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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.

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 togrowing 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 En- gland 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 under- pinned 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 com- missioners 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 con- sent for participation was taken prior to data collection. The authors

JE and EB conducted the group and individual interviews and each followed the same schedule. Field notes were made during all interviews/focus groups and discussed afterward.

3.1. Sample

Diabetes, colorectal cancer and stroke were selected as exemplar LTCs because they vary on important dimensions relevant to SM; disease trajectory and current health service provision for SM. The inclusion criteria varied slightly per stakeholder group. Criteria common to each group were: over the age of 18 years and living (patients/family care-givers) or working (HCPs and commissioners) within a 50-mile radius of Southampton, London or Leeds. Study localities were selected in order to encourage diversity within the sample in terms of socio-demographics.

Patients were interviewed if they were either living with diabetes (type 1 or 2), had been diagnosed with stroke or colorectal cancer (Tumour Node Metastases stages 1e3), and although some of the sample did not see themselves as having an 'active' diagnosis of colorectal cancer, they had at one stage received that diagnosis. Patients were excluded if they were living with gestational diabetes or had a stroke less than three months previously (see Table 1).

Family care-givers were interviewed if they had been nominated by a patient participant, or who self-identified as a supporter for individuals with one of the exemplar conditions (see Table 1).

HCPs were interviewed if they had expertise in one of the exemplar conditions or a generic self-management specialism (Table 2). HCPs could work either in the private sector or in the UK's publically funded health system: the National Health Service (NHS) (see Table 3).

In England commissioners are responsible for planning, agreeing and monitoring health services. Commissioning for health services is organised at four levels; NHS England national, NHS England regional, Clinical Commissioning Groups (CCGs) who commission services locally, and Commissioning Support Units (CSU) that provide administrative functions to CCGs (DoH, 2012). To gain a broad picture of commissioning, participants were recruited from each of these levels. Commissioners were invited to participate if their remit included commissioning services for LTCs or SM generally.

3.2. Analysis

All interview recordings were transcribed verbatim, and a deductive thematic analysis approach taken (Mills et al., 2010). A coding framework of the SM skills, attributes and outcomes that resulted from the first phase of the study, a systematic review of the literature on SM and SM interventions (Boger et al., 2015) was used. Adopting a deductive approach to this second phase of study pro- vided the opportunity to refine the phase one framework by examining how far stakeholder views aligned with the existing literature.

The qualitative data analysis software NVIVO was used to organise the data. The process of familiarisation, coding, framework modification, and interpretation was undertaken (Smith and Firth, 2011). 'Familiarisation' and 'coding' were carried out by more than one individual. The authors JE and EB independently coded half the dataset each and worked alongside three other researchers who each coded a third of the dataset to ensure all data was double coded. To promote reliability the researchers employed the same

Table 1
Socio-demographics: patients and family care-givers.

Stake-holder	Condition	Total	Age (years)			Gender		% White British	Diagnosis		
			18–35	35–55	55+	Male	Female		<2	2–10	>10
Patient	Diabetes	38	3[a]	6[a]	28[a]	21	17	97	3[a]	16[a]	16[a]
	Colorectal Cancer	19	1	5	13	4	15	100	6	9	4
	Stroke	40		9	31	21	19	85	6[a]	19[a]	8[a]
								Carer for			
								Spouse	Parent	Friend	Child
Family	Diabetes	14	4	4	6	3	11	64	10	3		
	Colorectal Cancer	10	1	2	7	2	8	100	7	2	1	1
	Stroke	11	2		9	4	7	82	8	2		

[a] Missing data.

Table 2
Socio-demographics: HCPs.

	Total	Gender		% White British	Years qualified			Condition			
		Male	Female		<5	5–15	15+	Diabetes	Colorectal cancer	Stroke	Generic
HPCs	20	5	15	95	1	7	12	3	3	6	8
Job role	GP (x4), nurse (x6), clinical nurse specialist (x2), occupational therapist (x1), speech and language therapist (x2), clinical psychologist (x1), consultant physician (x1), physiotherapist (x1), dietician (x1), stroke coordinator (x1),										

Table 3
Socio-demographics commissioners.

