6   Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on

7   the self-management of long-term health conditions

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9   **Abstract:**

10   Healthcare policy in developed countries has, in recent years, promoted self-
11   management among people with long-term conditions. Such policies are underpinned
12   by neoliberal philosophy, as seen in the promotion of greater individual responsibility
13   for health through increased support for self-management. Yet still little is known about
14   how self-management is understood by commissioners of healthcare services,
15   healthcare professionals, people with long-term conditions and family care-givers. The
16   evidence presented here is drawn from a two-year study, which investigated how self-
17   management is conceptualised by these stakeholder groups. Conducted in the UK
18   between 2013-2015, this study focused on three exemplar long-term conditions, stroke,
19   diabetes and colorectal cancer, to explore the issue. Semi-structured interviews and
20   focus groups were carried out with 174 participants (97 patients, 35 family care-givers,
21   20 healthcare professionals and 22 commissioners). The data is used to demonstrate
22   how self-management is framed in terms of what it means to be a 'good' self-manager.
23   The 'good' self-manager is an individual who is remoralised; thus taking responsibility
24   for their health; is knowledgeable and uses this to manage risks; and, is 'active' in using
25   information to make informed decisions regarding health and social wellbeing. This
26   paper examines the conceptualisation of the 'good' self-manager. It demonstrates how
27   the remoralised, knowledgeable and active elements are inextricably linked, that is, how
28   action is knowledge applied and how morality underlies all action of the 'good' self-
29   manager. Through unpicking the 'good' self-manager the problems of neoliberalism are
30   also revealed and addressed here.

31   **Key words:** United Kingdom, self-management, person-centred care, long-term conditions,
32   neoliberalism

33   **Introduction**

34   Healthcare in developed countries such as the UK, Canada, Australia and USA have undergone a

35   process of individualisation (Galvin, 2002) that has been underpinned by neoliberal philosophy. The

36   political rhetoric around the burden of health care needs is an example of the influences of

37   neoliberalism on healthcare policy. The focus on greater individual responsibility, one of the five key

38   tenets of neoliberalism (Ericson et al., 2000), has become embedded in health policy. At the same

39   time, there has been an emphasis on person-centred care (The Health Foundation (THF), 2014) and

40   increased support for SM (NHS England, 2014), which encourages patients to be active agents rather

41   than passive recipients of care (Bodenheimer et al., 2005). Person-centred care calls for an approach

42   that 'places the patient as the focus of any health care provision' (Lawn and Battersby, 2009:7) and

43   for healthcare professionals (HCPs) to respect patients' 'autonomy through the sharing of power and

44   responsibility' (THF, 2014). Whilst this agenda is underpinned by a respect for patients and their self-

45   determination, it is this construction of the patient as empowered, able to participate, autonomous

46   and capable of making choices that some have argued resonates with the neoliberal philosophy (Ayo,

47   2012). Patient-centred care has been part of health policy across the UK, Australia and the USA for

48   two decades, and it has arguably shifted the responsibility for health away from the state and onto

49   the individual (Ayo, 2012) by encouraging patients to self-manage.

50   The political focus on SM has emerged, in part, as a response to growing demands placed on

51   healthcare services, which have occurred due to people living longer and with an increased number

52   of long-term health conditions (LTC) (Sprague et al., 2006). In England fifteen million people live with

53   a LTC (NHS England, 2015). Management of LTCs accounts for 70% of the English health and social

54   care budget (DoH, 2012). In the USA the percentage of spending is 85% (Goodwin, 2006), as around

55   half of the population live with a LTC (Ward et al., 2014). In Australia 4.6% of the population live with

56   diabetes (Australia Bureau of Statistics, 2013), in Canada this figure is 6.8% (Public Health Agency of

57   Canada, 2011) and is estimated to rise to 11% by 2020 (Canadian Diabetes Association, 2008). How

58   policy makers, health providers and professionals from across these nations should respond to these

59   demands is a pertinent social issue. The main response so far in the UK and across other high income

60   nations has been to promote greater self-management (SM) by people with LTCs, with the view that

61   this will help to slow 'disease progression and [reduce] the need for unscheduled acute admissions

62   by supporting people to manage their condition(s)', and will, therefore, reduce health service costs

63   (DoH, 2012: 10).

64   Support for SM internationally has occurred through Stanford University's model of chronic

65   disease SM programme, which influenced the introduction of the Expert Patient Programme (EPP) in

66   the UK (Wilson, 2008), and Flinder's Patient-centered model of Chronic Disease SM in Australia. It is

67   recognised that 'everyone self-manages their condition to some extent' (Lorig and Holman, 2003),

68   however what is understood by SM is unclear. If SM is as universally promoted as it appears, it begs

69   the question about whether or not it has a universal definition. SM has been most frequently

70   underpinned by the construct of self-efficacy (Bandura, 1997), which the named initiatives above

71   have drawn upon in their design. SM has been recognised as a form of patient empowerment (Raven,

72   2015), has been understood in terms of patient engagement (NHS England, 2013), and

73   conceptualised in terms of activation whereby people who are more 'activated' are considered

74   better at SM (Hibbard et al., 2005). Activation is used to describe 'an individual's knowledge, skill,

75   and confidence for managing their health and health care' (Hibbard et al., 2005:1918). SM is defined

76   as 'the care taken by individuals towards their own health and wellbeing: it includes the actions

77   people take for themselves … to care for their LTC' (DoH, 2005:1). It is the reflexive self-monitoring

78   of one's health, the self-governance and personal responsibility that are reflective of neoliberal

79   philosophy.

