

International Encyclopedia of Rehabilitation

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Center for International Rehabilitation Research Information and Exchange (CIRRIE)
515 Kimball Tower
University at Buffalo, The State University of New York
Buffalo, NY 14214
E-mail: ub-cirrie@buffalo.edu
Web: <http://cirrie.buffalo.edu>

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Self-care

Julie Barlow

**Professor of Health Psychology,
Health Design & Technology Institute,
Coventry University,
Coventry, CV1 2TT, UK.
j.barlow@coventry.ac.uk**

This chapter will commence with definitions of self-care and related concepts, including self-management and self-management support and will consider the nature of self-care. The second part of the chapter will illustrate how self-care can be encouraged using examples from the field.

What is self-care?

There is no universally accepted definition of 'self-care' in rehabilitation or in the wider healthcare field. Indeed, the terms 'self-care', 'self-management' or even 'self-help' tend to be used interchangeably. A couple of decades ago, the term 'self-help' was adopted to describe the mutual support and aid provided by self-help groups, typically in relation to a specific diagnosis (e.g. back pain, depression or arthritis). Self-help groups are viewed as 'supplementary to professional assistance' (Damen, Mortelmans, Van-Hove, 2000) and usually play a supportive role rather than one of providing instruction in new skills that can be used in the self-care of a condition and its wider consequences. Self-help groups and organisations grew in popularity in the 1980s. Over time, many such self-help or voluntary organisations have responded to the needs of their members by providing more structured support in the form of workshops, seminars and interventions. Indeed, voluntary organisations have played a key role in promoting the development of self-care / self-management support.

In the 1990s, 'self-care' was used to refer to preventative strategies (i.e. tasks performed by healthy people at home) and was distinguished from 'self-management' – a term reserved for the strategies used by people with long term health conditions (LTHCs) such as diabetes, asthma or arthritis (Clark et al. 1991). Thus, self-management was defined as the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a LTHC or disability (Barlow, 2001). Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. A dynamic and continuous process of self-regulation is established, with individuals working in partnership with relevant health professionals.

Over time the boundaries between the concepts of self-care and self-management, as advocated by Clark et al. (1991), have become blurred and the terms are now used interchangeably. Furthermore, the notion of using preventative strategies to avoid disease onset has been incorporated in definitions of self-care. For example, the World Health Organisation (WHO) defines self-care as

“the ability of individuals, families and communities to promote health, prevent disease, and maintain health

and to cope with illness and disability with or without the support of a health-care provider.” (WHO, 2009).”

The inclusion of ‘prevention of disease’ by the WHO is an interesting development that extends the reach of self-care from its typical focus on managing existing LTHCs and disability. In the UK, the Department of Health (DH) maintains self-care refers to

“the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after acute illness or discharge from hospital.” (DH; Self-Care – A Real Choice, 2005).

The nature of self-care activities

It is clear from the above definitions that self-care can encompass a wide-ranging spectrum of activities that can include simple acts such as brushing one’s teeth regularly to prevent dental decay to total reliance on surgeons and other healthcare professionals during complex surgical procedures. In the field of rehabilitation, self-care has often been used in relation to behaviours such as a specific exercise regime, managing one’s diet, or personal care (e.g. dressing oneself). For many people living with LTHCs and disability, care is shared between the individual and the healthcare team who work in partnership to optimise well-being and quality of life. People attending rehabilitation fall in to this broad category of self-care. It is worth noting that most people with LTHCs and disability spend most of their time managing at home on their own with relatively small amounts of contact time with rehabilitation professionals. Hence, learning and performing self-care activities designed to promote well-being and enhance quality of life are vital.

Self-care activities are dependent on an individual’s needs at a given point in time and may vary over time and with the disease course. However, it is true to say that most conditions have specific self-care activities. Thus, for a person with arthritis the main focus of attention is likely to be on managing pain, inflammation, stiffness and fatigue. Self-care may comprise use of appropriate medication to help control inflammation and pain thus allowing the individual to perform appropriate exercises that will help stiffness and mobility. An individual with asthma has to learn how to manage symptoms of breathlessness, coughing and wheezing, management of medication (i.e. preventers and relievers), and understand when to seek emergency treatment. A person diagnosed with diabetes needs to learn how to monitor glucose levels and to adjust medication accordingly, to follow an appropriate diet and to be aware of the complications associated with diabetes (e.g. damage to vision, cardiovascular system and kidneys). Despite the unique nature of these condition-specific self-care activities, there are also many commonalities in terms of self-care. The impact of a LTHC or disability can be wide-ranging and pervasive affecting all aspects of life including psychological well-being, social support, social networks, ability to fulfil family and nurturant roles, ability to work and leisure activities. In addition, people living with LTHCs and disability need to be able to communicate

effectively with healthcare professionals including those involved in delivering rehabilitation.