	Total	Gender		% white British	Organisation			
		Male	Female		CCG	CSU	NHS England	
							Regional	National
Commissioners	22	8	14	100	15	1	1	3

coding framework, but met regularly to discuss if additional codes should be added. Once coding of the data had taken place JE and EB worked collaboratively to refine a framework, and interpret the data set. The data analysis did not aim to compare between conditions but rather generate data that has relevance across conditions, and will be presented here in this format.

4. Findings

4.1. Participants

17 focus groups (9 patient, 8 family carer-givers) and 61 interviews (14 patients, 5 family care-givers, 20 HCPs and 22 commissioners) were conducted. In total 174 people participated, 91% of whom considered themselves white British. Both patient and family care-givers stakeholder groups fell within the 3rd quartile of deprivation according to index of multiple deprivation (IMD) i.e. were from relatively deprived areas.

5. The 'good' self-manager

Both users (patients and family care-givers) and providers (HCPs and commissioners) of health services had a shared understanding of SM that has been framed using the term the 'good' self-manager. Although provided with the opportunity to discuss 'poor' SM, all stakeholders focused on operationalising 'good' SM. Therefore the focus here will be on the framing of the 'good' self-manager.

Shared understandings existed around constructing the individual as a 'good' self-manager if they engage in positive SM strategies, such as adopting healthy lifestyles and taking regular exercise.

"for a diabetic there are only a couple of ways you can cope: one is food and weight control, and two is exercise. If you can look after either or both of those you're on a winning streak" Stewart, patient, diabetes

Family care-givers also had this understanding as they explained, "*if you are a good self-manager … you know that you can stick to a healthy diet*" (Philly, family, diabetes). This framing of SM does not recognise different SM strategies as being of personal choice, but rather positions patients as either "*being a good patient ['good' self-manager] and a bad patient ['bad' self-manager]*" (Joanne, dietician). Achieving the aspirational position of the 'good' self-manager was seen as requiring support. Family care-givers, HCPs and commissioners particularly expressed a need to support the development of the 'good' self-manager through helping "*people identify what it is they need to do in order to self-manage*" (Caroline, CCG commissioner). Although all stakeholders framed SM in terms of the 'good' self-manager, there were areas of difference. This difference focused around the particulars of what constituted a 'good' self-manager. Specifically this discussion will focus on how far the 'good' self-manager is perceived to be 'remoralised', 'knowledgeable' and 'active' (see Fig. 1).

5.1. To be remoralised

UK social policy in the twenty first century has attempted to 'roll back the state' (Penn et al., 2015), shifting responsibility from the state towards the individual. The focus has been to create a remoralised social citizen, whereby citizenship becomes tied to one's capacity to be autonomous, proactive and responsible. In a health context, the patient is remoralised from a passive recipient of treatment to an empowered partner in the management of their health. The process of becoming remoralised is demonstrated by
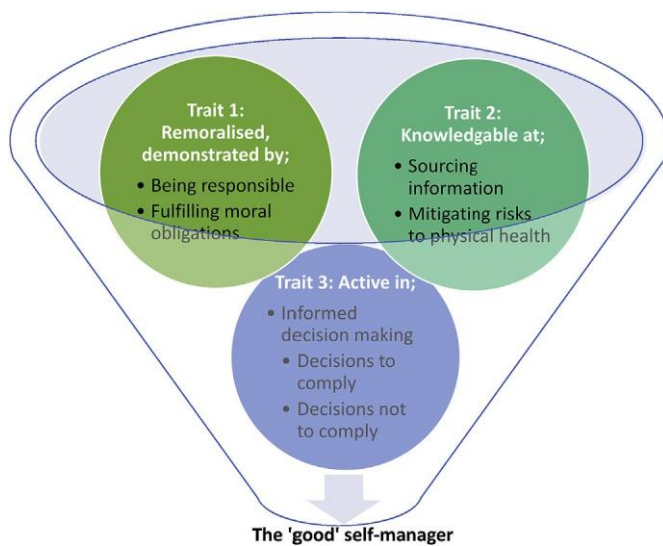
Fig. 1. Traits of the 'good' self-manager.

the patient taking on greater personal responsibility, fulfilling moral obligations by doing their best to manage health and well- being, and in doing so, minimising welfare dependency. This discourse was evidenced in all stakeholder accounts.

