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Do those over eighty seek more or less medical help? A qualitative study of health and illness beliefs and behaviours of the oldest old

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Running head: Health and illness beliefs and behaviours of the oldest old

Abstract

Increasing longevity and prevalence of long-term conditions have contributed to older adults being the greatest health service users in the United Kingdom. Both overuse of health services and delayed medical consultation have potentially significant consequences for individuals and health service providers. However, little is known about how the 'oldest old' perceive health and illness or how these beliefs influence their help-seeking behaviours. We conducted in-depth interviews and collected symptom diaries from working-class older people aged 80-93 in London. We found that a morally-grounded, hierarchical approach to health problems and help-seeking exists, similar to Jocelyn Cornwell's *Hard-Earned Lives* (1984) study findings, conducted with working-class 50-60 year-olds in London thirty years earlier. However, the different ages of the sample participants allows us to understand how adults modify their beliefs and behaviours in advanced older age. By being increasingly attributed to older age, some health problems are 'demedicalised' and self-managed; others are 'upgraded' and perceived as more serious, leading to earlier and increased medical consultation. A sense of empowerment appears fundamental to altering these beliefs and behaviours. Our findings further understanding of oldest old people's use of health services, and will aid in optimising help-seeking behaviours, reducing phenomena such as under- and over-consultation.

Keywords: older people, oldest old, health and illness beliefs, health behaviours, health service use, health service delivery, qualitative research, UK

Introduction

Although mortality rates of those over 65 are decreasing across the Western world, the proportion of people who report living with limiting long-term illness continues to rise with age (Office for National Statistics (ONS) 2005). Use of formal health and social care services, as well as support from lay networks and voluntary carers, also increases with age above 50 (ONS 2005), yet it has been observed that only a small proportion of health problems are brought to the attention of medical services (Scambler et al 1981); these problems are not always those most requiring attention (Morris et al 2003). Understanding how older adults' perceptions of health and illness influence their help-seeking behaviour may enable better delivery of appropriate healthcare and ultimately better life quality.

In adopting a temporal approach to investigating the experience of chronic illness, Bury argued that this may differ with an individual's life stage (1991). However, investigation of lay perceptions of health and illness and response to symptoms has predominantly focused on a static time point for adults of middle age (see for example Herzlich 1973, Zola 1973, Mechanic 1978). Furthermore, studies have tended to focus on perceptions of and consultations for single medical conditions; few consider more broadly how individuals' beliefs about health and illness may influence their help-seeking behaviours. Although more recent studies include those over 60, very few individuals over 80, the 'oldest old', are included, despite near-global ageing populations.

Older adults' health perceptions differ from those of younger adults. Adults over 60 tend to conceptualise health as functional capability rather than the 'physical fitness' described by younger participants (Blaxter 1990) and tend to have lower expectations of health than those in mid-life (Blaxter and Paterson 1982). More recently, Ebrahimi et al (2012) found that

adults aged 67-92 adjusted their expectations of what constituted good health as they aged; understanding health as the harmonious interaction between themselves and their environment. Here, two vital components of health were being able to master daily life and feeling validated as a worthy and competent person.

When exploring older people's ideas about their health and how their expectations and actions might change with age, it has been found that through three key beliefs older adults attribute certain health problems to their advanced age rather than to disease processes. First, health problems and physiological deterioration are perceived to constitute a 'normal' part of ageing; for example with regard to symptoms pertaining to certain body systems, such as the eyes, ears and genitourinary system (Gjørup et al 1987). Second, symptoms not considered significant enough to prevent activities of daily life are not usually attributed to 'illness' (Gjørup et al 1987); and lastly symptoms perceived as vague are often not attributed to 'illness', for example, forgetfulness, tiredness, and low mood (Morgan et al 1997). These three beliefs are reinforced when health problems are increasingly observed in contemporaries (Sanders et al 2002, Horrocks et al 2004) and may also explain why older adults with chronic illnesses give positive statements of their own level of health in contrast to more objective measures of morbidity (Blaxter 1990), and minimise the impact of illness on their lives in contrast to younger adults (Pound et al 1998, Sanders et al 2002).

Thus, it is clear that ideas, beliefs, and communication of health and illness may be modified at older ages, but how might subsequent illness behaviours be affected? When considering how older adults respond to health problems, it has been suggested that the experience and knowledge accumulated with age provides a certain additional perspective (Stoller et al 2011); adults aged 65-92 in rural America were found to evaluate each problem within their

own 'bricolage' of individual cognitive, emotional and social contexts. Yet here symptom characteristics that were observed to be important cues to seeking help from a doctor were the same as those reported by Zola (1973) and Mechanic (1978) for adults generally: a symptom's perceived severity; it being unusual or of unknown cause to the individual; and an individual's inability to manage the symptom with lay treatments.

