support as she faced debilitating, painful and ongoing symptoms and struggling to continue working alongside her husband in the family cafe:

*"I was limping like you wouldn't believe... in the cafe... it can get pretty high paced... it's just my husband and I and so it can be very... stressful... you want to give the service... I was hobbling a lot. So I would change the shoes... Well these shoes will work better for now... these shoes are good when my ankles are sore and these shoes are good for when my toes are really sore... And I slept... a lot. Any time I could. My husband actually has an easy*

*chair for me in the bath so I can put my feet up. So when we're not busy at the cafe I would be in the bath sleeping..." (Barbara-Anne)*

Others talked of not knowing what activities would help, or how far they should push their bodies. Rain, reflecting on his year wait for the specialist commented:

*You want to do it but you want to wait for the doctor's advice or the specialist's advice... you try to push your body but then you start thinking in the back of your mind, what is your limit? And like I say you get into doing physical activity at work and you feel a little bit of pain because you're lifting heavy objects. ... I went on the Internet to look for some support. (Rain)*

### Identity work

The majority of participants expressed that being able to continue with meaningful occupations was fundamental to their identity and sense of self. They self-managed in order to function in particular roles which defined them. Many expressed the importance of keeping active and continuing meaningful occupation in order to fulfill roles central to their identities:

*You've got inflammation, you read it in the newspaper... try this... it's a remedy and anything like that. ... in the back of my brain I kept thinking... I've got to keep moving... I like being active. I am not the type to sit and just watch a movie... .... I don't want to just sit and do nothing... I can't. That's not me... Especially because I am in the service industry and I want to make sure people are enjoying their visit at the cafe. It's just the type of nature I am... I'm more of a caregiver kind of personality. (Barbara-Anne)*

### Discussion

Strauss and Corbin describe living with chronic illness as 'unending work' (1988). Self-management must not mean 'unending work' as individuals strive to live their daily lives with little or inadequate support. People self-manage but they need support to manage effectively. People often don't have access to information or resources or supportive interaction with appropriate health professionals. In such cases, they may become more disabled, rather than enabled with professional support (Wyke, 2006). Currently, health systems are not organised in ways that enable people to maximise their skills and self-manage as effectively as they are able. Rather than formal care and self-management being mutually exclusive, they can be regarded as a combination of interconnected resources. Health professionals, occupational therapists in

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particular, have a pivotal role to play in providing people with the support that they need to manage to optimum capacity.

People and patients must be respected as co-producers of health and health care who will work with appropriate health providers to maintain health, prevent and treat illness and manage its impact in everyday life (Wyke, 2006). Occupational therapists are known for their client-centred focus to supporting people to engage in meaningful and desired occupations. Building capacity and capability amongst occupational therapists to support people to self-manage the impact of a chronic condition on daily life is a natural extension of current practice.

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# Occupational therapists online: Equity of access to fatigue self-management

Setareh Ghahari and Tanya Packer

Fatigue is one of the most common and debilitating symptoms experienced by people with chronic conditions. Between 50 and 95% of people with chronic neurological conditions report fatigue and mostly name it as their worst or one of their worst symptoms (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Kraft, Freal, & Coryell, 1986). Fatigue has a known impact on quality of life and health status (Benedict et al., 2005; Benito-Leon et al., 2003). It results in major life changes. For example fatigue is reported as a central cause of people with multiple sclerosis (MS) being unable to maintain full-time employment (Smith & Arnett, 2005).

## How do we support people to manage their fatigue?

Although the literature suggests different approaches to treatment of this pervasive symptom, there is no single, comprehensive and well-supported guideline to manage fatigue. Management includes pharmacological and non-pharmacological interventions. Systematic reviews show that most pharmacological interventions result in severe side-effects and risk becoming refractory to treatment (Brañas, Jordan, Fry-Smith, Burls, & Hyde, 2000; Solari et al., 2008). The literature also suggests a range of non-pharmacological solutions from cooling therapy to cognitive behavioural therapy, yoga, exercise and so on.

One of the only standardised interventions well supported by the literature is *Managing fatigue: A six week course for energy conservation* (Packer, Brink, & Sauriol, 1995). The efficacy of the program has been tested by several independent researchers (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005; Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007; Sauter, Zebenholzer, Hisakawa, Zeitlhofer, & Vass, 2008).