Self-care support

The importance of self-care is recognised in the healthcare development plans of a number of countries including the UK, Australia and Canada. For example, in the UK, self-care was highlighted in the National Health Service plan (NHS Plan 2000) as '*one of the key building blocks for a patient-centred health service*' and is a key component of the model for Supporting People with Long Term Conditions (DH 2005). In Australia, the National Health and Hospitals Reform Commission (NHHC 2009) recommended establishment of an independent national health promotion and prevention agency to promote individual and collective responsibility for building good health and well-being. The aim is to assist people in becoming 'active participants' in their own good health working in partnership with health professionals, carers, and families. An interesting development is the increasing focus on the support needed by individuals involved in self-care. For example in Canada, a five year programme designed to involve health professionals in the support of self-care was completed in 2003. In the UK, the DH (2005) advocated '*increasing the capacity, confidence and efficacy of the individuals for self-care*' and listed a number of options that can be used to provide self-care support including provision of appropriate and accessible information, individual care plans, use of self-monitoring devices, health education for basic skills and health literacy training, and self-care skills training for individuals living with LTHCs or disability (e.g. Expert Patient Programme). The focus on provision of support for self-care indicates a growing acceptance by healthcare professionals of the vital role they play in promoting and supporting self-care in the context of rehabilitation.

Acquisition of self-care skills

From the point of diagnosis onwards, individuals require the necessary knowledge, understanding, skills and confidence to make informed decisions concerning treatment options, to carry out treatment regimens, to cope with the psychosocial consequences of their condition, and to perform self-care activities. Some patients quickly become experts in their own self-care and are able to adjust and adapt to the changing demands of their condition. However, others fare less well and require support along the way. Evidence to support this view is provided by reports of poor adherence to treatment (e.g. Bradley, 1989; Deyo, 1982; Van Hecke, Gryphonck, & Defloor. (2009); poor quality of life (e.g. Bush, Ziegelstein, Tayback et al. 2001; Janssens, van Doorn, de Boer 2003) and poor psychosocial well-being (e.g. Benz-Scott, Ben-or & Allen, 2002; Dickens, McGowan, Clark-Carter and Creed 2002; Moussavi, Chatterji, Verdes et al. 2007; Patten, Beck & Williams 2003). In order to meet these needs, patient education in general and more specifically in relation to self-care has rapidly grown into an integral and important aspect of rehabilitation.

In the past, patient education has centred on provision of information either verbally, during a consultation, or as written materials (e.g. leaflets, information sheets). This information-giving model was based on the assumption that knowledge alone was sufficient to promote a lasting change in behaviours. This assumption has been shown to have little basis in reality since although knowledge about what self-care actions are appropriate for a given condition may be necessary, knowledge alone is

often not sufficient for behavioural changes to be effected (Coates & Boore 1996; Gibson, Powell, Coughlan et al. 2002). Traditionally, patient education approaches aimed to change behaviour (e.g. smoking or exercise) assuming contingency between behaviours and health. In addition, traditional patient education is often based on what the 'patient' needs to know as perceived by health professionals, and the interventions are typically lead by health professionals.

More recently, the importance of psychological, social and environmental variables that may act as mediators of health outcomes has received recognition. A number of social cognition models have been proposed and tested with varying degrees of success in predicting behaviours in health care settings including the health belief model (Sheeran and Abraham, 1995), locus of control (Wallston, 1992) and self-efficacy (Bandura, 1977). The last of these, (self-efficacy) has been used as the theoretical basis for a range of self-care interventions (see Self-efficacy chapter in this volume). In contrast to traditional patient education approaches, Lorig and Holman (2003) maintain that self-management interventions should help people to manage life with a LTHC or disability, increase skills and self-confidence, need to be patient-centred (e.g. derived from patients' own needs) and the course leader acts as a guide and model. These ideas have been developed and evaluated in a range of self-management programs commencing with the Arthritis Self-Management Program in the late 1980s (see Lorig & Holman (1993) for a review). The Arthritis Self-Management Program (ASMP) is important as it paved the way for development and implementation of the generic Chronic Disease Self-Management Course (CDSMC). The CDSMC is better known in the UK as the 'Expert Patients Programme' (EPP). This program will be used as an example of a self-care intervention as it is probably the most widely delivered self-care program in the world and comprises many of the techniques and strategies typically included in effective self-care interventions.