Where help-seeking amongst older adults has been compared to those of younger adults, a dichotomy exists within existing literature. One finding amongst adults over age 60 is that help-seeking is either reduced or delayed for particular problems (Gjørup et al 1987, Sanders et al 2002, Horrocks et al 2004, Corner et al 2006). This is thought to arise from the three key beliefs described above; 'normal', inevitable ageing processes are not considered amenable to medical treatment (Gjørup et al 1987, Morgan et al 1997); and a symptom that is vague or does not prevent the conduct of necessary activities does not warrant medical attention. Further reasons for delayed help-seeking include attributing the symptom to another pre-existing condition, and not wanting to waste a doctor's time (Corner et al 2006). Conversely, others argue that help-seeking occurs more readily after perceiving a symptom than for younger adults (Leventhal et al 1995) as part of a strategic adoption of 'resource conservation' and avoidance of uncertainty with increasing age.

In terms of whether and where people seek help, a phenomenon that has been observed to shape beliefs and subsequent use of health services amongst some older adults is a moral approach to managing health and illness (Blaxter and Paterson 1982, Cornwell 1984).

Although Cornwell's participants, working class East-Londoners in their fifties, noted they expected to experience worse health in later life, they emphasised the importance of being healthy and standing up to illness, rather than giving in to or complaining about it, and

possessed a strong regard for using health services appropriately. In understanding threats to health, a hierarchy of health problems and subsequent use of health services was noted. Problems could be perceived as 'normal' illnesses (e.g. common infections, such as colds and 'flu), 'real' illnesses (e.g. those considered to be potentially life-threatening and severe, such as cancer, diabetes, and heart conditions), or 'health problems which are not illnesses', thought to occur as a result of 'natural processes', such as ageing or reproductive changes (e.g. arthritis and menopausal symptoms). Each problem type was believed to have a morally appropriate behavioural response and health service to be used. 'Normal' and 'real' illnesses were both deemed to be treatable or at least within the domain of medicine, with 'normal' illnesses being the province of general practitioners (GPs) and 'real' illnesses believed to require hospital services. 'Health problems which are not illnesses' were believed to fall within the remit of community services. Cornwell's (1984) participants were generally respectful, trusting and grateful towards doctors and their knowledge although hospital doctors were treated with more respect than GPs, and both with more regard than community social workers.

Cornwell's (1984) study is of particular interest here because her participants in their fifties represent an equivalent birth cohort to our participants who are South-East Londoners, mostly of working class, now in their eighties and early nineties. We can therefore contrast our findings with Cornwell's in order to explore how illness beliefs and behaviours, particularly decisions to consult health services, may be modified in advanced old age. The aim of this paper therefore is to understand the beliefs and behaviours of an equivalent cohort in late old age, how these have changed as they have grown older, and how the dichotomy described above might be explained: why do some of the 'oldest old' consult health services less frequently, while others seek this help more readily?

Methods

Adults were recruited from attendees aged 80-95 at two day centres in South-East London. Recruiting from these centres allowed the meeting of older adults in a neutral environment. The day centres enabled older adults to socialise with others, have a cooked lunch and play games, for a small charge. Adults attended the day centres after the suggestion of a friend or relative, or were referred by their GP when loneliness was feared.

The first author spent eight weeks in each centre, conversing informally with clients and staff; in this way, she hoped to become a 'familiar' face, increase the trust of participants, and gain richer information at interview (Cornwell 1984). Older adults who could hear and communicate adequately in English were invited to participate in an in-depth interview. Those with memory impairment which day centre staff judged significant enough to affect health-related thinking and decision-making were excluded. Of 34 attendees eligible for the study, 15 were recruited; 16 declined to participate and three who wished to take part were unavailable for interview.

Data collection

Participants were interviewed by XX in a private room at their day centre in May-June 2011. Each interview lasted 29-104 minutes (mean 50 minutes) and was audio-recorded. Interviews were semi-structured using a topic guide informed by a review of the relevant literature, the clinical experience of the first author as a trainee geriatrician and the questions of the study.

Demographic information such as participants' living arrangements was gathered initially, providing context for their accounts. Participants were then asked to describe a time in the

last two weeks when they had “not felt right in themselves, physically or psychologically”, although all participants also related instances occurring prior to this time. The interviewer then asked what they “put this problem down to” and how they “decided what to do about it”. As interviewing progressed, common belief frameworks, attitudes and behaviours became apparent; later interviews therefore focused on exploring ideas that differed from the norm of the group or the literature.

A narrative approach was used throughout, allowing participants greater control in interviews to increase the richness of information gained (Cornwell 1984). The first author’s professional background as a medical doctor influenced her beliefs relating to health problems and help-seeking behaviour, and her interviewing style. During interviews she was therefore careful to reflect the language used by participants and transcripts were reflected upon after each interview by both authors. The authors also anticipated that participants’ awareness that the interviewer was a medical doctor might alter the nature of information gathered; they therefore decided, with the agreement of day centre managers, not to disclose the interviewer’s professional role unless participants directly asked this, which they did not.