5.1.1.   Responsibility

Commissioners considered their role in commissioning services to include discouraging an entitlement-based approach to health- care utilisation and "*encouraging people who don't understand that actually the responsibility for their condition is theirs; it's not the responsibility of others to support [their] illness*" (Lauren, CCG Commissioner). This view, shared by HCPs, positions the 'good' self-manager as an individual who is willing to take "*responsibility … with reference to their health*" (Victoria, diabetes nurse specialist). The promotion of greater individual responsibility, as found in commissioner and HCP accounts, places the consequences of any (in)action with the patient. What is of interest is that such discourse was also present in patients' and family care-givers' accounts.

"I thought you know, I've got to make a few changes now, it's really down to me"
Mary, patient, stroke

"It annoys me that people go to their GP and say, "put me right, give me a pill to put me right" because it's you that's got the problem … it's your responsibility … the problem is yours, not theirs"
Jennifer, patient, diabetes

5.1.2.   Moral obligations

Taking responsibility for one's health was seen to be to accept one's moral obligations to both society and to one's social network. The first obligation the 'good' self-manager has is to society. This was seen most notably in the moral obligation to be autonomous and not to use the welfare state inappropriately; a position taken by each stakeholder group to a greater or lesser extent.

"I know people who carry on smoking and I think 'for God's sake, give yourself every chance. The NHS is spending a fortune [on you]'''
Will, patient, cancer

This moral obligation to society, one's civic obligation, is reflective of neoliberalism that advocates a reduced state, and with this comes the need to ensure healthcare services are not over- burdened by dependency. The 'good' self-manager should fulfil the moral obligation to ease the pressure on the NHS by managing health "*because it's [NHS] not sustainable not to [self-manage]*" (Claire, CCG commissioner). Thus patients should SM to reduce their use of NHS resources which "*in turn saves money for the NHS … because if [patients] are more aware of what is going on they are not coming in all the time*" (Katy, nurse practitioner*).* By being autonomous the 'good' self-manager is less dependent upon healthcare provision, which, questionably, helps ease financial pressures.

The 'good' self-manager's moral obligation to society was most evident in the discourse around 'appropriate' use of healthcare services. All stakeholders were in agreement that the 'good' self-manager uses healthcare services appropriately. However, stake- holders disagreed about whether 'appropriate' use was concerned with limiting dependency on services, or whether it was concerned with seeking help early to prevent complications. Commissioners and HCPs, appeared to conceptualise appropriateness solely on frequency of use, and the 'good' self-manager was an individual who was more autonomous and less dependent.

> "Through having an empowered and knowledgeable patient you hopefully have less contact with health professionals"
> Sharon, colorectal cancer nurse

Conversely, patients and family care-givers felt the 'good' self- manager fulfilled their civic duty by seeking help from healthcare services early. For them 'appropriate' use was concerned with engaging with healthcare services based on perceived need. Further, it was felt that healthcare services had a responsibility to be available when the perceived need was present.

> "What you need is a point of contact every so often so if it goes wrong … we should be able to say [when we need help]; and when you need that support, it needs to be there."
> Colin, family, stroke

Perceived access to healthcare is important to patients as it provides reassurance (Rogers et al., 2004). For patients and family care-givers, help-seeking was not symptomatic of dependency but part of 'good' self-management.

> "When I ask for help, which is a very hard thing to do, I don't want to be told off or told I've failed. I want them to reciprocate the fact that I'm asking for help and give me some help." Samatha, patient, diabetes

It can be reasonably argued that using healthcare when one feels it is needed may actually contribute towards the fulfilment of one's civic duty to society. That is, if people avoid seeking help, they run the risk of developing costly problems, and thus engaging with services when they perceive it is needed might save the services money in the long-term. Making the judgement regarding when to use healthcare services is the patient's responsibility, and it is they who must balance their health with healthcare service use.

The second moral obligation the 'good' self-manager has is to themselves and their social network. A 'good' self-manager accepts that they have a "*responsibility to carry on getting better for them- selves and their families*" (Madeline, speech and language therapist); a view shared by HCPs, family care-givers and patients. The moral obligation a patient has to SM for their social network is reflective

of the discourse around individualisation and minimising de- pendency. In particular, a 'good' self-manager has a moral obligation to relatives to ensure they "*are not a burden to family due to poor health*" (Bernard, patient, diabetes), and in order to ensure they fulfil their own relationship commitments. That is, according to patients, "*[you] look after yourself so you can in turn look after your relatives*" (Pete, patient, diabetes).

