

# Developing Expert Patients: Insight from the UK

## Introduction

Over time, people living with long term health conditions (LTHCs) usually develop expertise in self-management. The latter can be defined as the individual's ability to manage not only the symptoms and treatment, but also the physical, psychosocial and life style consequences inherent in living with LTHCs. Competence in self-management encompasses the ability to monitor one's condition, and attaining the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established. Although many people living with LTHCs will develop self-management expertise naturally by a process of trial and error, others may need support and assistance. Indeed, the need to promote self-management competencies is now widely recognised.

One means by which people can receive support in this endeavour is via self-management interventions. Some of the most widely implemented self-management interventions are those developed by the Stanford Patient Education Research Centre, USA. The first such intervention was the Arthritis Self-management Programme (ASMP) developed by Lorig and colleagues in the 1980s (Lorig and Gonzalez, 1992) to meet the needs of people at the mild to moderate end of the disease spectrum. The ASMP was introduced to the UK by Roy Jones of Arthritis Care (a voluntary organisation) in the early 1990s and is somewhat unique in that it was designed to be delivered in community settings by pairs of lay tutors who themselves had arthritis. In the UK, the ASMP has been evaluated in a range of delivery settings (e.g. adult education) and modes of recruitment (e.g. community, primary care). A randomised controlled trial (RCT) of the ASMP focused on primary

care patients with osteoarthritis showed reductions in anxiety and improvement on self-efficacy (Buszewicz et al. 2006). Results of our studies based on community samples have consistently shown improvements on self-efficacy, use of self-management behaviours (e.g. cognitive symptom management, exercise, communication with physicians), anxious and depressed moods, positive affect and fatigue (Barlow, Williams & Wright, 1997; 1999; Barlow, Turner & Wright, 1998a & b, 2000). However, there is little effect on pain and health service usage. The latter contrasts with the results of US studies of the ASMP (Lorig & Holman, 1993) where large reductions in visits to physicians are reported. Results of qualitative analyses from interviews confirmed that participants perceive increased confidence (self-efficacy), and feel that they have the 'tools' and motivation to make changes. Within the group setting of course delivery, participants share information, compare themselves with similar others (social comparisons), experience role modelling, and feel they have found an appropriate peer group thus reducing their sense of isolation. Results of an eight-year follow-up study suggest that ASMP participants maintain improvements in use of self-management techniques, self-efficacy and positive well-being in the longer term despite a decline in physical health status (Barlow, Turner, Wright, Gilchrist & Swaby, 2006).

The ASMP is important as it paved the way for development of the generic Chronic Disease Self-Management Course (CDSMC).

### **Chronic Disease Self-management Course (CDSMC)**

The Chronic Disease Self-Management Course (Lorig, Sobel, Stewart et al. 1999) is being delivered in a number of countries including the USA and Australia. In the UK, the Chief Medical Officer set up an Expert Patients Task Force which published a Report in 2001 following which the CDSMC became the foundation of the National Health Service's Expert Patient Programme (EPP) being rolled out in the UK within the National Health Service via Primary Care Trusts. A Community Interest

Company has recently been established to oversee organisation of the EPP. In addition, a number of voluntary organisations continue to deliver the CDSMC. The CDSMC is grounded within the theoretical framework of self-efficacy (Bandura, 1977). The Course aims to increase self-efficacy through role-modelling, skills mastery, persuasion, re-interpretation of symptoms, problem solving, decision-making and action planning. Topics include an overview of self-management principles, diet and exercise, goal setting, problem-solving, confidence building, cognitive symptom management and communication with health professionals. Participants attend weekly, two hour, community-based group sessions facilitated by pairs of lay tutors, who themselves have LTHCs and have been trained in course delivery. Sessions are interactive, focusing on learning skills, sharing experiences and accessing support. A system of quality assurance has been established to ensure that high standards of delivery are maintained.

The CDSMC was first delivered in UK in 2000 within the context of the Living with Long-term Illness (LILL) project organised by the Long Term Medical Conditions Alliance (a voluntary organisation). The LILL project provided the sample for the first exploratory study of the CDSMC in the UK and included participants with a wide range of LTHCs including arthritis, endometriosis, depression, diabetes, myalgic encephalomyelitis, osteoporosis and polio (Wright, Barlow, Turner & Bancroft 2003). Improvements identified at 4 months, such as increased self-efficacy, decreased fatigue, depressed moods and health distress are maintained at 12 months and participants continue to use the self-management skills learned on the course, such as cognitive symptom management and communication skills (Barlow, Bancroft & Turner 2005). Furthermore, participants use the CDSMC as a forum for sharing experiences and used goal setting to help make changes. In essence, the CDSMC provides participants with the confidence to select self-management techniques (or

tools) that meet specific needs at a given point in time and helps them to develop the necessary competencies (Barlow, Wright et al. 2005).

