

# Re-thinking the relationship between long-term condition self-management education and the utilisation of health services

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## Abstract

Encouraging self-management has been viewed as one means of reducing health service utilisation and contributing to improved demand management. However, the processes and imputed relationship between self-management education skills and health service contact are poorly understood. This paper reports on data from an embedded qualitative study which ran alongside a randomised controlled trial in England designed to test the clinical and cost effectiveness of a self-care support policy which found no statistically significant reductions in health service utilisation. Drawing on concepts from the sociology of chronic illness, analyses suggest that the biographical and social context relevant to individuals' experience of living with a long-term condition, history of health service utilisation, and relationships with health professionals are relevant to understanding the impact of self-management education and related policies aimed at bringing about changes in service use. Our study suggests that future health policy assumptions about utilisation in the context of chronic disease management and self-care support policies may benefit by acknowledging the complex, contextual and recursive nature of health service utilisation operating in the life worlds of patients' experience of living with a long-term condition.

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## Introduction

The prevalence of long-term conditions has been identified as a key factor placing increased demand on health services and requiring active management to prevent the costs of health services spiralling out of control. Policies for managing long-term condi-

tions increasingly envisage their care being based around three tiers: *case management* for patients with multiple, complex conditions; *disease management* for patients at some risk, through guideline-based programmes in primary care (Department of Health, 2005a; Wagner et al., 2001); and *self-care support* for low risk patients (70–80% of those with long-term conditions). Self-care has been defined as 'the care taken by individuals towards their own health and well being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their

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long-term condition; and to prevent further illness or accidents' (Department of Health, 2005b). One of the aims of top-down policy programmes of self-management support has been to contribute to more effective chronic disease management. Self-management education has also been identified as having a key role to play in utilisation reduction and containing health care spending (Department of Health, 1999, 2005b). However, the evidence supporting the impact of self-management and other chronic disease management initiatives on health service utilisation is more equivocal than policy statements often imply (Roland, Dusheiko, Gravelle, & Parker, 2005) and the mechanisms underlying the purported relationship between increases in self-care activities and a reduction in utilisation remain under-explored. In this paper we argue that utilisation needs to be understood more broadly as part of a complex pre-existing relationship that individuals have with health care services. Drawing on a longitudinal qualitative study embedded within an RCT of a national programme of self-care support in England (Department of Health, 2001), the aim of this paper is to illuminate the nature and the processes of utilisation which accompany self-management skills-training by exploring the way in which patients related to services prior and subsequent to participation in a self-care intervention.

The Expert Patients Programme (EPP) is an anglicised version of the Chronic Disease Self-Management Programme (CDSMP) developed in the USA (Lorig et al., 1999) (also being implemented in the US and Australia). One of the primary outcome measures used to judge the effectiveness of these interventions is an impact on utilisation: "Confident, knowledgeable patients practicing self-management will experience improved health status and will utilise fewer health care resources" (Lorig et al., 1999). Some self-management interventions have reported significant impacts on health services utilisation. For example, an RCT of self-management in inflammatory bowel disease (Kennedy et al., 2004) found that following the intervention, patients made significantly fewer hospital visits at one year follow-up (difference  $-1.04$  (95% confidence interval (CI)  $-1.43$  to  $-0.65$ );  $p < 0.001$ ). Furthermore, an RCT of self-management in irritable bowel syndrome (Robinson et al., 2006) found that at one year, patients in the intervention group had a 60% reduction in primary care consultations ( $p < 0.001$ ). For others the impact on

utilisation has been more equivocal. A trial of the CDSMP (Lorig et al., 1999) carried out in the USA found that compared with a control group, the intervention group reported no significant changes in the physician visits but there were fewer episodes of hospitalisation and nights spent in hospital. However, evidence for utilisation change from other CDSMP trials appears to be the weakest of all outcome improvements (Fu et al., 2003; Lorig, Ritter, & Gonzalez, 2003). Trial outcomes measure changes in the *levels* of utilisation but tell us little about the purported mechanisms and processes. Trial measures of utilisation are particularly limited because they fail to take into account people's existing relationships and past experiences of health services and the way in which these might feed into current and future patterns of service use. There is also uncertainty about the extent to which self-care acts as an alternative or supplement to, formally provided services and the relationship between health services utilisation, self-care and living with a chronic condition. By contrast, studies of help-seeking and sociological research on the experience of living with a chronic illness point to the complexities of specifying a relationship between illness behaviour and health care utilisation.

### **The experience of living with a long-term condition and help-seeking**

There have been a number of different approaches taken to explain help-seeking behaviour and health service utilisation. These include 'clinical iceberg' studies (Hannay, 1979), the cultural model of health care systems (Kleinman, 1978), rational choice and economic models of decision making (Kahneman & Tversky, 1984; Pescosolido, Gardner, & Lubell, 1998); psychological approaches (Barker, Pistrang, Shapiro, & Shaw, 1990) and the social behavioural model (Anderson, 1995). These approaches offer an extensive list of contingencies that affect the use of services (e.g. patient demographics, health beliefs, accessibility of care) (Rogers, Hassell, & Nicolaas, 1999). A social process approach to health care utilisation questions the assumption that individuals are consistent in their preferences, knowledge level and ability to make rational decisions. Rather than conceptualising an individual's decision to seek medical help in terms of a static framework which involves the making of choices from a range of possibilities at one time point, social process models view the process of

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