The remoralised individual who takes responsibility and fulfils their civic duty towards society and their social network was considered by each stakeholder group to be characteristic of a 'good' self-manager. Taking on responsibility might be the first step towards the good self-manager, but once an individual accepts this they require the knowledge to know how to fulfil this responsibility.

5.2. To be knowledgeable

In the UK, discourse surrounding SM has focused on supporting the individual to 'develop knowledge, skills and confidence' (THF, 2014) to self-manage effectively. This discourse was found in the understandings of what is it to be a 'good' self-manager, according to all groups, "*knowledge is key, without knowledge [they'd] be* fi*ghting blind*" (Harry, patient, diabetes). All stakeholders agreed that through the acquisition of information one can become knowledgeable, which is integral to the development of the 'good' self-manager.

"If they don't come to the education sessions then I'm not quite sure how they can self-manage"
Jonathan, diabetes consultant physician

5.2.1. Sourcing information

In order to become a 'good' self-manager an individual requires knowledge of the condition and of SM practices; a view all stake- holders held. However, different opinions existed regarding just how an individual acquires this knowledge. One stance is that individuals are transformed from an unknowing individual to a knowledgeable individual through attending education pro- grammes; a view that resonated most with HCPs and commissioners. Commissioners and HCPs tended to imply that the acquisition of information via formal education sessions results in a knowledgeable individual. However, de Silva (2011) found more didactic forms of SM education programmes to have the lowest success in supporting SM and behavioural change. Thus a second perspective is that individuals are not transformed from an 'un- knowledgeable' to a 'knowledgeable' individual in one instance. Rather, an individual gradually becomes more knowledgeable through acquiring information about how to manage when it is needed; a position taken by patients and family care-givers.

"further down the line you think, 'Well now we've sorted this out and we can think straight for a while, how do I now go about finding out what's out there?' It would be nice if there were a central point you could go back to"
Jane, family member, stroke

Whilst accessing information on an ad hoc basis is one means of becoming the 'good' self-manager, this is made problematic by the absence of follow up after education courses to monitor if individuals require additional advice or information updates (Penn et al., 2015). For patients and family care-givers individualised in- formation delivered gradually was important. Thus the absence of monitoring and the opportunity to acquire advice when needed

may prevent an individual from becoming a 'good' self-manager.

"There should be a little follow up, ask you more about what is happening now … They [HCPs] don't even know we exist anymore"
Dianne, family, stroke

According to family care-givers "*knowing who to ask [for advice]
… would help*" (Denise, family, cancer) as the 'good' self-manager requires accessible, specialist information that is "*practical and holistic*" (Colin, family, stroke). While stakeholders differed in their opinions regarding how an individual should acquire knowledge, they all agreed knowledge is integral to becoming a 'good' self- manager.

5.2.2. Mitigating risks

The knowledgeable aspect of the 'good' self-manager is not solely knowing how to source information, but it is also specifically about knowing the risks associated with one's condition; a view shared by all stakeholders. The 'good' self-manager, through acquiring information, is knowledgeable in risk management. HCPs and commissioners saw their role as being the educators, and "*supporting individuals to have the information they need about their condition*" (Pauline, NHS England Commissioner). The focus on condition-specific information means that for all stakeholders risk management is concerned specifically with mitigating risks to physical health.

"Obviously education is important for the understanding the nature of strokes … they may not understand and may still smoke … that furthers their risk of a second stroke"
(Gareth, Physiotherapist)

Mitigating risks to physical health was concerned, for all stakeholders, with achieving targets associated with biomedical indicators of health; such as blood pressure, symptoms or blood glucose level. It is assumed that by having "*the information one needs about themselves, their condition, which will help HbA1C [or condition management more generally]*" (Pauline, NHS England commissioner). For patients especially, the importance of man- aging such risks served also to reaffirm the 'good' self-manager status. Managing these biomedical markers "*provides the evidence that [they] are fine*" (Ruby, patient, diabetes) and managing well. Being able to prove one is managing risks associated with their condition may be linked to the neoliberal philosophy that the individual has to be self-governing and responsible.