80   Each of these conceptualisations of self-management are rooted in individualistic

81   behavioural change approaches. They are criticised for failing to adequately account for the

82   important role social networks play in SM (Vassilev et al., 2013). An individual rarely manages in

83   isolation, but manages with support of others. SM has been taken to refer to the work an individual

84   and social network members engage in (Vassilev et al., 2013). From 'illness' work, 'everyday' work to

85   'emotional' work (Vassilev et al., 2013), a social network contributes towards SM. With this more

86   collective understanding of SM, collective efficacy, rather than self-efficacy, becomes important

87   (Vassilev et al., 2014).

88   SM appears to lack a universal definition, with conceptualisations varying between more

89   individualistic and more collective terms. In light of these different conceptualisations, it is important

90   to know whether key players share the same view, as this will influence forms of service provision

91   offered, public uptake of services, and the outcomes of SM that are likely to be considered

92   important. Furthermore, this will also affect the ability of key players to work in partnership.

93   However, very little is known about how SM is understood in practice by these stakeholders,

94   identified here as those who commission health services, HCPs and users of services (patients and

95   family care-givers). Given the importance of this, this papers aims to address this gap.

96

97   **The Study**

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

99   1. Identify how stakeholders (people with LTCs, family care-givers, HCPs and commissioners)
100   conceptualise SM.
101   2. Identify which outcomes of SM support are considered important by these stakeholder
102   groups.
103   This paper focuses solely on the first aim. For the purpose of this paper we refer to people with LTCs
104   as 'patients'.

105   Ethical approval was granted from the Faculty of Health Sciences' Ethics and Research

106   Committee at the University of Southampton prior to data collection. Pseudonyms are used

107   throughout this paper.

108

109 **Method**

110   To explore the narratives stakeholders held about SM it was felt appropriate to utilise the

111 interview method, with focus groups and 1:1 semi-structured interviews conducted. Experiences of

112 SM are personal and because focus groups allow participants to share and compare their

113 experiences they were favoured. Conducting focus groups with patients and family care-giver

114 stakeholders provided the opportunity to share, question and reflect on their SM strategies and

115 goals. Through the group interaction participants discussed not only what they thought but also the

116 reasoning and justification behind this. It is for these reasons that focus groups were selected.

117 Condition-specific focus groups were conducted separately with patients and family care-givers and

118 held at community venues. Those unable to attend focus groups were offered the opportunity of

119 individual interviews. HCPs' and commissioners' work commitments made it unfeasible to conduct

120 focus groups; individual interviews offered the flexibility to suit their schedules. Interviews were

121 conducted in person either at participants' homes, or over the telephone. Stakeholder-specific

122 interview guides were used, and although varying slightly in terminology, each broadly asked the

123 same questions. We asked for;

124   • An introduction (either condition (patient / family care-giver) or job role (HCP /

125   commissioner).

126   • Their understanding of SM.

127   • The important outcomes of SM.

128 To facilitate respondents to think about SM outcomes a prompt of 'what would someone who is

129 managing well / struggling to manage look like?' was asked.

130   Participants were experts (by experience or education) in one of three exemplar LTCs;

131 diabetes, colorectal cancer and stroke. Recruitment adverts placed in regional newspapers, online

132 forums and associated charity / professional body newsletters were used for all stakeholders. The

133 research team also invited HCPs and commissioners with appropriate expertise using publically

134 available data. Interested individuals responded to an advert or invitation by contacting the research

135 team. Sociodemographic information was taken at this juncture. Participants were purposively

136 sampled to ensure compliance with the inclusion criteria and to maximise sample diversity in terms

137 of time since diagnosis, age and ethnicity for patients and family care-givers stakeholder groups, and

138 professional expertise for HCP and commissioner stakeholder groups. Interviews and focus groups

139 were then arranged and written consent for participation was taken prior to data collection.   The

140 authors JE and EB conducted the group and individual interviews and each followed the same

141 schedule. Field notes were made during all interviews/ focus groups and discussed afterward.

142

143 *Sample*

144 Diabetes, colorectal cancer and stroke were selected as exemplar LTCs because they vary on

145 important dimensions relevant to SM; disease trajectory and current health service provision for SM.

146 The inclusion criteria varied slightly per stakeholder group. Criteria common to each group were:

147 over the age of 18 years and living (patients/ family care-givers) or working (HCPs and

148 commissioners) within a 50-mile radius of Southampton, London or Leeds. Study localities were

149 selected in order to encourage diversity within the sample in terms of socio-demographics.

150   Patients were interviewed if they were either living with diabetes (type 1 or 2), had been

151 diagnosed with stroke or colorectal cancer (Tumour Node Metastases stages 1-3), and although

152 some of the sample did not see themselves as having an 'active' diagnosis of colorectal cancer, they

153 had at one stage received that diagnosis. Patients were excluded if they were living with gestational

154 diabetes or had a stroke less than three months previously.

155   Family care-givers were interviewed if they had been nominated by a patient participant, or

156 who self-identified as a supporter for individuals with one of the exemplar conditions.

157   HCPs were interviewed if they had expertise in one of the exemplar conditions or a generic

158   self-management specialism (table 2). HCPs could work either in the private sector or in the UK's

159   publically funded health system: the National Health Service (NHS).

