

British Sociological Association: Phil Strong Memorial Prize

Chronic illness and self-management in primary care: characterizing the 'work' carried out by older patients with coronary heart disease

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Section 1

Background to the study

This study has been triggered by the modernisation agenda of the National Health Service (NHS) implemented by the Labour government in 1998 (Department of Health 1999, Department of Health 2000) and the subsequent introduction of the chronic disease management, self-care and self-management policy (Department of Health 2001, Department of Health 2004, Department of Health 2005a, Department of Health 2005b). Although self-care and self-management are conflated in the literature and therefore used interchangeably within this thesis, self-care has been described as preventative strategies employed by 'healthy' people in contrast to the notion of self-management that is predominantly associated with coping and treating existing disease (Clark et al., 1991). The self-management policies specifically promoted opportunities for people with long-term conditions and chronic disease to improve their health and wellbeing, manage symptoms and adopt healthy life-style strategies by becoming active agents in their care.

A key building block of this health strategy in the UK was the introduction of the Expert Patient Programme (EPP) (Department of Health 2001, Donaldson 2003) adapted from the work of Lorig and colleagues in the USA and their programme of lay-led generic self-management education sessions devised for chronic disease sufferers (Lorig et al., 2001, Lorig et al., 1999). Self-management policy in the UK professed to increase patients' independence, choice and control over their health and promote patient-centeredness and shared decision-making with health care professionals (Department of Health 2005b). As a consequence responsibility would be devolved to the public and patients to maintain health and manage illness and help to address a rising older population and ensuing costs to the NHS. However, this policy also appeared to assume that the public supported, understood and accepted an increased responsibility for their care and more importantly that health care policy was beneficial and therefore ethical and inclusive.

Increasingly published empirical research and commentary highlighted the ambiguities associated with patients' varied preferences for involvement and engagement in health care decision-making (Paterson et al., 2001), acceptance

of autonomy (Kielmann et al., 2010), variations in health literacy and a patient's ability to 'navigate' around the health care environment (DeWalt et al., 2004, Morrow et al., 2006). Further ambiguities included the social, emotional and contextual factors which impact on chronic disease sufferers (Bury, 1982, Charmaz, 1983, Corbin and Strauss, 1985, Kelly and Field, 1996), the potential bias towards 'younger, better educated people' in self-management policy (Corbin and Rosen, 2005, p. 4), and the possibility that there was a fragmented professional approach (Greaves and Campbell, 2007). More importantly, the 'work' of self-management appeared to require certain knowledge and skills as well as particular attributes and personal characteristics in order to participate. Normative statements embedded in the self-management literature suggested that '*patients must continuously engage in different health care practices*' (Holman and Lorig, 2004, p. 239) and '*must learn to self-manage their condition accordingly*' (Lindsay et al., 2009, p. 646). Moreover, researchers sought to identify the '*passive*' and '*active*' self-managers with reference to 'skills' and 'tasks' (Jerant et al., 2005, p. 301), with passive approaches defined as '*ineffectual*' and '*erratic*', perhaps attaching negative connotations to those patients who are 'unsuccessful' at the work of self-management.

In the light of these ambiguities and the correlation between an increasing aging population and the overall burden of chronic disease, particularly coronary heart disease (CHD), questions remained concerning how this 'modern' NHS policy related to the older generation in society and how or whether they would engage in self-management. Moreover, research highlighted the competing and complex factors that affect 'optimal self-management' of CHD including '*cognitive performance, symptom experience, comorbidity, mental health status and social support*', as well as untreated depression and anxiety and non-adherence to medication regimes (Schoenberg et al., 2009 p. 227). These considerations became increasingly relevant in the light of the Department of Health's conclusions that the eldest members of the public and the socio-economically deprived, '*whilst tending to be of poorer health, they are less active in self care and less confident in their knowledge and understanding of how to self care*' (Department of Health 2005c) (p1). Consequently this research study was prompted by the ambiguities associated with self-management policy, the specific needs of older patients (Clark et al., 1992, Department of Health 2003) and factors related to equity, responsibility and competence.