Arguably the notion of biomedical risk management is born out of a desire to prevent condition deterioration; evidenced in all stakeholder accounts. That is "*[self]-management* is *about stopping complications*" (Jonathan, consultant physician, diabetes), and to put frankly "*preventing people from dying early*" (Owen, NHS England National Commissioner). Reflective of the moral imperative of neoliberal philosophy to be responsible, the 'good' self-manager is knowledgeable and "*clear about the [national] guidelines*" (Hansa, family care-giver, diabetes) for the LTC. It is the responsibility of the individual to use this information to manage biomedical risks, a view shared by patients as they considered the 'good' self- manager to "*read up on the available leaflets … and make sure [they're] fully informed*" (Jen, patient, cancer). Through doing this the 'good' self- manager is able to "*reduce the risk of reoccurrence, and live a longer life*" (Frank, patient, cancer). That being said, patients did also favour a more balanced approach to biomedical risk management, talking of SM strategies that accounted for everyday life as well as biomedical outcomes, as explored further below.

For all stakeholder groups the 'good' self-manager is an individual who is knowledgeable in the condition and self- management practices, but who also uses knowledge to mitigate the risk to their physical health. However, knowing the risks and how to manage them is only one characteristic of the 'good' self- manager. Accepting responsibility for your health is the first step towards becoming a 'good' self-manager, acquiring knowledge the second step, and the third step, to bridge what has been phrased the third translational gap (The Third Gap Research Group, 2016), is applying that knowledge. After all, one "*can be an absolute expert on your condition, but knowing that stuff and actually acting on it are two different things*" (Celia, family, diabetes).

5.3. To be 'active'

The 'good' self-manager, by taking on responsibility, is required to be 'active' in their personal healthcare. This is achieved through utilising knowledge to enact behaviour expected of a 'good' self-manager; a view expressed exclusively by commissioner and HCP stakeholders.

"An effective self-manager would be able to problem solve themselves, be able to carry out most of their activities of daily living, and with minimal support."
Gareth, Physiotherapist

The 'good' self-manager utilises knowledge and skills to achieve independence from HCPs, a view all stakeholders shared, however, only commissioners labelled this behaviour to be characteristic of an 'activated' individual (Hibbard et al., 2005).

"More activated people are much better able to manage their own health at home outside of the system and they are much better prepared for the consultations, they make better use of their interactions with the NHS which in effect reduces the number of times that they have to come into contact with the NHS[00]
Owen, NHS England National commissioner

In the UK and USA, Patient Activation is not a new concept, and it has gained political support, but it is exclusively reflected in the accounts of commissioners only, who equate the 'good' self- manager with the notion of the 'activated' individual. The term 'activation' itself is criticised for the way it ignores social and wellbeing factors (Entwistle and Cribb, 2013). While the term 'activation' did not resonate with patients or family care-givers, all stakeholders were in agreement that the 'good' self-manager has to want to act ('appropriately') on the knowledge they have, and failure to do so means they are not self-managing.

"They need to want to do it. I mean people who are not interested and just want it sorted, they're not going to self-manage." Jonathan, diabetes Consultant Physician

Being 'active' is recognised by "*being clear about what you want [from SM] and being determined about going to get it*" (Beth, patient, cancer); a view all stakeholders shared.

5.3.1. Informed decision making
The 'good' self-manager should be able to use their knowledge and "*information to make informed choices and decisions*" (Beryl, patient, cancer). The 'good' self-manager makes informed decisions regarding their health and social wellbeing.

"I would want them to be confident in making choices … just the confidence in knowing their choices and to be able to problem solve"
Joanne, Dietician

Two types of decision-making emerged that highlighted some disparity between stakeholder groups.

5.3.1.1. Making decisions to comply. All stakeholders, to a greater or lesser extent, saw informed decision-making to align with a compliance based-framework, whereby the 'good' self-manager makes 'appropriate' choices and by doing so exercises "*control over [the] things that [they] can make a decision about*" (Celia, patient, diabetes). As part of the active component of the 'good' self- manager, the individual is required to reflexively monitor (Giddens, 1984) their behaviour so that it fits within the parameters set by the health service. This is because, as family care-givers and HCPs voiced; "*you should take the advice of the doctors because there's a reason that they're telling you all that*" (Fran, family, diabetes). 'Good' self-management was understood exclusively, by family care-givers and a selection of HCPs, in terms of compliance.