Example of an intervention to enhance self-care

One generic, self-care intervention that provides participants with a range of skills and strategies is the Chronic Disease Self-Management Course (CDSMC) (Lorig, Sobel, Stewart, et al. 1999) that has been delivered in over 29 countries around the world (e.g. UK, US, Australia, Canada). This intervention utilises a number of strategies that are common to many self-care interventions such as cognitive behavioural principles, problem solving, role modelling and social, group processes for providing mutual support. This intervention is not disease-specific; rather participants with any LTHC can attend together. The focus of the CDSMC is the promotion of the individual's ability to select the self-care activity that will meet her individual needs at that time. Other unique features of the program are that it is delivered in the community rather than clinical settings by pairs of lay leaders who have been trained in course delivery.

In the UK, delivery of the CDSMC was pioneered by voluntary organisations such as the Long Term Medical Conditions Alliance, and the Multiple Sclerosis Society and was later adopted as the foundation of the Department of Health's Expert Patient Programme (EPP) that was rolled out across primary care in England. The CDSMC comprises six, weekly sessions, each lasting approximately two hours, and is delivered in community settings (e.g. church halls, senior centres, or libraries) by pairs of lay tutors trained in course delivery. Each session is guided by a Leaders' Manual to ensure consistency of content and each participant receives a manual

designed to accompany the Program. The CDSMC utilises the tenets of self-efficacy theory (Bandura, 1977), providing mastery experience, role modelling, persuasion and reinterpretation of physiological and affective states to assist participants in making changes (see Self-efficacy chapter in this volume). The CDSMC covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g. guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and health professionals, problem solving and goal setting. Goals should be achieved during the following week, be personally relevant, achievable, challenging, have proximal outcomes and depend largely upon a person's own efforts. Participants report back to the group on their achievements at the next weekly session. The format of the course is largely interactive, with short 'lecturettes' to introduce topics, group discussion, problem solving, role plays and mastery experience (i.e. trying out the skills introduced on the course). Participants are encouraged to apply these generic skills to their own situation. In the UK, tutors are trained and accredited to a rigorous set of quality standards (i.e. Stepping Stones to Quality), with training and course delivery focusing on adherence to protocol to ensure content and delivery fidelity. (See <http://patienteducation.stanford.edu/programs/cdsmp.html> and <http://www.expertpatients.co.uk> for full descriptions of course content, tutors training programme and quality assurance framework.) Finally, people with any LTHC or disability can self-refer and enrol on the course without the need for referral or consultation from a health professional.

Effectiveness of the CDSMC

In the US, randomised controlled trials (RCT) have found the CDSMC to be effective in improving self-efficacy, use of self-management techniques, improving physical and psychological health status, and reducing health care utilisation among participants with arthritis, lung disease, heart disease and stroke (Lorig et al. 1999). Griffiths, Foster, Ramsay et al. (2007) reviewed four UK randomised controlled trials (RCTs) examining the effectiveness of the CDSMC (Kennedy, Reeves, Bower et al. 2007; Griffiths, Motlib, Azad et al. 2005) and the related Arthritis Self-management Programme (ASMP) (Buszewicz, Rait, Griffin et al. 2006; Barlow, Turner, & Wright 2000). The ASMP is very similar to the CDSMC but has a focus on arthritis. Griffiths et al. found that self-efficacy improved in all studies, psychological distress improved in three studies (Kennedy et al. 2007; Buszewicz et al. 2006; Barlow et al. 2000) and generic quality of life improved in one study (Kennedy et al. 2007) based on intent-to-treat analysis. However, effect sizes were small to moderate and healthcare utilisation remained unchanged. The review focused on a limited range of outcomes and thus did not report effectiveness for outcomes such as positive affect (Barlow et al. 2000), energy (Kennedy et al. 2007), exercise and relaxation (Kennedy et al. 2007, Barlow et al. 2000), cognitive symptom management (Barlow et al. 2000; Kennedy et al. 2007) and communication skills (Barlow et al. 2000). The study by Kennedy, Reeves, Bower et al., (2007) was a national evaluation of the CDSMC which also assessed cost-effectiveness showing that the intervention produced a small reduction in costs. The authors report that valuing a quality adjusted life year at £20,000 results in a 70% probability of the CDSMC being effective leading to the conclusions that the CDSMC may be a cost-effective alternative to usual care (Richardson, Kennedy, Reeves et al., 2007). A related paper by Reeves, Kennedy, Fullwood et al., (2008) focused on predicting who benefited from the CDSMC, and showed that participants with lower self-efficacy and health-related quality of life at