This face-to-face fatigue program includes six weekly sessions. Each is highly structured and includes an education session, practice activities, discussions and a homework assignment. All content (topics: the importance of rest, communication, body mechanics, re-arranging activity stations, setting priorities and standards, and balancing a schedule), worksheets, handouts and homework assignments are standardized in a manual for facilitators. Based on self-efficacy theory (Bandura, 1997) each session incorporates strategies known to increase confidence in the ability to engage in specific behaviours. Facilitators support participants to develop problem solving skills, set goals and to take action to meet these goals. The facilitators are most often occupational

therapists; their specialized knowledge of occupation, expertise in task analysis and group facilitation skills are ideal competencies to facilitate the program.

## Problem: Not many people have access to face-to-face programs

Despite its effectiveness, most people with fatigue have limited access to this self-management program. Those who live in rural and remote areas, have transportation difficulties, work full-time or are confined to the house due to disability are often denied access to the face-to-face version of the program.

## Solution: An online fatigue self-management program

There is sufficient evidence that in many countries including Australia and Canada many people have access to the Internet every year (Australian Bureau of Statistics, 2006; Statistics Canada, 2010) therefore, delivering programs online is a way to increase equity of access to programs such as the fatigue self-management program.

The online program mimics the face-to-face protocol developed by Packer and colleagues (1995). A research team in the Centre for Research into Disability and Society at the School of Occupational Therapy and Social Work, Curtin University, Western Australia undertook deconstruction of the face-to-face program and reconstruction into an online prototype and then followed with three pilot tests. Content, activities and discussion topics from each of the six weekly sessions were captured and transferred to the alternative medium (Ghahari, Packer, & Passmore, 2009). During and after the pilot tests, feedback from users and facilitators was sought and electronic program records scrutinised. Collected information was used for quality improvement. The end result was a standardized online fatigue self-management program, user-friendly for people with basic computer skills.

The program:

- includes all aspect of the face-to-face program including weekly information, activities and group discussions;
- is guided by self-management principles. For example, to facilitate behaviour change based on vicarious learning and social persuasion, 'blogs' from previous participants in face-to-face programs (an expert panel) are included in the weekly content;

- is seven-weeks long. An extra week solves technical problems and allows participants to meet each other and become familiar with online navigation;
- provides opportunity for participants to share information and experiences, express their ideas or feelings and offer advice and support to one another through a discussion forum;
- is easily accessible and user-friendly for participants with limited computer knowledge and literacy (defined as the ability to use the internet for simple searches and send/receive emails);
- uses asynchronous participation, such that participants can log on and remain online at their convenience;
- expects a weekly commitment of approximately 2–3 hours per week (facilitator and participants), similar to participation in the face-to-face version; and
- requires individual usernames and passwords to enter the online program.

### Occupational therapists online

Facilitators for the online program are usually occupational therapists experienced in working with people with neurological conditions, experienced in group facilitation and with knowledge of self-efficacy and self-management theory and practice. They receive specific training on the technical aspects of the platform and instruction on online facilitation. Facilitators log on daily, respond to participant entries, pose questions and provide encouragement.

### Is the online fatigue self-management program effective?

The program was tested on 105 individuals with multiple sclerosis, Parkinson's disease or post-polio syndrome in Australia (Ghahari & Packer, Under review; Ghahari, Packer, & Passmore, 2010). The participants were allocated to four groups: face-to-face, online, information only and a no intervention control group. The results of the study suggest that both the face-to-face and online versions of the fatigue management program effectively helped people with neurological conditions to manage their fatigue. Both groups showed significant improvement in their fatigue over time. However, while the face-to-face group significantly decreased the fatigue level in comparison to the control group, the online fatigue self-management group helped people to manage depression and stress and improved their self-efficacy in comparison to the control group. Further, the online program reached people with poorer baseline scores; participants in the online fatigue management program had lower activity levels

and higher fatigue levels than the participants who had access to the face-to-face program. Therefore, providing services using two delivery mechanisms appears to increase access and decrease known inequities, particularly between metropolitan and rural and remote areas.

The participants of the online fatigue self-management program reported that the program was easy to follow, completing the activities online was straightforward and interesting and that the most popular part of the program was the group discussions.

### Conclusion

Although fatigue is a common problem for people with neurological conditions, to our knowledge, this online fatigue self-management program is the first of its kind. Through the application of a fatigue self-management program, occupational therapists and other health professionals can expect that the participants will learn self-management skills, make corresponding behaviour changes and experience a reduction in the effect of fatigue on their lives. Occupational therapists, with their specialized knowledge of occupation and expertise in task analysis, have the skills required to help people with chronic conditions manage their fatigue and improve their lives.