"If somebody's not very good at compliance … [they're] not going to be very good at self-management."
Fran, family, diabetes

This demonstrates how compliance to medical advice is a central concern for 'good' SM, and illuminates how SM overlays a moralised rhetoric of 'choice' upon compliance based medicine. Complying with medical advice also links back to the mitigating of risk, specifically the mitigation against risks to physical health. Compliance, for family care-givers, was important as the individual will "*not suffer*" (Zoe, family, cancer) if they follow medical advice. The compliant framework, however, assumes behavioural change is easy to achieve and fails to account for the difficulties and complexities around achieving this change (Vassilev et al., 2014). It also fails to adequately acknowledge that making compliant decisions and acting on them may be hard for individuals, or indeed may not be what individuals want.

5.3.1.2. Making decisions not to comply. At the core of the notion of the 'active' individual is a recognition that the 'good' self-manager is able to exercise agency; that is, to act freely and make their own informed decisions. For patients, the 'good' self-manager exercises this agency by making informed decisions, but not necessarily al- ways what HCPs would perceive as compliant decisions, in order to enact SM practices so they minimally interfere with daily life.

"There's a negotiation to see what I'm prepared to do because of other factors in my life. It might be that X is the perfect solution. But actually, not with my work day and what I do in my life and what I want to do."
Lou, patient, diabetes

Everyday experiences of living with a LTC include balancing illness management objectives with social roles and commitments (Vassilev et al., 2014). The balancing of symptom management with sense of self (Townsend et al., 2006) is where tension arises be- tween making decisions that are compliant and decisions that are non-compliant. Although commissioners recognised SM practices "*have to be interpreted in the context of what is achievable for the person in the context of their lives*" (David, CCG commissioner), it was patients who exclusively advocated making decisions that were more influenced by lifestyle and sometimes prioritised

achieving social wellbeing over complying with medical advice.

> "nobody was telling me anything useful that was actually practical and fitted in with a life that you could sustain, yes you could do it for a month but then actually I have got a life." Rachel, patient, diabetes

Managing symptoms or biomedical risks, when they clashed with patients' sense of self or enjoyment in life, created tensions for patients just as Townsend et al. (2006) found: patients could prefer to achieve social wellbeing that may very well be in direct contradiction to medical advice.

> "Yes, I smoke. It's taken everything else, it's not taking my cig- arettes. I know I shouldn't have another smoke but I don't care." Jill, patient, stroke

Patient stakeholders considered the 'good' self-manager to engage in 'strategic non-compliance' (Campbell et al., 2003) or 'rationalised non-adherence' (Demain et al., 2015); that is selectively applying medical advice to either suit lifestyle or minimise treatment burdens respectively. Thus for patients the 'good' self- manager makes 'appropriate' decisions to achieve social well- being, which for them, was defined as meaningful participation in social and work life.

In summary, all stakeholders agreed that the 'good' self- manager was 'active', and uses knowledge to make 'appropriate' decisions to achieve wellbeing. However, two critical tensions exist. The first is a difference in terminology that despite gaining political support the term patient activation was used only by providers of healthcare and was meaningless to users of healthcare, demon- strating how the public may not accept political rhetoric. The second lies in what is understood by 'appropriate' decisions. For patients it was appropriate that they engage in strategic non- compliance to fit in with their everyday social roles, whereas for family care-givers and HCPs it was appropriate for the 'good' self- manager to adhere to medical advice, which may be at the expense of freedom in their social lives.

6. Discussion

This paper is unique in presenting an understanding of SM from four key stakeholder perspectives, using three different exemplar long-term conditions; diabetes, colorectal cancer and stroke. A limitation of this study is the predominately white British sample, however this study does offer an understanding of how commissioners, HCPs, patients and family care-givers understand SM, which has not, to our knowledge, been investigated previously. This paper reveals how SM is understood by users and providers of healthcare services in the framework of the 'good' self-manager.

This paper resonates with that of Vassilev et al. (2016) work in demonstrating that the neoliberal health discourse is present in users' and providers' (of healthcare services) conceptualisations of the 'good' self-manager. The good self-manager is remoralised, knowledgeable and active. These aspects were presented separately in order to better understand their unique characteristics. They are, however, inextricably linked. This is seen most notably in the knowledgeable and active aspects, whereby action is knowledge applied, and where the remoralised aspect infuses both. The findings also serve to highlight how neoliberal health discourse is taken on by users and providers of healthcare in their conceptualisation of SM. Additionally the concept of the 'good' self- manager highlights the problematic nature of neoliberal discourse. Neoliberal health discourse of patient empowerment, choice

and information is present in health policy that has focused on developing individuals' 'knowledge, skills and confidence' (THF, 2014). The policy focus on personal development is characteristic of a neo-liberal model of governing that promotes individual choice but 'under guidance of distant expert' (McNay, 2009:56). The consensus around the 'knowledgeable' and 'active' elements, particularly the consensus on risk management and informed decision-making, illustrate how the very concept of the 'good' self-manager lends itself to value certain behaviour types. The findings illustrate that there is a moral imperative underlying all action. That is, there is a moral imperative for the 'good' self-manager to act appropriately by acquiring knowledge and using this to act out informed decisions. This raises three points.