160   In England commissioners are responsible for planning, agreeing and monitoring health

161   services. Commissioning for health services is organised at four levels; NHS England national, NHS

162   England regional, Clinical Commissioning Groups (CCGs) who commission services locally, and

163   Commissioning Support Units (CSU) that provide administrative functions to CCGs (DoH, 2012). To

164   gain a broad picture of commissioning, participants were recruited from each of these levels.

165   Commissioners were invited to participate if their remit included commissioning services for LTCs or

166   SM generally.

167

168   *Analysis*

169   All interview recordings were transcribed verbatim, and a deductive thematic analysis approach

170   taken (Mills et al., 2010). A coding framework of the SM skills, attributes and outcomes that resulted

171   from the first phase of the study, a systematic review of the literature on SM and SM interventions

172   (Boger et al., 2015) was used. Adopting a deductive approach to this second phase of study provided

173   the opportunity to refine the phase one framework by examining how far stakeholder views aligned

174   with the existing literature.

175   The qualitative data analysis software NVIVO was used to organise the data. The process of

176   familiarisation, coding, framework modification, and interpretation was undertaken (Smith and Firth,

177   2011). 'Familiarisation' and 'coding' were carried out by more than one individual. The authors JE

178   and EB independently coded half the dataset each and worked alongside three other researchers

179   who each coded a third of the dataset to ensure all data was double coded. To promote reliability

180   the researchers employed the same coding framework, but met regularly to discuss if additional

181 codes should be added. Once coding of the data had taken place JE and EB worked collaboratively to

182 refine a framework, and interpret the data set. The data analysis did not aim to compare between

183 conditions but rather generate data that has relevance across conditions, and will be presented here

184 in this format.

185

186 **Findings**

187 *Participants*

188 17 focus groups (9 patient, 8 family carer-givers) and 61 interviews (14 patients, 5 family care-givers,

189 20 HCPs and 22 commissioners) were conducted. In total 174 people participated, 91% of whom

190 considered themselves white British. Both patient and family care-givers stakeholder groups fell

191 within the 3rd quartile of deprivation according to index of multiple deprivation (IMD) i.e. were from

192 relatively deprived areas.

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

Stake-holder	Condition	Total	Age (years)			Gender		% White British	Diagnosis (years)		
			18-35	35-55	55+	Male	Female		<2	2-10	>10
Patient	Diabetes	38	3*	6*	28*	21	17	97	3*	16*	16*
	Colorectal Cancer	19	1	5	13	4	15	100	6	9	4
	Stroke	40		9	31	21	19	85	6*	19*	8*
									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		

*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

203 **The 'good' self-manager**

204 Both users (patients and family care-givers) and providers (HCPs and commissioners) of health

205 services had a shared understanding of SM that has been framed using the term the 'good' self-

206 manager. Although provided with the opportunity to discuss 'poor' SM, all stakeholders focused on

207 operationalising 'good' SM. Therefore the focus here will be on the framing of the 'good' self-

208 manager.

209   Shared understandings existed around constructing the individual as a 'good' self-manager if

210 they engage in positive SM strategies, such as adopting healthy lifestyles and taking regular exercise.
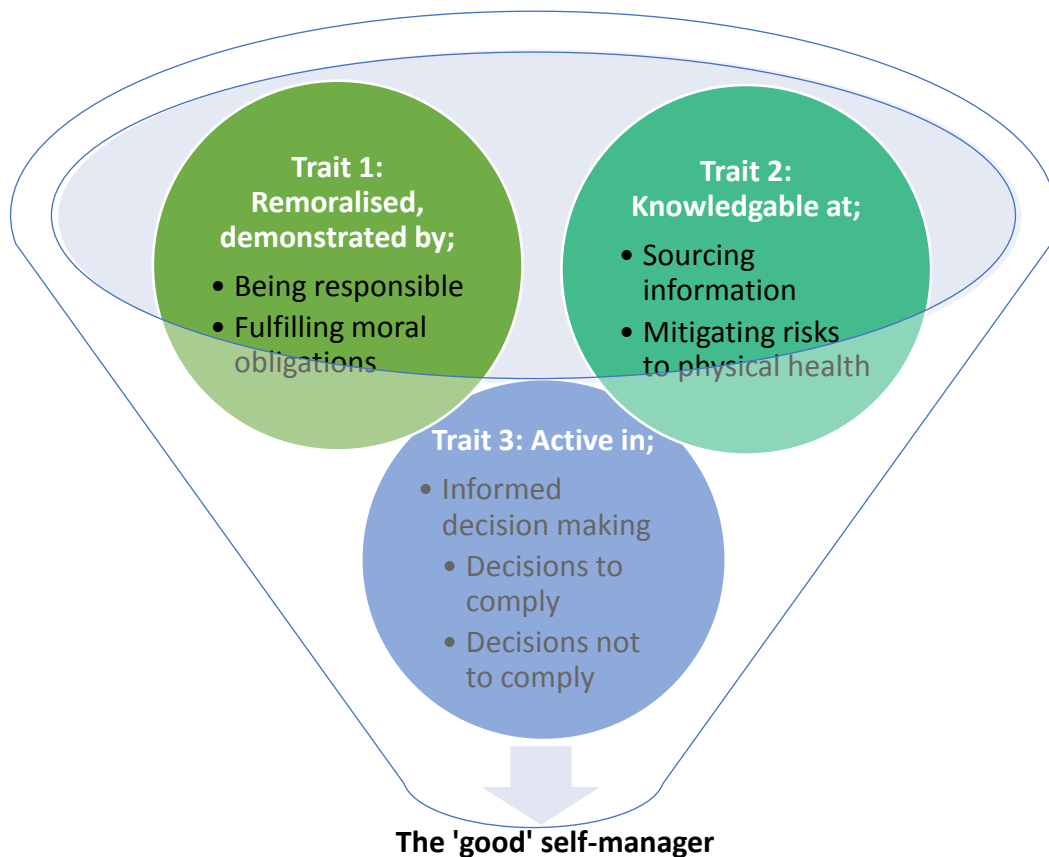
211   *"for a diabetic there are only a couple of ways you can cope: one is food and*