Following their interview, participants were asked to complete a symptom diary for two weeks, noting whenever they “did not feel right physically or psychologically”, what they thought this might be caused by, and how they responded to this problem. Diaries were used to minimise the risk of obtaining potentially mis-recalled information from interviews alone (Bloor 1997) and to give a snapshot of participants’ experience of health problems. However, despite reminders, only four participants returned completed diaries, the remainder reporting a lack of time, poor eyesight, losing the diary or forgetting to complete it.

Analysis

Interviews and symptom diaries were transcribed verbatim and anonymised by the first author. Transcripts were then re-read, with the first author designating codes for segments of text (Strauss 1987), such as ‘problems put down to old age’, which were catalogued using NVivo 8 software. Codes were cross-checked with the second author and then organised into broader categories, such as ‘Moralistic beliefs relating to help-seeking for health problems’. Transcripts were then re-read by the first author to understand how these categories existed and interacted for participants (Strauss 1987). Finally, these thematic frameworks were considered, challenged and modified by both authors after reviewing negative cases (Pope et al 2000).

Ten women and five men participated, aged 80-93 (median 86 years). Eleven lived alone; one lived with her spouse, two lived with offspring and one lived with his spouse and offspring. The only non-British participant was Indian but had lived in the UK for almost 50 years. This participant had attended university, while school-leaving ages amongst the remainder were 11-16 (median 14 years). The majority reported significantly limited, restricting mobility for which they used mobility aids.

In presenting our analysis, we first describe how these participants, nearly 30 years on from Cornwell’s *Hard-Earned Lives* (1984), adopted a similar moral, hierarchical approach to health and illness. Contrasting with Cornwell’s (1984) findings, we then explore how participants recounted and modified their beliefs and behaviours in the context of varying states of health, their own perceived age, and level of independence. Finally, we examine to what extent the interventions of others in circumstances surrounding a threat to health could

act as a threat to participants' sense of empowerment, competence and mastery, and to what extent this reinforced their health beliefs and behaviours in late old age.

Findings

A moral framework for health problems and responses

Consistent with the hierarchical approach to health problems described by Cornwell's participants, the health problems that our participants described can also be stratified into a three-tier hierarchy. We term these: 'serious' illnesses, 'normal' illnesses, and 'non-illness health problems'. Each group is defined by the believed nature, causes and appropriate responses to its constituent health problems.

'Serious' illnesses

This group was termed 'serious' as participants referred to acute and 'serious' symptoms when considering these health problems. This term differs from Cornwell's (1984) 'real' illnesses, which referred to chronic, medical conditions considered severe enough to be potentially life-threatening. However, the nature, perceived significance, and relevant response to both 'serious' and 'real' sets of health problems was similar for both sets of participants.

Participants in the current study determined a health problem to be 'serious' by a range of features. A health problem could be believed 'serious' according to its physical characteristics, which is also consistent with findings of Stoller et al's (2011) qualitative study of older adults; for example problems such as bleeding, severe pain or breathlessness at rest were 'serious' since they were considered particularly concerning or frightening. A problem was also perceived to be 'serious' if it was associated with certain features felt to be

concerning, such as weight loss following mouth pain or loss of appetite after abdominal discomfort. The bodily location of a problem was significant; problems believed to relate to the 'insides' such as the heart, lungs or abdomen, were considered 'serious', unlike musculoskeletal aches and pains, giddiness, urinary symptoms or psychiatric problems, similar to Gjørup et al's findings (1987).

Problems could also be considered 'serious' according to an individual's personally perceived risks and experiences: new or unfamiliar problems; problems perceived to be due to a participant's own medical history; or problems which had caused negative consequences for a participant's acquaintance. Problems perceived to be associated with certain medical conditions, such as cancer, were considered 'serious' by some. This concern was attributed either to participants' knowledge of someone having previously experienced the condition and it having had significant health consequences, or, with regard to cancer, to having 'heard so much about it' as a 'serious' problem. Problems lasting more than a certain amount of time could be also defined as 'serious'. Similarly, symptoms occurring just once might not be viewed as concerning, but a second episode was likely to raise concern. Finally, health problems were thought to be 'serious' when initial self-management failed, when medical and often hospital treatment in particular were believed necessary, or when medical and hospital treatment had been previously beneficial to a participant or their acquaintances.

As to the cause of these 'serious' problems, fate, bad luck, the hereditary nature of some 'serious' diseases, and medical conditions and terms were referred to, consistent with the beliefs of Cornwell's (1984) participants. Although lifestyle choices, such as smoking and diet, were also believed to contribute to 'serious' health problems, these were only perceived relevant in relation to others' illnesses. Thus there appeared to be a process by which

participants presented 'serious' illness as something which had happened to them, but for which they were usually not responsible, a phenomenon also observed by Cornwell (1984).