The first concerns that of 'choice'. The central moral imperative for some stakeholders was to comply with medical advice. How- ever, favouring one SM strategy not a choice and is at conflict with the understanding that an individual 'cannot not manage … the only question is how one manages' (Lorig and Holman, 2003:1). Contrasting this, the discourse of the 'good' self-manager gives a sense of either being in; self-managing, or being out; not self- managing. The discourse leaves no room for an understanding that an individual's behaviour is reflective of a SM style (Lorig and Holman, 2003). It is questionable then how far the 'good' self- manager is able to make informed decisions free from structural, society, and cultural constraints. This is demonstrative of one of the very critiques of neoliberalism, in that choice is a façade (Ayo, 2012). Normative values and behaviours govern the choices of the 'good' self-manager as these normative discourses set limits on what is considered appropriate SM behaviour. This was seen in the disparity around decision-making where patients engaged in strategic non-compliance to suit lifestyle. Through doing this patients were positioned in a place where their sense of moral duty, and status as a 'good' self-manager, could be questioned. The findings illustrate the interconnectedness of the three aspects of the good self-manager. Whereby the good self-manager is morally bound to make 'appropriate' choices based on knowledge, for not doing so will mean they are not fulfilling their responsibility.

The second relates to how knowledge is acquired. One view, and that of the logic of choice model (Mol, 2008:14), is that an expert informs a patient who is then able to utilise this in their decision- making. This process is unidirectional (Mol, 2008). Health policy has focused on increasing the uptake of education programmes, and SM interventions aim to enhance an individual's ability to SM through improved information and skills development (Coster and Norman, 2009). The findings resonate with Mol's logic of choice critique, whereby the logic of choice fails to account for the context in which self-management occurs. Seen in the context of patients' preferences for engaging in strategic non-compliance this draws attention to the complexities of social life. The findings illustrate that lifestyle specific knowledge is currently absent from self- management support as patients choose strategic non- compliance to ensure SM strategies suit the 'messiness' of their everyday lives. This illuminates the need for SM programmes to be less directive and engage less in 'one size fits all' (Jones, 2013), and rather focus on incorporating individuals' social circumstances (Kennedy et al., 2007). It comes then that rather than SM pro- grammes being unidirectional they should be multidirectional, where the patient and healthcare professional work collaboratively to situate the medical knowledge in the everyday context of the patient.

The third follows in that the focus on 'good' SM may exacerbate health disparities. The 'good' self-manager by focusing on the in- dividual's morality, knowledge and action, focuses also on re- sources and access to resources to facilitate the achievement of the 'good' self-management status. However, it is presumptuous to

believe all individuals have access to the required resources and support structures. It is known that social network members facilitate resource assess and support (Vassilev et al., 2013, 2014) but for some individuals with limited resources and network sup- port they may find it difficult (Townsend et al., 2006). The individualistic nature of the 'good' self-manager can then exacerbate health disparities between those with the necessary resources to be a 'good' self-manager and those without, it may in turn also lead to those who do not reach the 'good' self-manager status to be stigmatised as the deserving sick.

The concept of the good self-manager has highlighted the moral dimension of self-management. The decisions individuals make, and the actions they perform, are influenced by their moral com- pass. Whether they are directed by obligations to society or to their social network, SM is more than following instructions and being 'good' at SM. It is a balancing act of managing one's illness with managing the demands of society and social life (Townsend et al., 2006). The 'good' self-manager acts with direction from their sense of moral duty. Finally, it comes then that the 'good' self- manager acts in a manner that is right for them in the context of their lives. Therefore, it might be pertinent to attempt to move away from this neoliberal discourse and move towards truly valuing patient choice without moral judgement and critique.

Acknowledgements

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