212   *weight control, and two is exercise. If you can look after either or both of*

213   *those you're on a winning streak"*

214   *Stewart, patient, diabetes*

215 Family care-givers also had this understanding as they explained, "*if you are a good self-manager …*

216 *you know that you can stick to a healthy diet"* (Philly, family, diabetes). This framing of SM does not

217 recognise different SM strategies as being of personal choice, but rather positions patients as either

218 "*being a good patient ['good' self-manager] and a bad patient ['bad' self-manager]*" (Joanne,

219 dietician). Achieving the aspirational position of the 'good' self-manager was seen as requiring

220 support. Family care-givers, HCPs and commissioners particularly expressed a need to support the

221 development of the 'good' self-manager through helping "*people identify what it is they need to do*

222 *in order to self-manage"* (Caroline, CCG commissioner). Although all stakeholders framed SM in

223 terms of the 'good' self-manager, there were areas of difference. This difference focused around the

224 particulars of what constituted a 'good' self-manager. Specifically this discussion will focus on how

225 far the 'good' self-manager is perceived to be 'remoralised', 'knowledgeable' and 'active'.

226

227   <u>Figure 1: Traits of the 'good' self-manager</u>

Trait 1:
Remoralised,
demonstrated by;
• Being responsible
• Fulfilling moral
  obligations

Trait 2:
Knowledgable at;
• Sourcing
  information
• Mitigating risks
  to physical health

Trait 3: Active in;
• Informed
  decision making
• Decisions to
  comply
• Decisions not
  to comply

The 'good' self-manager

228

229

230   <u>To be remoralised</u>

231   UK social policy in the twenty first century has attempted to 'roll back the state' (Penn, 2015),

232   shifting responsibility from the state towards the individual. The focus has been to create a

233   remoralised social citizen, whereby citizenship becomes tied to one's capacity to be autonomous,

234   proactive and responsible. In a health context, the patient is remoralised from a passive recipient of

235   treatment to an empowered partner in the management of their health. The process of becoming

236   remoralised is demonstrated by the patient taking on greater personal responsibility, fulfilling moral

237   obligations by doing their best to manage health and wellbeing, and in doing so, minimising welfare

238   dependency. This discourse was evidenced in all stakeholder accounts.

239

240 *Responsibility*

241 Commissioners considered their role in commissioning services to include discouraging an

242 entitlement-based approach to healthcare utilisation and *"encouraging people who don't*

243 *understand that actually the responsibility for their condition is theirs; it's not the responsibility of*

244 *others to support [their] illness"* (Lauren, CCG Commissioner). This view, shared by HCPs, positions

245 the 'good' self-manager as an individual who is willing to take "*responsibility …with reference to their*

246 *health"* (Victoria, diabetes nurse specialist). The promotion of greater individual responsibility, as

247 found in commissioner and HCP accounts, places the consequences of any (in)action with the patient.

248 What is of interest is that such discourse was also present in patients' and family care-givers'

249 accounts.

250 *"I thought you know, I've got to make a few changes now, it's really down*

251 *to me"*

252 *Mary, patient, stroke*

253 *"It annoys me that people go to their GP and say, "put me right, give me a*

254 *pill to put me right" because it's you that's got the problem… it's your*

255 *responsibility … the problem is yours, not theirs"*

256 *Jennifer, patient, diabetes*

257 *Moral Obligations*

258 Taking responsibility for one's health was seen to be to accept one's moral obligations to

259 both society and to one's social network. The first obligation the 'good' self-manager has is to society.

260 This was seen most notably in the moral obligation to be autonomous and not to use the welfare

261 state inappropriately; a position taken by each stakeholder group to a greater or lesser extent.

262   *"I know people who carry on smoking and I think 'for God's sake, give*

263   *yourself every chance. The NHS is spending a fortune [on you]'''*

264   *Will, patient, cancer*

265 This moral obligation to society, one's civic obligation, is reflective of neoliberalism that advocates a

266 reduced state, and with this comes the need to ensure healthcare services are not over-burdened by

267 dependency. The 'good' self-manager should fulfil the moral obligation to ease the pressure on the

268 NHS by managing health *"because it's [NHS] not sustainable not to [self-manage]"* (Claire, CCG

269 commissioner)*.* Thus patients should SM to reduce their use of NHS resources which *"in turn saves*

270 *money for the NHS…because if [patients] are more aware of what is going on they are not coming in*

271 *all the time"* (Katy, nurse practitioner*).* By being autonomous the 'good' self-manager is less

272 dependent upon healthcare provision, which, questionably, helps ease financial pressures.