baseline had more positive outcomes as did younger participants who benefited much more than their older counterparts. The authors conclude that the CDSMC will have positive outcomes in a wide variety of people although it may be particularly beneficial for younger people and those lacking in confidence or not coping well with their LTHC.

Two RCTs examined the effectiveness of the CDSMC focusing on specific target groups (i.e. Myocardial Infarction (MI) patients and people with multiple sclerosis). A RCT of the CDSMC (Barlow, Turner, Edwards & Gilchrist, 2009), focused on people with Multiple Sclerosis (MS) and recruited nationally. The CDSMC was open to anyone with a LTHC, thus, participants with MS learned alongside participants with conditions such as asthma, diabetes or heart disease. Results showed that at 4-months, the CDSMC was effective in terms of self-efficacy and depression and although effect sizes were small, these improvements were maintained at 12-months. The study was designed to examine the characteristics of people with MS who had expressed an interest in the Course and received information about it but then decided not to attend. This group of 'informed non-attenders' were invited to take part in the study and formed a Comparison Group. Compared to the Intervention Group, the 'informed non-attenders' had longer disease duration, were less anxious, experienced less psychological impact, and fatigue at baseline. A nested qualitative study based on interviews (Barlow, Turner & Edwards, 2009) revealed that MS participants compared themselves to other CDSMC attendees with similar symptoms (but not necessarily the same diagnosis) and drew inspiration and hope from those perceived to be coping well. Thus, the use of social comparisons across and within diagnostic groupings can be beneficial, suggesting that generic self-management interventions do not compromise the opportunity for making relevant informative comparisons. Participants learned new self-care techniques, such as goal setting, that were catalysts for mastering new skills. Achieving small, realistic goals enhanced self-efficacy and led to feelings of empowerment and positive outlook. As in earlier studies, the self-care competencies gained by participants were generalised to other situations not directly connected to MS, such as parenting, social activities and work. Equally, 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.

The effectiveness of the CDSMC for MI patients was examined in a RCT (n = 192, mean age 65.9 years and a median duration of one year since the first MI) (Barlow, Turner & Gilchrist, 2009). This study may be of particular interest to readers of this chapter given that all participants had completed Cardiac Rehabilitation within the previous two years. The CDSMC was run specifically for the MI patients and was delivered by two lay tutors who themselves had experienced an MI. Analysis revealed no statistically significant differences between the groups although a pattern of small improvements among the Intervention Group on self-efficacy, anxiety, depression and cognitive symptom management was observed. It should be noted that this sample comprised mainly men (72%) and duration since the first MI was relatively short (i.e. median of one year), which contrasts with most other studies of lay led self-management where the majority of participants are women and mean disease duration tends to be ten years or more. In addition, participants in this study

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. Interviews with a sub-sample of intervention group participants showed that they perceived an overlap between the CDSMC and cardiac rehabilitation particularly around diet and exercise. However, they viewed cardiac rehabilitation as being more about instruction whereas the CDSMC was more about discussion, mutual support, and goal setting.

‘Well, the rehab is different really because the rehab is mainly exercising. The self-management course is the fact that, basically you’re coming back to setting yourself a goal to do and get on with it.’

‘The self-management course was better because you got to talk to people about their problems. At the cardiac rehab, it was nurses standing in front talking about things’.

‘The action planning [on the CDSMC] made me get up and do some exercise. I was going to ride my exercise bike which I’ve never got round to using. And I set myself a plan to do 5 minutes a day on that. And now I go out and for a walk ... and I have joined an exercise class.’