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# Self-management: A close companion to recovery in mental illness

Catherine M. White

*“Being more in control of one’s own life and managing one’s own mental health is the key to regaining self-respect and self-esteem, [and is a] major plank of recovery.” (Wallcraft, 2005, p. 209)*

As Canada moves to challenge the supremacy of the medical model and incorporate a vision of recovery as a guide for mental health services (MHCC, 2009), significant changes will be required, both in the way services are provided, and in the way they are received. Recovery places a focus on self-determination with the goal of recovering a meaningful life, moving forward and assuming valued roles with or without ongoing symptoms. People with mental illness have a right to access effective interventions and want to see meaningful outcomes that relate to employment, relationships and quality of life, not just the prevention of relapse and re-hospitalization (Drake et al., 2001). Thus, attention to a range of the determinants of health better supports a vision of recovery.

## The role of self-management in recovery

Self-management strategies, which are gaining momentum in response to rising levels of chronic disease (Holman & Lorig, 2004), share a common perspective with recovery, highlighting attention to self-direction and living well in spite of ongoing impacts of the illness (Sterling, von Esenwein, Tucker, Fricks, & Druss, 2010). Davidson (2005) sees self-management as an aspect of recovery that generates skills for everyday living, such as agency or coping. Tools such as the Illness Management and Recovery program (IMR) (Mueser et al., 2006) and the Wellness and Recovery Action Plan (WRAP) have been specifically designed to align self-management with recovery (Scott & Wilson, 2011; Sterling, et al., 2010). In both self-management and recovery, the client is viewed as an active agent, rather than a passive recipient of services, and while medical management remains in the picture, maintaining or increasing participation in meaningful occupations gains prominence. The two processes are client-centred or individualized, and both see the client as a valuable untapped

resource. Both focus on empowering clients, and look to enhance self-efficacy (Davidson, Tondora, Lawless, O’Connell, & Rowe, 2009; Lorig & Holman, 2003).

## A role for occupational therapists

With their explicit attention to client-centred practice and a desire to empower clients to take action for themselves, occupational therapists are well suited to partner with clients as they take a self-directed approach toward recovery. Occupational therapists recognize that competencies for enabling participation are very different from competencies to contain an illness (Davidson et al., 2009) but, like other health care professionals, occupational therapists are required to pay attention to the ways in which self-management and recovery require a different kind of partnership, “a new

professionalism” embracing the values of recovery (Piat, Sabetti, & Bloom, 2010, p. 173). According to Townsend (1998), an overall shift in organizational processes is needed if there is to be a transition from an expert care-giving perspective which

perpetuates dependence, to a collaboration that can enable people to become active participants, experts in their own lives. She invoked and revised an old proverb, stating “You can care for people for a day. But if you educate people to become involved, you have helped them to care for themselves and others for a lifetime” (p. 3). Likewise, in self-management, clients are taught a problem-solving process, rather than the solution to their problems (Lorig & Holman, 2003), thus enhancing self-efficacy and autonomy.

## A wider focus

Self-management is embedded within the Chronic Care Model, which has now been expanded to include greater attention to the social determinants of health (Barr et al., 2003), but the expansion has not been matched by policies to address them. Many people with mental illness say they are more disabled by the social implications of their illness than the symptoms themselves (Davis, 2006). For example, stigma, a product of the social environment, can contribute significantly

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*“With their explicit attention to client-centred practice and a desire to empower clients to take action for themselves, occupational therapists are well suited to partner with clients as they take a self-directed approach toward recovery.”*

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to feelings of inadequacy and exclusion, working in direct opposition to recovery. Krupa (2008) discussed the need to shift the focus from individuals to populations, suggesting that client-centred practice is often too individually oriented to have an impact on such things as stigma and discrimination. Hammell (2006) confirmed that focusing primarily at the individual level without adequate consideration of the interplay between impairment and the cultural, social, physical, political, economic and legal dimensions of the environment limits responsiveness to the real needs of our clients.