273   The 'good' self-manager's moral obligation to society was most evident in the discourse

274 around 'appropriate' use of healthcare services. All stakeholders were in agreement that the 'good'

275 self-manager uses healthcare services appropriately. However, stakeholders disagreed about

276 whether 'appropriate' use was concerned with limiting dependency on services, or whether it was

277 concerned with seeking help early to prevent complications. Commissioners and HCPs, appeared to

278 conceptualise appropriateness solely on frequency of use, and the 'good' self-manager was an

279 individual who was more autonomous and less dependent.

280   *"Through having an empowered and knowledgeable patient you hopefully*

281   *have less contact with health professionals"*

282   *Sharon, colorectal cancer nurse*

283 Conversely, patients and family care-givers felt the 'good' self-manager fulfilled their civic duty by

284 seeking help from healthcare services early. For them 'appropriate' use was concerned with

285 engaging with healthcare services based on perceived need. Further, it was felt that healthcare

286 services had a responsibility to be available when the perceived need was present.

287   *"What you need is a point of contact every so often so if it goes wrong … we*

288   *should be able to say [when we need help]; and when you need that support,*

289   *it needs to be there."*

290   *Colin, family, stroke*

291 Perceived access to healthcare is important to patients as it provides reassurance (Rogers et al.,

292 2004). For patients and family care-givers, help-seeking was not symptomatic of dependency but

293 part of 'good' self-management.

294   *"When I ask for help, which is a very hard thing to do, I don't want to be told*

295   *off or told I've failed. I want them to reciprocate the fact that I'm asking for*

296   *help and give me some help."*

297   *Samatha, patient, diabetes*

298 It can be reasonably argued that using healthcare when one feels it is needed may actually

299 contribute towards the fulfilment of one's civic duty to society. That is, if people avoid seeking help,

300 they run the risk of developing costly problems, and thus engaging with services when they perceive

301 it is needed might save the services money in the long-term. Making the judgement regarding when

302 to use healthcare services is the patient's responsibility, and it is they who must balance their health

303 with healthcare service use.

304   The second moral obligation the 'good' self-manager has is to themselves and their social

305 network. A 'good' self-manager accepts that they have a "*responsibility to carry on getting better for*

306 *themselves and their families"* (Madeline, speech and language therapist); a view shared by HCPs,

307 family care-givers and patients. The moral obligation a patient has to SM for their social network is

308 reflective of the discourse around individualisation and minimising dependency. In particular, a

309   'good' self-manager has a moral obligation to relatives to ensure they "*are not a burden to family*

310   *due to poor health"* (Bernard, patient, diabetes), and in order to ensure they fulfil their own

311   relationship commitments. That is, according to patients, "*[you] look after yourself so you can in turn*

312   *look after your relatives"* (Pete, patient, diabetes).

313   The remoralised individual who takes responsibility and fulfils their civic duty towards

314   society and their social network was considered by each stakeholder group to be characteristic of a

315   'good' self-manager. Taking on responsibility might be the first step towards the good self-manager,

316   but once an individual accepts this they require the knowledge to know how to fulfil this

317   responsibility.

318

319   To be knowledgeable

320   In the UK, discourse surrounding SM has focused on supporting the individual to 'develop knowledge,

321   skills and confidence' (THF, 2014) to self-manage effectively. This discourse was found in the

322   understandings of what is it to be a 'good' self-manager, according to all groups, "*knowledge is key,*

323   *without knowledge [they'd] be fighting blind"* (Harry, patient, diabetes). All stakeholders agreed that

324   through the acquisition of information one can become knowledgeable, which is integral to the

325   development of the 'good' self-manager.

326   *"If they don't come to the education sessions then I'm not quite sure how*

327   *they can self-manage"*

328   *Jonathan, diabetes consultant physician*

329

330   *Sourcing Information*

331 In order to become a 'good' self-manager an individual requires knowledge of the condition and of

332 SM practices; a view all stakeholders held. However, different opinions existed regarding just how an

333 individual acquires this knowledge. One stance is that individuals are transformed from an

334 unknowing individual to a knowledgeable individual through attending education programmes; a

335 view that resonated most with HCPs and commissioners. Commissioners and HCPs tended to imply

336 that the acquisition of information via formal education sessions results in a knowledgeable

337 individual. However, de Silva (2011) found more didactic forms of SM education programmes to have

338 the lowest success in supporting SM and behavioural change. Thus a second perspective is that

339 individuals are not transformed from an 'unknowledgeable' to a 'knowledgeable' individual in one

340 instance. Rather, an individual gradually becomes more knowledgeable through acquiring

341 information about how to manage when it is needed; a position taken by patients and family care-

342 givers.

343   *"further down the line you think, 'Well now we've sorted this out and we*

344   *can think straight for a while, how do I now go about finding out what's out*

345   *there?' It would be nice if there were a central point you could go back to"*

346   *Jane, family member, stroke*

347 Whilst accessing information on an ad hoc basis is one means of becoming the 'good' self-manager,

348 this is made problematic by the absence of follow up after education courses to monitor if individuals

349 require additional advice or information updates (Penn et al., 2015). For patients and family care-

350 givers individualised information delivered gradually was important. Thus the absence of monitoring

351 and the opportunity to acquire advice when needed may prevent an individual from becoming a

352 'good' self-manager.

353   *"There should be a little follow up, ask you more about what is happening*

354   *now…They [HCPs] don't even know we exist anymore"*

356   According to family care-givers "*knowing who to ask [for advice]…would help*" (Denise, family,

357   cancer) as the 'good' self-manager requires accessible, specialist information that is "*practical and*

358   *holistic*" (Colin, family, stroke). While stakeholders differed in their opinions regarding how an

359   individual should acquire knowledge, they all agreed knowledge is integral to becoming a 'good' self-

360   manager.