When turning to the response believed appropriate for 'serious' illness, features noted by all participants were that, under these circumstances, it is *right* to seek medical attention and that there *will* be medical treatment available. This is again consistent with beliefs observed by Cornwell (1984). Once medical help was sought for a 'serious' illness, it was then considered right to accept and comply with advice and treatment given. For example, when Elsie, 85, was asked whether she took all her prescribed tablets because they helped her, she replied, surprised that it was not obvious:

"Well, no, [I take them] because the hospital gives 'em to me."

The nature of a 'serious' illness and the response believed appropriate were therefore closely linked and indeed appeared to interact and reinforce one another. For example, the specialist treatment of certain medical conditions in hospital often seemed to increase their perceived 'seriousness', a feature also described by Cornwell's (1984) participants, and which further promoted the notion of swift help-seeking from a hospital in the future.

'Normal' illnesses

The term 'normal' illness was used for problems which participants described as 'illnesses' because they often made them feel unwell but had no 'serious' features. They included problems such as coughs, colds, diarrhoea, minor rashes, and longstanding headaches.

'Normal' illnesses were often attributed to external causes with an everyday nature: longstanding headaches attributed to 'heavy weather'; diarrhoea, sickness, and indigestion to

eating the wrong thing; and sore lips and a swollen hand to the use of certain medications.

Again, this concept of 'normal' illnesses was the same as that of Cornwell's (1984) younger participants.

'Normal' illnesses were manageable by the sufferer, often with the help of lay treatments such as creams or ointments, which many had 'in store' at home. Alternatively, they may warrant consulting a practice nurse, optician, dentist, or GP via a non-urgent appointment, similar to the management strategies described as appropriate by Cornwell's (1984) participants. Jean, 84, described in her symptom diary the painful eyes she had recently suffered, explaining her response:

Well, I did mention it to the nurse at the doctors and she said dry eye and get some stuff from the chemist, Boots or somewhere, there are different ones you can get, but er I have got a little bit of Optrex [eye drops] indoors.

'Non-illness' health problems

The remainder of the health problems described differed in that participants emphasised that these were not 'illnesses' but more often expressed them in terms of threats to functional ability rather than symptoms or conditions. Rather than believing the causes of these problems to be external to the body, such as infection or disease processes, 'non-illness' problems were believed to be intrinsic; the body was often believed to 'wear down' or deteriorate as one got older. This is again similar to participants in Cornwell's (1984) study who reported diseases such as rheumatism and arthritis to be a natural part of growing old and so 'non-illness' health problems. Problems in this group were chronic, often with a

gradual onset, and without any 'serious' features. Examples included 'aches and pains', poor balance and mobility, poor eyesight or vision, minor lapses in memory, and sleepiness.

Given that these problems were not considered 'illnesses', participants usually believed that medical science and doctors could not help them, again echoing opinions of Cornwell's (1984) participants. Rather than seeking medical help, participants believed that these problems should be 'put up' with and not complained about or dwelt upon. If medical help was sought, it was to seek relief from symptoms rather than provide a cure. Thomas, 87, discussing his painful knees, summed up what was consistently expressed: "*There's nothing much you can do about it, love*", reflecting the belief found amongst adults aged over 50 with osteoarthritis (Sanders et al 2002) and over 65 with urinary incontinence (Horrocks et al 2004).

During interviews and in three of the four symptom diaries, participants commented on their almost daily 'usual' joint pains, which restricted their abilities to carry out daily activities. The most common remedies noted for these were creams, patches, massage, and exercise. Lay remedies, or those procured from non-medical community sources, such as incontinence pads or mobility aids from social services, were more commonly used than medical treatments for these health problems. If medical treatments were prescribed, they were often not complied with or used only when believed 'absolutely necessary', in contrast to managing 'illnesses'.

Health

Closely related to participants' beliefs and approaches to dealing with 'non-illness' health problems were their ideas about health. Participants perceived being able to function as they

wished or deemed necessary to be an important feature of good health, as Blaxter (1990) also found. Thus, when asked about their health, participants tended to mention their functional restrictions, which they often put down to ‘non-illness’ health problems. As Cornwell (1984) and Blaxter and Paterson (1982) noted, participants also emphasised that they were healthy, even if they suffered considerable health problems or limitations. Art, 89, who had high blood pressure, diabetes, asthma and bladder cancer gave a typical answer when asked about his health; he played down medical conditions, focused on his perceived functional ability, but generally seemed positive:

Pretty good really. Exceptin’ me breathing, you know? Can’t walk all that far, you know?