A randomized controlled trial (RCT) examined the effectiveness of the CDSMC for Myocardial Infarction (MI) patients (n = 192) who had completed Cardiac Rehabilitation (Barlow, Turner & Gilchrist 2006). Results showed significant improvements on anxiety, and use of cognitive symptom management, with trends towards improvement on physical functioning and depression. It should be noted that this sample were relatively high in self-efficacy and self-management competencies at the start of the study as may be expected among MI patients who have recently completed cardiac rehabilitation (CR). Indeed, in comparing the CDSMC with CR, participants reported some overlap particularly around diet and exercise advice. However, the CDSMC was believed to be more successful at providing the motivation and techniques to translate the advice into positive behaviour change. Interestingly, qualitative findings from interviews and focus groups showed that women valued emotional support whereas men preferred information support. Courses such as the CDSMC may have a valuable role to play in providing the additional support needed by the most vulnerable patients, such as those who are anxious or lacking in confidence or motivation to carry out important treatment recommendations such as exercise.

We are nearing completion of a RCT of the CDSMC for people living with Multiple Sclerosis (MS). Although we are focusing on people with MS, the intervention (i.e. the CDSMC) has been open to anyone with a LTHC thus participants with MS learn alongside participants with conditions such as asthma, diabetes or heart disease. A nested qualitative study has been completed and findings show that participants compare themselves to other CDSMC attendees with similar symptoms (but not necessarily the same diagnosis) and draw inspiration and hope from those perceived

to be coping well (Edwards, Barlow, Turner, & Hammond 2006). The use of social comparisons across and within diagnostic groupings is perceived as beneficial, suggesting that generic self-management interventions do not compromise the opportunity for making relevant informative comparisons. Participants learnt from others with different diagnoses, yet similar symptoms such as pain or fatigue. They learned new self-management techniques, such as goal setting that was used as a catalyst for mastering new skills on the CDSMC. Achieving small, realistic goals enhanced participants' self-efficacy and led to feelings of empowerment and positive outlook. Participants generalised the competencies learned to other situations not directly connected to MS, such as parenting, social activities and work. Although, participants felt more in control of their MS, many reported that they had not learned any new information or skills; rather, the benefits of the CDSMC were viewed in terms of reinforcing and honing existing competencies to further improve quality of life. Importantly, participants had learned to manage illness around their lives as opposed to managing their lives around their illness.

Other studies of the CDSMC in the UK have focused on delivery of the Course in a workplace setting (Barlow & Ellard, 2007), determining the effectiveness of an adapted version of the CDSMC for Bengali speaking participants (Griffiths et al. 2005), and a preliminary evaluation of an adapted Course (Supporting Parents) for parents of children living with a LTHC (Swaby et al. 2006). Participants who go on to train as CDSMC tutors have the opportunity to further develop self-management and other competencies. We have conducted several studies of tutors of both the ASMP and CDSMC (Barlow & Hainsworth, 2001; Hainsworth and Barlow 2001, 2003; Barlow, Bancroft & Turner, 2004; Barlow, Turner, Hammond & Gailley 2006). Results suggest that tutors experience increased confidence; gain a renewed sense of purpose in life; feel useful and valued members of society; enjoy passing on their

own learning through helping others (altruism); and find that delivering the Course acts as a reminder of ways to manage their own condition.

In sum, our UK data show evidence that the CDSMC increases self-efficacy, use of some self-management techniques (e.g. cognitive symptoms management, communication with physicians, exercise among people with arthritis), improvements on anxious and depressed moods and health distress, increased positive affect, and reduction in fatigue. There is no change in pain, shortness of breath, or self-reported use of health services. However, there is evidence of floor effects among large proportions of our samples, particularly in terms of pain, shortness of breath, and use of health care (e.g. A&E and hospitalisations). A national evaluation of the EPP is due to report shortly and is being lead by Rogers and colleagues based in Manchester. In conclusion, the CDSMC and related courses (e.g. ASMP) offer participants and tutors the opportunity to develop self-management competencies, to enhance their self-efficacy and to improve their psychological well-being not only in terms of reducing psychological distress by also in terms of increasing positive outlook.

### **Author**

Julie Barlow

Professor of Health Psychology,

Research Director

Self-management Programme,

Applied Research Centre in Health & Lifestyle Interventions,

Faculty of Health & Life Sciences,

Coventry University,

Priory St.,

Coventry,

CV1 5FB

j.barlow@coventry.ac.uk

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