361

362   *Mitigating Risks*

363   The knowledgeable aspect of the 'good' self-manager is not solely knowing how to source

364   information, but it is also specifically about knowing the risks associated with one's condition; a view

365   shared by all stakeholders. The 'good' self-manager, through acquiring information, is

366   knowledgeable in risk management. HCPs and commissioners saw their role as being the educators,

367   and "*supporting individuals to have the information they need about their condition*" (Pauline, NHS

368   England Commissioner). The focus on condition-specific information means that for all stakeholders

369   risk management is concerned specifically with mitigating risks to physical health.

370   *"Obviously education is important for the understanding the nature of*

371   *strokes…they may not understand and may still smoke…that furthers their*

372   *risk of a second stroke"*

373   *(Gareth, Physiotherapist)*

374   Mitigating risks to physical health was concerned, for all stakeholders, with achieving targets

375   associated with biomedical indicators of health; such as blood pressure, symptoms or blood glucose

376   level. It is assumed that by having "*the information one needs about themselves, their condition,*

377   *which will help HbA1C [or condition management more generally]*" (Pauline, NHS England

378   commissioner). For patients especially, the importance of managing such risks served also to

379   reaffirm the 'good' self-manager status. Managing these biomedical markers "*provides the evidence*

380   *that [they] are fine*" (Ruby, patient, diabetes) and managing well. Being able to prove one is

381   managing risks associated with their condition may be linked to the neoliberal philosophy that the

382   individual has to be self-governing and responsible.

383   Arguably the notion of biomedical risk management is born out of a desire to prevent

384   condition deterioration; evidenced in all stakeholder accounts. That is "*[self]-management* is *about*

385   *stopping complications*" (Jonathan, consultant physician, diabetes), and to put frankly "*preventing*

386   *people from dying early*" (Owen, NHS England National Commissioner). Reflective of the moral

387   imperative of neoliberal philosophy to be responsible, the 'good' self-manager is knowledgeable and

388   "*clear about the [national] guidelines*" (Hansa, family care-giver, diabetes) for the LTC. It is the

389   responsibility of the individual to use this information to manage biomedical risks, a view shared by

390   patients as they considered the 'good' self-manager to "*read up on the available leaflets…and make*

391   *sure [they're] fully informed*" (Jen, patient, cancer). Through doing this the 'good' self-manager is

392   able to "*reduce the risk of reoccurrence, and live a longer life*" (Frank, patient, cancer). That being

393   said, patients did also favour a more balanced approach to biomedical risk management, talking of

394   SM strategies that accounted for everyday life as well as biomedical outcomes, as explored further

395   below.

396   For all stakeholder groups the 'good' self-manager is an individual who is knowledgeable in

397   the condition and self-management practices, but who also uses knowledge to mitigate the risk to

398   their physical health. However, knowing the risks and how to manage them is only one characteristic

399   of the 'good' self-manager. Accepting responsibility for your health is the first step towards becoming

400   a 'good' self-manager, acquiring knowledge the second step, and the third step, to bridge what has

401   been phrased the third translational gap (The Third Gap Research Group, 2016), is applying that

402   knowledge. After all, one *"can be an absolute expert on your condition, but knowing that stuff and*

403   *actually acting on it are two different things"* (Celia, family, diabetes).

404

405   <u>To be 'active'</u>

406   The 'good' self-manager, by taking on responsibility, is required to be 'active' in their personal

407   healthcare. This is achieved through utilising knowledge to enact behaviour expected of a 'good'

408   self-manager; a view expressed exclusively by commissioner and HCP stakeholders.

409   *"An effective self-manager would be able to problem solve themselves, be*

410   *able to carry out most of their activities of daily living, and with minimal*

411   *support."*

412   *Gareth, Physiotherapist*

413   The 'good' self-manager utilises knowledge and skills to achieve independence from HCPs, a view all

414   stakeholders shared, however, only commissioners labelled this behaviour to be characteristic of an

415   'activated' individual (Hibbard et al., 2005).

416   *"More activated people are much better able to manage their own health*

417   *at home outside of the system and they are much better prepared for the*

418   *consultations, they make better use of their interactions with the NHS which*

419   *in effect reduces the number of times that they have to come into contact*

420   *with the NHS"*

421   *Owen, NHS England National commissioner*

422   In the UK and USA, Patient Activation is not a new concept, and it has gained political support, but it

423   is exclusively reflected in the accounts of commissioners only, who equate the 'good' self-manager

424   with the notion of the 'activated' individual. The term 'activation' itself is criticised for the way it

425   ignores social and wellbeing factors (Entwistle and Cribb, 2013). While the term 'activation' did not

426   resonate with patients or family care-givers, all stakeholders were in agreement that the 'good' self-

427   manager has to want to act ('appropriately') on the knowledge they have, and failure to do so means

428   they are not self-managing.

429   *"They need to want to do it. I mean people who are not interested and just*

430   *want it sorted, they're not going to self-manage."*

431   *Jonathan, diabetes Consultant Physician*

432   Being 'active' is recognised by "*being clear about what you want [from SM] and being determined*

433   *about going to get it"* (Beth, patient, cancer); a view all stakeholders shared.