Overall, a clear, moralistic, and hierarchical framework of beliefs and behaviours was found in our participants’ accounts. For each type of health problem, a morally-appropriate behaviour was described, intrinsically linked to beliefs about the causes, nature and effective management of that problem. Although Cornwell’s (1984) participants referred to medical conditions rather than symptoms, the moral framework of beliefs and behaviours found amongst individuals in their eighties and nineties was very similar to those interviewed by Cornwell. Her participants were from a similar social and geographical background, but thirty years younger, suggesting that the social, historical and political context of individuals may be influential in beliefs of health, illness and help-seeking for health problems. However, now aged 80-93, participants here described and explained important modifications that they had made to their belief-behaviour framework in the context of bringing health problems to the attention of health services, which they attributed to their perceived advanced age. Here

health problems could be ‘demedicalised’ whereby help was sought less, or ‘upgraded’ and presented to medical services more readily.

‘Demedicalisation’ of health problems

Whilst the conceived ‘non-illness’ health problems of both our oldest old and Cornwell’s (1984) participants shared many similarities, our participants attributed almost all these problems to their ‘old age’. Other ‘natural processes’ such as the reproductive cycle and personality, believed by Cornwell’s participants to be responsible for certain health conditions, were not suggested. Furthermore, participants here described their perceived advanced age as the cause of both a greater number and of an increasing diversity of health problems. ‘Old age’ became the default cause of health problems, as one octogenarian day centre attendee stated on hearing about the aims of the study:

You’ll find everything’s down to old age here, dear.

A problem was attributed to old age in several ways. Thomas, 87, described how social comparisons could underpin this belief:

*I mean nine out of ten men my age ’ave got it, see? You get a bit up your...
arthritis in me neck, a few muscles ’ere achin’ see? [rubbing neck]*

Alternatively, a problem may be attributed to old age when it was believed that there was no medical condition causing it, thus it was not an ‘illness’. Importantly, direct comments from healthcare professionals, or healthcare professionals omitting to comment on a problem being of concern or an ‘illness’, also reinforced this idea:

Well it's just age as far as I'm concerned. What they [doctors] say. They turn around an' say it's your age, an' that's it. (Harry, 90)

Of note, problems also appeared to be considered 'non-illnesses' once participants perceived that there was no possible medical treatment available *because of* their age, which they stated often being told by doctors.

In addition, participants' belief that declining functional ability was not the province of 'normal' or 'serious' health problems was intrinsic to deciding what normal health was, and what constituted 'illness' as a deviation from this. This belief may be particularly significant for older adults who experience more functional impairments than younger individuals (Brayne et al 2001). Indeed, participants here described large numbers of 'non-illness' health problems by their consequent functional impairments, attributing them to advanced age. Ethel, 93, described how problems she attributed to old age were different to illnesses as they related to functional ability:

Well it's things that happen that you know you could, you used to do, but you can't do now.

Underlying this was a much reduced expectation of health and functional ability in later life, as described in the literature, which was reinforced by healthcare professionals, relatives, friends, and wider society. Participants often voiced sentiments of gratitude and feelings that they were "lucky to be alive", particularly at their age. The effect of these firmly-held beliefs was that participants were also certain of the morally-appropriate response for symptoms

arising from what participants believed to be ‘non-illness’ health problems: tolerance and self-management. Jessie, 89, describes below the social unacceptability of complaining about ‘non-illness’ health problems, which were often referred to as ‘ailments’:

Well as I say, livin’ in a sheltered accommodation, okay, different people get classed, “Oh she moans all the time! She’s Mrs Moaner!” So that is what it’s like. Because people moan about their ailments, not thinkin’ that all of us there ’ave got something wrong with us.

The believed importance of not complaining about symptoms was strengthened by participants’ desire not to burden others. Many perceived that doctors were increasingly busy with rising numbers of patients, and others expressed not wanting to trouble their lay network, especially their children. If participants did report mentioning ‘non-illness’ health problems to doctors, it appeared to be only in passing when consulting for a different problem or when a doctor specifically asked about that problem. More commonly, participants recounted discussing these problems with friends, although the intent was not to gain advice or help; even doing this was admitted to with reluctance, as Cornwell (1984) also found.

The desire not to be a ‘burden’ to others also reflected the emphasis placed upon independence in older age. Although Kusum, 81, reported having two daughters who advised her regularly on health matters, she explained her preferred approach:

I have not to tell anybody, I have to deal myself, so in that way, so that way you feel easy in that business... children they also got their own lives, their own

friends, they want to enjoy themselves, so it's too much for them to have us bothering in that case. Better to not to take too much – but better do our ways.

