Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions

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ABSTRACT

Healthcare policy in developed countries has, in recent years, promoted self-management among people with long-term conditions. Such policies are underpinned by neoliberal philosophy, as seen in the promotion of greater individual responsibility for health through increased support for self-management. Yet still little is known about how self-management is understood by commissioners of healthcare services, healthcare professionals, people with long-term conditions and family care-givers. The evidence presented here is drawn from a two-year study, which investigated how self-management is conceptualised by these stakeholder groups. Conducted in the UK between 2013 and 2015, this study focused on three exemplar long-term conditions, stroke, diabetes and colorectal cancer, to explore the issue. Semi-structured interviews and focus groups were carried out with 174 participants (97 patients, 35 family care-givers, 20 healthcare professionals and 22 commissioners). The data is used to demonstrate how self-management is framed in terms of what it means to be a 'good' self-manager. The 'good' self-manager is an individual who is remoralised; thus taking responsibility for their health; is knowledgeable and uses this to manage risks; and, is 'active' in using information to make informed decisions regarding health and social wellbeing. This paper examines the conceptualisation of the 'good' self-manager. It demonstrates how the remoralised, knowledgeable and active elements are inextricably linked, that is, how action is knowledge applied and how morality underlies all action of the 'good' self-manager. Through unpicking the 'good' self-manager the problems of neoliberalism are also revealed and addressed here.

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1. Introduction

Healthcare in developed countries such as the UK, Canada, Australia and USA have undergone a process of individualisation (Galvin, 2002) that has been underpinned by neoliberal philosophy. The political rhetoric around the burden of health care needs is an example of the influences of neoliberalism on healthcare policy. The focus on greater individual responsibility, one of the five key tenets of neoliberalism (Ericson et al., 2000), has become embedded in health policy. At the same time, there has been an emphasis on person-centred care (The Health Foundation (THF), 2014) and increased support for SM (NHS England, 2014), which

encourages patients to be active agents rather than passive recipients of care (Bodenheimer et al., 2005). Person-centred care calls for an approach that 'places the patient as the focus of any health care provision' (Lawn and Battersby, 2009:7) and for healthcare professionals (HCPs) to respect patients' 'autonomy through the sharing of power and responsibility' (THF, 2014). Whilst this agenda is underpinned by a respect for patients and their self-determination, it is this construction of the patient as empowered, able to participate, autonomous and capable of making choices that some have argued resonates with the neoliberal philosophy (Ayo, 2012). Patient-centred care has been part of health policy across the UK, Australia and the USA for two decades, and it has arguably shifted the responsibility for health away from the state and onto the individual (Ayo, 2012) by encouraging patients to self-manage.

The political focus on SM has emerged, in part, as a response to

growing demands placed on healthcare services, which have occurred due to people living longer and with an increased number of long-term health conditions (LTC) (Sprague et al., 2006). In England fifteen million people live with a LTC (NHS England, 2015). Management of LTCs accounts for 70% of the English health and social care budget (DoH, 2012). In the USA the percentage of spending is 85% (Goodwin, 2006), as around half of the population live with a LTC (Ward et al., 2014). In Australia 4.6% of the population live with diabetes (Australian Bureau of Statistics, 2013), in Canada this figure is 6.8% (Public Health Agency of Canada, 2011) and is estimated to rise to 11% by 2020 (Canadian Diabetes Association, 2008). How policy makers, health providers and professionals from across these nations should respond to these demands is a pertinent social issue. The main response so far in the UK and across other high income nations has been to promote greater self-management (SM) by people with LTCs, with the view that this will help to slow 'disease progression and [reduce] the need for unscheduled acute admissions by supporting people to manage their condition(s)', and will, therefore, reduce health service costs (DoH, 2012: 10).