Oliver (2004), a key proponent of the social model of disability (which situates disability in the environment rather than the individual) supports the idea that collective efforts have greater potential to bring about social and political change. Nikelly (2001) confirms that the role of social and environmental factors in both causing and controlling some aspects of mental illness have been underestimated, and suggests that interventions should be shifted to focus on collective efforts to reduce such things as unemployment, poverty and social alienation. Paul-Ward (2009) agrees, asserting that individual success empowers clients, which can lead to social change when efforts are directed toward advocacy for themselves and others. Occupational therapists are encouraged to “ensure that people have the skills to take action in lobbying, activism, advocacy, community development, public education and research” (Townsend, 1998, p. 49). Thus, occupational therapists themselves may need to further develop these skills (Restall & Ripat, 2008; Wilkins, Pollock, Rochon, & Law, 2001), before taking a leadership role in guiding clients to undertake these challenges. Occupational therapy remains positioned as a health care service governed within a hierarchy. The profession must claim increased power in the institutional environment, and increase points of contact with the community at the social or political levels to seize opportunities to engage in such collective actions if they are to expand avenues of influence either on behalf of or in concert with clients.

Going forward, Kielhofner (2005) suggested that occupational therapists increase awareness of social, political and economic barriers, and questioned how occupational therapists might empower clients to engage in self-advocacy in the fight against discrimination. As clients increasingly seek partnerships for self-management, and work toward recovery, they will need support to “contradict negative stereotypes, balance inequities in social status, reduce social distancing, and reverse social disadvantage” (Krupa, 2008, p. 201). Through changes in education and training programs, increased awareness of the importance of political and social action and burgeoning leadership in the profession, occupational therapists are becoming increasingly well positioned to “either advocate consciously with others for justice, or comply with occupational injustices through silence and inaction” (Townsend & Wilcock, 2004, p. 83). The choice is clear.

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# You're in Charge: Engaging youth in designing and delivering an early preparation self-management program

Joan Versnel

Living with a chronic disease as an adolescent impacts daily life and affects participation in activities, roles and relationships. For some youth, the need to carry out complex medical routines prevents them from being able to respond to the spontaneity of adolescent activity. Others are forced to cope with restrictions in their capacity for employment or post-secondary education. Many also face the need to cope with overwhelming emotional and psychological consequences that impact their relationships with parents, siblings and peers. Youth with chronic conditions can also experience an opportunity for positive youth engagement through involvement in initiatives where their experience with a chronic condition can be used to assist younger adolescents and their families who are in the early stages of preparing to self-manage. This article describes a pilot initiative designed using principles of youth engagement and was developed through a partnership between a faculty member at a School of Occupational Therapy and a group of health care providers at a pediatric tertiary care centre. The occupational therapist provided direction on the content of the intervention to ensure youth participants dealt with issues of daily living and participation in addition to symptom control and disease management. An environmental scan and scoping review were conducted as the initial phase of the partnership.

Recommendations from this review included:

- Develop and deliver a youth focused, developmentally appropriate self-management intervention in a non-clinical setting.
- Follow-up the face-to-face component of the intervention with online support, which would allow youth to remain connected to the social support network they established.
- Develop a program/approach that would provide parents with the opportunity to connect with one another and build on their ability to enable/empower their children to begin to independently manage their chronic condition.

In recognition of existing programs under development in Canada which target older youth and the knowledge that transition planning needs to start at an early age, it was decided to develop an intervention that would fit the needs of youth in the junior high school age group: 13 -15 years. This age range was deemed important to target from a developmental perspective, as this is an appropriate stage to encourage increased independence and decision-making.

## Youth engagement

Youth engagement is meaningful participation and sustained involvement of a young person in an activity with a focus outside of him or herself (Centres of Excellence for Children's Well-Being, Youth Engagement, 2009, p. 1). Youth involvement in all aspects of intervention development was sought to ensure that the unique needs and strengths of youth were reflected. At the start of the project, a youth engagement strategy was developed, and shared with the pediatric health facility's Youth Advisory Committee, where feedback and ideas were solicited to strengthen our planned approach. A team of youth who lived with a chronic health condition were invited to participate in the development and implementation of the intervention. These youth leaders were engaged in determining the name Youth Wellness Project: You're in Charge! to reflect the focus on living well rather than the burden of living with chronic illnesses or health conditions.

Youth leaders were engaged in developing the key content and the method of delivery for the intervention. Youth also recommended designing special t-shirts for all youth leaders and participants, and providing wellness toolkits. Youth leaders were actively involved in creating the content for the online follow-up supports, and determining how to use that as a tool to engage with the teens. A consultant from a local media development centre met with the youth around creating online content in the form of blogs and photo essays.