Furthermore, while health was often perceived in functional terms for this group, these oldest old participants were more specific, describing good health as *functional independence*. This desire to be independent explains why, when considering responses to problems attributed to 'old age' or 'normal' illnesses not warranting medical attention, participants unanimously stated that they would seek medical help only if their function was so impaired that going to the doctor was "absolutely necessary". Yet, participants' requirements of "essential" function also contracted, as also observed in adults aged 67-92 by Ebrahimi et al (2012). For example Vera, 83, who had recently begun treatment for Parkinson's disease, tolerated a tremor for several months until she was dropping teacups because she believed she could "manage" until then. Jean, 84, compared herself to a friend, deciding that she should tolerate knee pain that stopped her climbing stairs:

Well because some of my older friends 'ave got bad knee, this Doris, she's now 90 and her feet have gone over, so I know how bad. An' she'll come down[stairs] on her bottom! She can still go up the stairs... If Doris 'as to do it, I've gotta do it. You never 'ear 'er moaning, she's never moaned or anythin'.

Tolerance and self-management in managing problems and functioning independently was highly valued. Although as expectations of functional ability diminished, fewer health problems were brought to medical attention. Perceived old age thus led to a 'demedicalisation' of certain health problems, and responses believed morally-appropriate for

these problems were downgraded, adjusting the moralistic framework described by Cornwell's (1984) participants (Figure 1).

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'Upgrading' health problems

In contrast to the 'demedicalisation' of health problems, certain 'illnesses' were 'upgraded' amongst these oldest old adults due to their own perceived advanced age. This occurred when participants believed themselves to be more vulnerable to 'illness' which was perceived to be potentially more serious in older age, and so in greater need of prompt medical attention and treatment.

Reasons for this modified belief included perceived greater susceptibility to illness, perceived greater likelihood of complications, or feared slower recovery with age. Some participants noted that their living arrangements at older age made them feel more vulnerable to 'illnesses'. For example, Thomas, 87, felt he should take greater care of himself now that he was older and lived alone, "*'Cause if I don't look after meself, no one will!*" Others felt they did not have a lay network of support to consult for health problems, or worried about burdening this network, citing this as a reason for calling a doctor sooner about an 'illness'. The perception that physical access to the doctor was more difficult due to their age also encouraged medical help-seeking by some. Elsie, 85, reported consulting earlier in the course of an 'illness' than she might have when younger, lest she could not access her GP if she became more unwell.

When ‘illnesses’ were ‘upgraded’ by participants, seeking medical help was viewed as the morally correct response for a problem now more likely believed to be ‘serious’ in its consequences. This resembles those described by Leventhal et al (1995) who sought medical help more quickly to conserve their perceived diminishing health resources. The moralistic framework as described by Cornwell (1984) was again adjusted at perceived older age (Figure 1), but this time in the opposite direction to ‘demedicalisation’, reflecting the dichotomy observed in existing literature of response to health problems amongst the over 65s.

Importantly, the changes to participants’ morally-accepted belief-behaviour framework of ‘demedicalisation’ and ‘upgrading’ of problems were adopted readily as participants were explaining their *own* changes to their beliefs and behaviours, which they believed to be right for their perceived old age. Participants were empowered in making these changes to their beliefs and, in these cases, described their experiences with medical services positively. There were, however, situations when participants felt disempowered and displayed negative attitudes towards medical services or professionals, and it is to these which we now turn.

Negative Accounts and Disempowered Behaviours

Negative accounts occurred when participants recounted receiving medical treatment against their own judgement, or when they believed necessary treatment had not been given. In both scenarios participants felt disempowered, echoing findings by Cornwell (1984) who noted negative attitudes towards medical services or professionals often when there was a perceived power imbalance between participant and doctor. We now describe the situations in which our participants gave negative accounts, revealing the perceived disempowerment for these

oldest old participants and consequences for their moral framework of health and illness beliefs and behaviours.

Receiving medical treatment against participants' judgement

The first situation where negative feelings about medical professionals and services were voiced occurred when participants recounted receiving medical help that they did not perceive necessary or beneficial for the problem experienced, which they believed to be a 'non-illness'. For example, Peggy, 87, expressed her opinion of her recent interaction with medical services:

Peggy: The nurse that gives me the warfarin tablet every night decided that, now what did she decide? Um, that I needed to see the doctor, right? So she notifies the office that the doctor's gotta come an' see me, an' all 'e would do was accept a phone call, right? Anyway, she got on the phone to 'im, and she, she took me temperature, she took me blood thing [pressure], er, she reeled it off on the phone to 'im... So 'e said, "Right, I'll give 'er some antibiotics." [Then loudly] Now I just don't know 'ow 'e knew what antibiotic to give me! I mean I've just took five days of four a day – four, five, that's twenty tablets I've taken. And I don't really know 'ow 'e knew which ones to give me! 'Cause there's a lot of different ones, in't there?

XX: Do you feel any different?

Peggy: No! I just felt worse.

Eileen, 85, who had suffered with recent low mood and memory lapses, described a similar attitude towards her GP who had referred her to the day centre to prevent social isolation which she felt she did not need.