Participants positively reappraised their situation as being ‘more manageable’ and believed that *‘there is life after a heart attack’*. Some were *‘coping better’* after the CDSMC as they now realised that they were not on their own. A few participants felt that that had not *‘improved or got worse in terms of MI-related problems’* but nonetheless they felt *‘a bit more positive.’* It appears that there are few additional benefits from CDSMC attendance for this target group who had recently completed cardiac rehabilitation and had comparatively short disease duration. Interestingly, the proportion of women (28%) in this study was greater than the proportion of women attending cardiac rehabilitation, which is reported to be 11-20% of those eligible (Barber, Stommel, Kroll et al., 2001). This suggests that shifting the focus from rehabilitation to self-care may be more attractive to women.

Further examples of self-care approaches with a community perspective

This section provides some examples of other approaches to community self-care remaining with the topic of heart disease as an exemplar. The Heart Manual is a facilitated, home-based, 6-week programme for post-MI patients and is set in a cognitive-behavioural framework. The programme comprises written materials, a workbook to record progress and 2 audio tapes. Topics covered include simple exercises, pacing activities, advice about risk factors and lifestyle change, relaxation, stress management and vignettes of patients' experiences. Trained healthcare professionals work with patients and their carers over the course of the programme. A RCT showed that the incidence of clinical anxiety was reduced by 50% in the Heart Manual group compared to a control group who received standard care, information

about MI and lifestyle change, and informal counselling (Lewin, Robertson, Cay et al. 1992). Patients who were clinically anxious or depressed at discharge from hospital showed the greatest improvement. In addition, there was a reduction in GP visits in the following 12 months and a reduction in admission to hospital in the first 6 months following discharge. A later study by Linden, (1995) reported similar findings although sample size was small. A comparison between the Heart Manual and hospital-based CR showed no clinically or statistically significant differences (Jolly, Taylor, Lip et al. 2007). However, Heart Manual participants who failed to adhere to exercise attributed their lack of motivation to difficulties in exercising on their own at home suggesting that some form of group support may have been beneficial. Further manuals have been developed for Coronary Artery Disease and Revascularisation (see <http://www.theheartmanual.com>).

Increasing and maintaining physical activity levels is one important aspect of self-care included in Cardiac Rehabilitation (CR). Following CR, maintenance of physical activity over time, can be difficult. A range of interventions have been designed and tested to help participants maintain physical activity over time. Cognitive interventions are based on techniques such as self-efficacy enhancement, management of barriers to physical activity and problem solving. Behavioural interventions are based on self-monitoring, prompting, goal setting and feedback and some interventions use a combination of cognitive and behavioural techniques. A systematic review of such interventions following CR found that whereas cognitive interventions showed inconsistent findings, behavioural and combination interventions had consistent outcomes and positive findings.

Increasingly, electronic technology is being incorporated in to self-care interventions. Such technology enables virtual on-line communities to be formed with the aim of providing group support in a similar manner to the face-to-face, group-based approach discussed above (i.e. the CDSMC). The impact of adding on-line community features to an internet -mediated walking program was examined among people who were overweight or had coronary artery disease or type II diabetes (Richardson , Buis, Janney et al. 2010). An RCT showed that although there was no difference in terms of increased daily step count, participant attrition was reduced among the on-line group. In addition, participants with low baseline social support made greater use of the on-line features than those with high baseline social support. An alternative use of technology is where data is transmitted via telephone lines thus enabling electronic communication between individuals in their own homes and their clinical team (i.e. telehealth). The influence of telehealth on self-management was examined among patients with heart failure (Dansky, Vasey & Bowles 2008). An RCT found that self-management behaviours were predicted by confidence and that participants using video-based telehealth demonstrated greater gains in confidence compared with control participants who received routine home visits only.

Further examples of self-care in rehabilitation can be found in other chapters of this Encyclopedia covering conditions such as asthma, chronic obstructive pulmonary disease, fibromyalgia, and myalgic encephalomyelitis/chronic fatigue syndrome.

Conclusions

The terms 'self-care' and 'self-management' tend to be used interchangeably. Self-care has been used to refer to specific rehabilitation strategies such as a particular exercise

regime for a specific condition. However, broader definitions of self-care include not only management of symptoms and treatment but also management of psychosocial consequences and lifestyle changes. There is an increasing range of interventions being developed to enhance self-care using cognitive, behavioural, or cognitive-behavioural frameworks. Given the importance of social support for encouraging and maintaining behaviour change, many interventions involve group support either in face-to-face group settings or via on-line communities. The advent of generic courses, such as the CDSMC, provides an additional resource for those people who require additional support or further guidance in techniques such as goal setting, communication with family and healthcare professionals or managing psychosocial consequences of their conditions.

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