Support for SM internationally has occurred through Stanford University's model of chronic disease SM programme, which influenced the introduction of the Expert Patient Programme (EPP) in the UK (Wilson, 2008), and Flinder's Patient-centered model of Chronic Disease SM in Australia. It is recognised that 'everyone self-manages their condition to some extent' (Lorig and Holman, 2003), however what is understood by SM is unclear. If SM is as universally promoted as it appears, it begs the question about whether or not it has a universal definition. SM has been most frequently underpinned by the construct of self-efficacy (Bandura, 1997), which the named initiatives above have drawn upon in their design. SM has been recognised as a form of patient empowerment (Raven, 2015), has been understood in terms of patient engagement (NHS England, 2013), and conceptualised in terms of activation whereby people who are more 'activated' are considered better at SM (Hibbard et al., 2005). Activation is used to describe 'an individual's knowledge, skill, and confidence for managing their health and health care' (Hibbard et al., 2005:1918). SM is defined as 'the care taken by individuals towards their own health and well-being: it includes the actions people take for themselves … to care for their LTC' (DoH, 2005:1). It is the reflexive self-monitoring of one's health, the self-governance and personal responsibility that are reflective of neoliberal philosophy.

Each of these conceptualisations of self-management are rooted in individualistic behavioural change approaches. They are criticised for failing to adequately account for the important role social networks play in SM (Vassilev et al., 2013). An individual rarely manages in isolation, but manages with support of others. SM has been taken to refer to the work an individual and social network members engage in (Vassilev et al., 2013). From 'illness' work, 'everyday' work to 'emotional' work (Vassilev et al., 2013), a social network contributes towards SM. With this more collective understanding of SM, collective efficacy, rather than self-efficacy, becomes important (Vassilev et al., 2014).

SM appears to lack a universal definition, with conceptualisations varying between more individualistic and more collective terms. In light of these different conceptualisations, it is important to know whether key players share the same view, as this will influence forms of service provision offered, public uptake of services, and the outcomes of SM that are likely to be considered important. Furthermore, this will also affect the ability of key players to work in partnership. However, very little is known about how SM is understood in practice by these stakeholders, identified here as those who commission health services, HCPs and users of services (patients and family care-givers). Given the importance of this, this papers aims to address this gap.

2. The study

The evidence presented in this paper is drawn from a larger study that aimed to:

1. Identify how stakeholders (people with LTCs, family care-givers, HCPs and commissioners) conceptualise SM.
2. Identify which outcomes of SM support are considered important by these stakeholder groups.

This paper focuses solely on the first aim. For the purpose of this paper we refer to people with LTCs as 'patients'.

Ethical approval was granted from the Faculty of Health Sciences' Ethics and Research Committee at the University of Southampton prior to data collection. Pseudonyms are used throughout this paper.

3. Method

To explore the narratives stakeholders held about SM it was felt appropriate to utilise the interview method, with focus groups and 1:1 semi-structured interviews conducted. Experiences of SM are personal and because focus groups allow participants to share and compare their experiences they were favoured. Conducting focus groups with patients and family care-giver stakeholders provided the opportunity to share, question and reflect on their SM strategies and goals. Through the group interaction participants discussed not only what they thought but also the reasoning and justification behind this. It is for these reasons that focus groups were selected. Condition-specific focus groups were conducted separately with patients and family care-givers and held at community venues. Those unable to attend focus groups were offered the opportunity of individual interviews. HCPs' and commissioners' work commitments made it unfeasible to conduct focus groups; individual interviews offered the flexibility to suit their schedules. Interviews were conducted in person either at participants' homes, or over the telephone. Stakeholder-specific interview guides were used, and although varying slightly in terminology, each broadly asked the same questions. We asked for;

- An introduction (either condition (patient/family care-giver) or job role (HCP/commissioner).
- Their understanding of SM.
- The important outcomes of SM.

To facilitate respondents to think about SM outcomes a prompt of 'what would someone who is managing well/struggling to manage look like?' was asked.

Participants were experts (by experience or education) in one of three exemplar LTCs; diabetes, colorectal cancer and stroke. Recruitment adverts placed in regional newspapers, online forums and associated charity/professional body newsletters were used for all stakeholders. The research team also invited HCPs and commissioners with appropriate expertise using publically available data. Interested individuals responded to an advert or invitation by contacting the research team. Sociodemographic information was taken at this juncture. Participants were purposively sampled to ensure compliance with the inclusion criteria and to maximise sample diversity in terms of time since diagnosis, age and ethnicity for patients and family care-givers stakeholder groups, and professional expertise for HCP and commissioner stakeholder groups. Interviews and focus groups were then arranged and written consent for participation was taken prior to data collection. The authors