434

435   *Informed decision making*

436   The 'good' self-manager should be able to use their knowledge and "*information to make*

437   *informed choices and decisions"* (Beryl, patient, cancer). The 'good' self-manager makes informed

438   decisions regarding their health and social wellbeing.

439   *"I would want them to be confident in making choices…just the confidence*

440   *in knowing their choices and to be able to problem solve"*

441   *Joanne, Dietician*

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

443   groups.

444   Making decisions to comply

445   All stakeholders, to a greater or lesser extent, saw informed decision-making to align with a

446   compliance based-framework, whereby the 'good' self-manager makes 'appropriate' choices and by

447   doing so exercises *"control over [the] things that [they] can make a decision about"* (Celia, patient,

448   diabetes). As part of the active component of the 'good' self-manager, the individual is required to

449   reflexively monitor (Giddens, 1984) their behaviour so that it fits within the parameters set by the

450   health service. This is because, as family care-givers and HCPs voiced; *"you should take the advice of*

451   *the doctors because there's a reason that they're telling you all that"* (Fran, family, diabetes). 'Good'

452   self-management was understood exclusively, by family care-givers and a selection of HCPs, in terms

453   of compliance.

454   *"If somebody's not very good at compliance …[they're] not going to be very good*

455   *at self-management."*

456   *Fran, family, diabetes*

457   This demonstrates how compliance to medical advice is a central concern for 'good' SM, and

458   illuminates how SM overlays a moralised rhetoric of 'choice' upon compliance based medicine.

459   Complying with medical advice also links back to the mitigating of risk, specifically the mitigation

460   against risks to physical health. Compliance, for family care-givers, was important as the individual

461   will "*not suffer*" (Zoe, family, cancer) if they follow medical advice. The compliant framework,

462   however, assumes behavioural change is easy to achieve and fails to account for the difficulties and

463   complexities around achieving this change (Vassilev et al., 2014). It also fails to adequately

464   acknowledge that making compliant decisions and acting on them may be hard for individuals, or

465   indeed may not be what individuals want.

466

467   Making decisions not to comply

468   At the core of the notion of the 'active' individual is a recognition that the 'good' self-

469   manager is able to exercise agency; that is, to act freely and make their own informed decisions. For

470   patients, the 'good' self-manager exercises this agency by making informed decisions, but not

471 necessarily always what HCPs would perceive as compliant decisions, in order to enact SM practices

472 so they minimally interfere with daily life.

473 *"There's a negotiation to see what I'm prepared to do because of other*

474 *factors in my life. It might be that X is the perfect solution. But actually, not*

475 *with my work day and what I do in my life and what I want to do."*

476 *Lou, patient, diabetes*

477 Everyday experiences of living with a LTC include balancing illness management objectives with social

478 roles and commitments (Vassilev et al., 2014). The balancing of symptom management with sense of

479 self (Townsend et al., 2006) is where tension arises between making decisions that are compliant and

480 decisions that are non-compliant. Although commissioners recognised SM practices *"have to be*

481 *interpreted in the context of what is achievable for the person in the context of their lives"* (David,

482 CCG commissioner), it was patients who exclusively advocated making decisions that were more

483 influenced by lifestyle and sometimes prioritised achieving social wellbeing over complying with

484 medical advice.

485 *"nobody was telling me anything useful that was actually practical and*

486 *fitted in with a life that you could sustain, yes you could do it for a month*

487 *but then actually I have got a life."*

488 *Rachel, patient, diabetes*

489 Managing symptoms or biomedical risks, when they clashed with patients' sense of self or enjoyment

490 in life, created tensions for patients just as Townsend et al. (2006) found: patients could prefer to

491 achieve social wellbeing that may very well be in direct contradiction to medical advice.

492 *"Yes, I smoke. It's taken everything else, it's not taking my cigarettes. I know*

493 *I shouldn't have another smoke but I don't care."*

495   Patient stakeholders considered the 'good' self-manager to engage in 'strategic non-compliance'

496   (Campbell et al., 2003) or 'rationalised non-adherence' (Demain et al, 2015); that is selectively

497   applying medical advice to either suit lifestyle or minimise treatment burdens respectively. Thus for

498   patients the 'good' self-manager makes 'appropriate' decisions to achieve social wellbeing, which for

499   them, was defined as meaningful participation in social and work life.

500   In summary, all stakeholders agreed that the 'good' self-manager was 'active', and uses

501   knowledge to make 'appropriate' decisions to achieve wellbeing. However, two critical tensions exist.

502   The first is a difference in terminology that despite gaining political support the term patient

503   activation was used only by providers of healthcare and was meaningless to users of healthcare,

504   demonstrating how the public may not accept political rhetoric. The second lies in what is

505   understood by 'appropriate' decisions. For patients it was appropriate that they engage in strategic

506   non-compliance to fit in with their everyday social roles, whereas for family care-givers and HCPs it

507   was appropriate for the 'good' self-manager to adhere to medical advice, which may be at the

508   expense of freedom in their social lives.

509

510   **Discussion**

511   This paper is unique in presenting an understanding of SM from four key stakeholder perspectives,

512   using three different exemplar long-term conditions; diabetes, colorectal cancer and stroke. A

513   limitation of this study is the predominately white British sample, however this study does offer an

514   understanding of how commissioners, HCPs, patients and family care-givers understand SM, which

515   has not, to our knowledge, been investigated previously. This paper reveals how SM is understood

516   by users and providers of healthcare services in the framework of the 'good' self-manager.