A second instance of negative accounts of medical professions and services occurred where participants, believing an 'illness' to be 'normal' rather than 'serious', were obliged to seek help from relatives against their own beliefs. However, unlike those above, these participants believed, in retrospect, that the help received was beneficial. Jean, 84, and Ethel, 93, for example, developed what they perceived to be mild vomiting and a 'bad cold' respectively. They both reported opting to manage this themselves, or with the help of a short course of treatment from the GP in Ethel's case, until their granddaughters called an emergency doctor who sent them straight to hospital. This demonstrated a challenge to these participants' beliefs: both were obliged to act according to another's beliefs and receive help against their own judgement. Yet unlike Peggy and Eileen above, both subsequently accepted that their relatives' decisions were vindicated. In doing so, both appeared to experience a sense of their own vulnerability, realising they had been at risk of serious consequences by making the wrong help-seeking decisions. Indeed, both repeatedly emphasised in frightened tones how close they had been to death.

However, despite experiencing this sense of vulnerability, both Jean and Ethel cited several reasons why they still would not act differently on a subsequent occasion. When asked how she would feel about going into hospital if a similar situation arose, Ethel explained:

Well I don't bother with doctors [laughs]. They keep puttin' me in hospital, and I've had enough of hospitals. I've been in and out of hospitals all me life.

In both situations of perceived ‘unnecessary’ treatment, participants experienced a sense of disempowerment either by medical professionals or relatives when forced into receiving help against their own beliefs. They found themselves acting outside of what they believed morally-appropriate according to their belief-behaviour framework (Figure 1). Furthermore, unlike the empowered modifications to participants’ belief-behaviour frameworks of ‘demedicalisation’ or ‘upgrading’ of health problems described in positive accounts, participants did not modify their belief-behaviour frameworks.

Not receiving medical treatment believed necessary

The second situation where participants expressed negative sentiments about medical professionals and services occurred when they experienced reactions from healthcare professionals *opposing* their beliefs to seek help. For example, Annie, 86, who frequently sought help for palpitations which she found frightening, and so perceived to be a ‘serious’ illness, reported being repeatedly sent home from the Emergency Department. Arthur, 82, felt a deep sense of injustice at only having been given ‘half a hip’ replacement rather than ‘a full hip’, which he felt he needed after suffering a fracture, a ‘serious’ injury.

In these cases, participants felt disempowered by doctors, and again described having to behave differently to that which they believed to be morally appropriate, by not receiving the treatment they felt was necessary for a ‘serious’ illness. Yet, similar to those receiving treatment believed unnecessary, these participants did not modify their beliefs (Figure 1). Rather than alter her help-seeking behaviour as she said her doctor advised, Annie reported attending the Emergency Department twelve times for palpitations without being admitted to

hospital. Similarly, Arthur became increasingly certain of his doctor's nihilistic attitude towards interventions for older patients, and mentioned this repeatedly.

In all situations described above, those giving negative accounts of doctors and services were those expressing difficulty adapting to what they perceived as their increasingly threatened independence. These participants were more likely to voice frustrations or sadness at a perceived loss of function and increasing dependence. In contrast to the 'good health' and independence they expressed in answer to direct questions, these frustrated accounts were often excused by expressions of apology or guilt, emphasising their departure from the morally-accepted attitude of gratitude for good health without complaint or reliance on others. Finally, then, we suggest that participants perceiving disempowerment as above became more resolute in their health and illness beliefs and behaviours as a direct response to perceiving a threat to their independence.

Discussion

Participants aged 80-93 attending two day centres in South-East London describe a clear, moralistic framework of beliefs regarding health, health problems and appropriate help-seeking behaviour. There are many similarities between these ideas and beliefs described by Cornwell (1984) amongst working-class adults in their fifties nearly 30 years ago, suggesting the importance of this cohort's historical, social and political experiences.

This study gives important insight into modifications made to this moralistic belief-behaviour framework due to an individual's own perceived 'old age', shedding light on conflicting findings within pre-existing literature and furthering our understanding of why certain health problems may or may not be brought to the attention of health services. Both

‘demedicalisation’ of problems, where problems are increasingly considered ‘non-illnesses’ and attributed to age, and ‘upgrading’ of ‘illnesses’, which are perceived as more ‘serious’ at older ages, occurred amongst these oldest old adults. In both situations, participants emphasised making independent decisions and empowered modifications to their beliefs and behaviours: in the first case, self-management of problems believed to be ‘non-illnesses’ was emphasised; in the second, help was sought more readily due to perceived greater vulnerability at older age. Beliefs regarding a health problem’s nature, cause and appropriate management were reinforced by social comparisons, medical opinion, lay advice and actions, or older people’s own beliefs about ‘old age’ itself. In the latter case, ‘old age’ was expected to be a period of worsening health and function, with a fear of becoming a burden to one’s lay network and wider society.