## Training youth leaders

Through a partnership with a local agency that specializes in youth engagement for positive community change, a facilitator training program was developed and included a Youth Leaders Kit. As part of the training process, youth leaders were also asked to reflect on the questions that related to their own experience as younger teens.

Youth leaders were also asked to complete a goal setting activity. A day long retreat was held to focus on practising facilitation skills, reviewing elements of the intervention and the logistics for the day. At the end of the day, youth worked with a local filmmaker to create four short videos that would be shown at the intervention. The intervention for the younger participants was held over a Friday evening and Saturday.

## Youth leadership

The intervention launched with an evening at a school of circus arts. This activity was selected for a variety of reasons. From our earlier research it was known that youth responded well to camp experiences, and an activity that would match something they

experienced at camp would be needed. Circus school provided an opportunity to model the concepts that were the focus of the intervention: watching others model something new, taking chances and trying new things, learning from others, and taking risks. Most importantly, circus school was fun, and participants were able to start Saturday feeling more comfortable with each other.

As participants arrived for the workshop on Saturday morning, they were greeted with a photo slide show with images from their circus school experience. The workshop started at 10am with a short introduction and welcome from the youth leaders, a video and an icebreaker. Participants learned about what being in charge meant for each of the youth leaders by watching one of the videos created for the project. After a short break, participants viewed another video on wellness and what wellness meant for each of the youth leaders. At lunch the wellness toolkits were introduced and given to each of the participants. Each wellness toolkit contained a day planner, water bottle, healthy snacks, juggling balls, hand sanitizer, lip balm, silly putty, pens, a recreation day pass, a copy of the Canada Activity Guide and Food Guide, a copy of a walk/bike/hike guide and a USB stick loaded with interactive websites, downloadable information, extra pages for the day planner, the Upopolis (a web-based communication platform) user guide and more.

Following lunch the action plan worksheet was introduced and each youth leader worked with a participant to develop an action plan around one goal related to self-management or their overall health and well-being. Participants set goals such as packing their own lunch, taking medication without reminders, getting more sleep, substituting one healthy snack for a less healthy one each day, making their own doctors appointment and interacting with the doctor. The parents were welcomed back at 3pm and participants shared their action plans.

### Online support

All participants were registered to use Upopolis by the Project Coordinator. Youth leaders created and posted content in order to engage with participants and keep them coming back to the website. New content was posted every week, including photos from circus school and from the intervention, new goal setting forms, personal stories from the youth leaders, and ideas and challenges on getting enough sleep, ways of dealing with stress, and motivation. Emails were sent by the coordinator to each teen via Upopolis email, as well as to each teen's regular email.

### Outcomes for youth leaders

Youth leaders experienced a variety of benefits as a result of their participation in the project, including a sense of accomplishment, and a desire to “do something more meaningful with my life.” These outcomes were articulated in

the focus group conducted with youth leaders following the completion of the online component of the intervention. In addition to traditional methods, qualitative data was collected using a graphic illustrator (see Figure 1). The project partners wanted to collect data in ways that would be appealing to the youth as a reflection of their experiences in the intervention. The illustration above contains the data from the youth leaders' focus group. The illustration contains many of the practical and conceptual suggestions the youth leaders identified.

When asked what they gained from the experience, some youth leaders responded:

- A sense of accomplishment—following something through from start to finish
- It felt good to give of myself
- I got out of my shell

They identified additional impacts, including:

- I want to volunteer more
- I want to do something more meaningful with my life
- I used goal-setting to help my sister who has ADD
- Better time-management
- Accomplishment
- Self-respect

### Summary

Participation as a youth leader in an early preparation for chronic disease self-management program resulted in a number of positive outcomes reflective of positive youth engagement. Chronic disease self-management interventions provide a rich context to meet the dual purpose of 1) providing much needed support for young adolescents and their families as they embark on the journey toward self-management and 2) creating an opportunity for youth leaders to become engaged in an initiative they find important and meaningful. The youth leaders' engagement results in personal outcomes such as competence, control, and agency. Occupational therapists can create contexts that utilize principles of youth engagement to address issues of participation and client-centred care for youth with a variety of chronic health conditions. Research has also linked positive youth engagement to other positive health outcomes such as decreased alcohol and drug use, lower rates of school failure, lower rates of risk-taking behaviours such as unprotected sexual activity, pregnancy, anti-social and criminal behaviours and lower rates of depression (CEC, Children's Well-being, 2009). Win-Win.

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