Aims and objectives of the study

The aim of this thesis was to explore the self-management work of older people with coronary heart disease (CHD) and to identify the skills and attributes required to carry out this work. My principal research question was:

- 1. Do older patients with coronary heart disease understand and participate in self-management strategies and if so how?**

- How do these patients engage in self-management in the context of their life world?
- What attributes, skills and levels of health literacy are required to successfully engage?

This research sought to understand how patients with heart disease and chronic illness experienced and perceived self-management and what kinds of strategies, activities, decisions or help-seeking behaviour they used in order to cope and manage. This included the possibility they may draw on health literacy skills. The perspective of general practitioners and practice nurses working in primary care was also sought in order to answer questions concerning patients' experiences, comparative and contextual issues and levels of patient participation in self-management.

Outline of methods

A qualitative research approach was employed using two specific methods namely, diary-interviews with patients and semi-structured interviews with professionals based at three contrasting general practice settings. These practices were purposefully selected from a low deprivation, high deprivation and rural area. These methods are summarised below:

- **Method one**

Patients who were aged 60 years and above and diagnosed with CHD, were asked to complete a two-week health/self-management diary followed by a semi-structured interview in the fourth week.

- **Method two**

Health professionals working in each practice where patients were registered were asked to participate in one semi-structured interview at their general practice.

The diary-keeping and interviews with patients and professionals took place at different times of the year, starting from November 2009 and ending in July 2010. Twenty-one patients and eight professionals took part in the study. The methods and data collection strategy incorporated the use of diary-interviews and visits to the practice areas and patient homes during the recruitment and diary-keeping process that generated ethnographic fieldnotes.

Summary of analysis and conclusions

The analytical process drew on features of grounded theory and was undertaken in relation to three sets of data produced for the study. These included written diaries by patients, interviews with patients and professionals and ethnographic fieldnotes. A review of the literature on self-management employed an iterative

process leading to an exploration of the ideology, assumptions and attributes associated with self-management policy. Through a mind mapping process of this literature, a 'policy' model was produced, identifying 4 concepts described as active, competent, efficacious and responsible. The analysis was carried out in the context of this 'policy' model of self-management and tested throughout data collection.

However, as data collection and analysis progressed, drawing on concepts of governmentality and the reflexive self, an alternative 'occupational' model of self-management was produced. This used the metaphor of work and included 5 dominant occupational roles and 3 levels of occupational status. This occupational model identified the breadth and depth of self-management practices by older patients with CHD. It incorporated the diversity of self-management strategies seen in relation to the everyday management of health problems, life and illness perspectives and challenges associated with bereavement, retirement and parallel responsibilities as carers and sufferers of co-morbidities. It clearly demonstrated where patients had the interest, knowledge and confidence to modify their behaviour for an improved health outcome. It also highlighted the struggles associated with social, physical and emotional circumstances as well as the spectrum of relationships with health care professionals and significant others that improved or impacted upon optimum self-management.

This occupational model provides a sociologically sensitive method of describing the older person's experience of living with CHD. This thesis outlines recommendations for primary care professionals based on this occupational model.

Section 2

Activities supported by the Phil Strong Prize

I am most grateful to the British Sociological Association (Medical Sociology Group) for awarding me the Phil Strong Memorial Prize in 2011. This award provided me with subsistence and support whilst completing my research and allowed me the peace of mind to concentrate on completing my analysis, writing my findings and submitting my PhD in April 2012. I was successfully awarded my doctorate in Medical Studies in June 2012 and I am in the process of writing papers for publication. I hope to disseminate my findings to the medical sociological community, health care professionals in primary care and policy makers. In my work I also embraced the '*zestful love of fieldwork*' attributed to Phil Strong (Bloor 1996 p555). I also remain hopeful that in some small way these findings may resonate with an NHS '*under new management*' (Strong & Robinson 1990).

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