517   This paper resonates with that of Vassilev et al.'s (2016) work in demonstrating that the

518   neoliberal health discourse is present in users' and providers' (of healthcare services)

519   conceptualisations of the 'good' self-manager. The good self-manager is remoralised, knowledgeable

520   and active. These aspects were presented separately in order to better understand their unique

521   characteristics. They are, however, inextricably linked. This is seen most notably in the

522   knowledgeable and active aspects, whereby action is knowledge applied, and where the remoralised

523   aspect infuses both. The findings also serve to highlight how neoliberal health discourse is taken on

524   by users and providers of healthcare in their conceptualisation of SM. Additionally the concept of

525   the 'good' self-manager highlights the problematic nature of neoliberal discourse.

526   Neoliberal health discourse of patient empowerment, choice and information is present in

527   health policy that has focused on developing individuals' 'knowledge, skills and confidence' (THF,

528   2014). The policy focus on personal development is characteristic of a neo-liberal model of

529   governing that promotes individual choice but 'under guidance of distant expert' (McNay, 2009:56).

530   The consensus around the 'knowledgeable' and 'active' elements, particularly the consensus on risk

531   management and informed decision-making, illustrate how the very concept of the 'good' self-

532   manager lends itself to value certain behaviour types. The findings illustrate that there is a moral

533   imperative underlying all action. That is, there is a moral imperative for the 'good' self-manager to

534   act appropriately by acquiring knowledge and using this to act out informed decisions. This raises

535   three points.

536   The first concerns that of 'choice'. The central moral imperative for some stakeholders was

537   to comply with medical advice. However, favouring one SM strategy not a choice and is at conflict

538   with the understanding that an individual 'cannot not manage…the only question is how one

539   manages' (Lorig and Holman, 2003b:1). Contrasting this, the discourse of the 'good' self-manager

540   gives a sense of either being in; self-managing, or being out; not self-managing. The discourse leaves

541   no room for an understanding that an individual's behaviour is reflective of a SM style (Lorig and

542 Holman, 2003). It is questionable then how far the 'good' self-manager is able to make informed

543 decisions free from structural, society, and cultural constraints. This is demonstrative of one of the

544 very critiques of neoliberalism, in that choice is a façade (Ayo, 2012). Normative values and

545 behaviours govern the choices of the 'good' self-manager as these normative discourses set limits on

546 what is considered appropriate SM behaviour. This was seen in the disparity around decision-making

547 where patients engaged in strategic non-compliance to suit lifestyle. Through doing this patients

548 were positioned in a place where their sense of moral duty, and status as a 'good' self-manager,

549 could be questioned. The findings illustrate the interconnectedness of the three aspects of the good

550 self-manager. Whereby the good self-manager is morally bound to make 'appropriate' choices based

551 on knowledge, for not doing so will mean they are not fulfilling their responsibility.

552 The second relates to how knowledge is acquired. One view, and that of the logic of choice

553 model (Mol, 2008:14), is that an expert informs a patient who is then able to utilise this in their

554 decision-making. This process is unidirectional (Mol, 2008). Health policy has focused on increasing

555 the uptake of education programmes, and SM interventions aim to enhance an individual's ability to

556 SM through improved information and skills development (Coster and Norman, 2009). The findings

557 resonate with Mol's logic of choice critique, whereby the logic of choice fails to account for the

558 context in which self-management occurs. Seen in the context of patients' preferences for engaging

559 in strategic non-compliance this draws attention to the complexities of social life. The findings

560 illustrate that lifestyle specific knowledge is currently absent from self-management support as

561 patients choose strategic non-compliance to ensure SM strategies suit the 'messiness' of their

562 everyday lives. This illuminates the need for SM programmes to be less directive and engage less in

563 'one size fits all' (Jones, 2013), and rather focus on incorporating individuals' social circumstances

564 (Kennedy et al., 2007). It comes then that rather than SM programmes being unidirectional they

565 should be multidirectional, where the patient and healthcare professional work collaboratively to

566 situate the medical knowledge in the everyday context of the patient.

567   The   third   follows   in   that   the   focus   on   'good'   SM   may   exacerbate

568   health disparities. The 'good' self-manager by focusing on the individual's morality, knowledge and

569   action, focuses also on resources and access to resources to facilitate the achievement of the 'good'

570   self-management status. However, it is presumptuous to believe all individuals have access to the

571   required resources and support structures. It is known that social network members facilitate

572   resource assess and support (Vassilev et al., 2013 and 2014) but for some individuals with limited

573   resources and network support they may find it difficult (Towsend et al., 2006). The individualistic

574   nature of the 'good' self-manager can then exacerbate health disparities between those with the

575   necessary resources to be a 'good' self-manager and those without, it may in turn also lead to those

576   who do not reach the 'good' self-manager status to be stigmatised as the deserving sick.

577   The concept of the good self-manager has highlighted the moral dimension of self-

578   management. The decisions individuals make, and the actions they perform, are influenced by their

579   moral compass. Whether they are directed by obligations to society or to their social network, SM is

580   more than following instructions and being 'good' at SM. It is a balancing act of managing one's

581   illness with managing the demands of society and social life (Townsend et al., 2006). The 'good' self-

582   manager acts with direction from their sense of moral duty. Finally, it comes then that the 'good'

583   self-manager acts in a manner that is right for them in the context of their lives. Therefore, it might

584   be pertinent to attempt to move away from this neoliberal discourse and move towards truly valuing

585   patient choice without moral judgement and critique.

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