Participants’ negative attitudes towards medical professionals and services expose experiences of disempowerment when they are obliged to behave outside their belief-behaviour framework. Reactions to this disempowerment reveal that participants do not always modify their beliefs and behaviours following challenges to these. Rather, the oldest old may retain and even reinforce their original beliefs as one way of exerting independence, which is particularly significant as these adults find themselves in transition from independence to perceived dependence on others.

The oldest old’s emphasis upon ability to function independently, as central to health itself, may explain why the areas of health, illness and help-seeking became important domains in which to maintain one’s independence. Through empowered choices, modifications to one’s belief-behaviour framework, and resisting modifications of beliefs after disempowered behaviour, health and illness beliefs and behaviours become a significant arena in which an

older person perceiving increasing personal dependence can exert agency, with important implications for use of health and other services. While others have suggested that health beliefs may become a site for 'self-empowerment' (Conway and Hockey 1998), health and illness beliefs and behaviours have not previously been considered together, which has important practical implications. Nor have they been considered amongst oldest old adults, an increasingly significant demographic group, who may perceive maintaining agency as particularly important.

Although our sample was relatively small and most participants were of a similar demographic, a similarity of age, social class, living arrangement and increasing dependency allowed patterns of health beliefs and behaviours, which may be influenced by these characteristics, to be explored more deeply. Furthermore, the findings here of symptom response support recent work with rural-dwelling North American elders (Stoller et al 2011). Participants all volunteered and so may have differed from those not wishing to take part. Furthermore, those with significant memory impairment were excluded due to the methods of data collection. In-depth interviews relied on retrospective interpretations by participants, however supplementation with symptom diaries supported interview accounts. The completion rate of diaries was poor, often due to functional limitations, a point relevant for future research with older adults. However, the narrative nature of the in-depth interviews gave participants equality with the interviewer as far as possible, allowing negative expressions and threatened beliefs and behaviours to be voiced and explored.

The similarities of social class and geography with Cornwell's (1984) sample group also allowed differences with age to be further explored. The similarities between the moral framework of beliefs and behaviour of these two groups suggest that health beliefs may be

socially and historically influenced. Different understandings of and approaches to health preservation may therefore be necessary for socially or geographically-disparate cohorts. Differences between findings of the two studies, however, demonstrate modifications of health and illness beliefs and behaviours with perceived advancing age.

Adults aged over 85 are increasing in number and proportion faster than any other age group in the UK (ONS 2010). While a heterogeneous group, those becoming physically- or psychologically-dependent represent a potentially vulnerable group with high medical and social care needs. Understanding how individuals' health, illness and help-seeking beliefs are formed within their perceived social, emotional and physical contexts, is essential to advancing theoretical understanding and has significant practical benefits. Greater understanding aids the effective design and implementation of programmes and policies aimed at optimising help-seeking, such as preventing potentially harmful delays or clinically unnecessary consultation.

Further work relating to how certain health problems become 'demedicalised' or 'upgraded' in advanced age would allow further insights into the help-seeking behaviour of older people, as well as compliance with treatments. Exploring why some individuals feel a sense of empowerment while others feel disempowered could encourage sustainable methods of behaviour optimisation and target and prevent loss of agency. Little is known from this study about those with minimal or no lay network support; some individuals in this position might call the doctor more in response to perceived isolation, whilst others might not seek help due to believing there is no one to tell. As older adults are the greatest users of health and social care services, understanding the health and illness beliefs and behaviours of this group,

whose functional capacity, real and perceived, may be diminishing, is a subject of growing and urgent importance.

Despite the existence of many newer treatments for individuals of all ages, healthcare professionals' nihilistic approaches towards older adults are well-documented (Timonen 2008). A better understanding of the observed 'demedicalisation' of functional problems with age and preference for independent self-management may help to avoid delays or omissions of help-seeking, avoidable suffering, and potentially less effective or economically efficient treatment when sought at this late stage. Similarly, understanding the process of 'upgrading' certain health problems may allow clinically unnecessary consultation, with its impacts for health service provision, to be reduced. Finally, understanding the importance of preserving independence and empowerment in the formation of health beliefs and behaviours by older old adults can also assist in the design of strategies to optimise patterns of health service use.

Statement of ethical approval

This study was approved by King's College London's Research Ethics Committee, reference number [KCL/10-11 599].

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Declaration of contribution of authors

TE wrote the proposal, collected and analysed data and wrote the first draft of the paper. KL supervised the study, contributed to refining of coding and analysis and conceptual framework and redrafted the paper in collaboration with TE.

Statement of conflict of interest

The authors declare they have no conflict of interest with regard to this study.

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Figure 1. Framework of help-seeking behaviours (vertical axis) according to health problem type (horizontal axis) for the oldest old

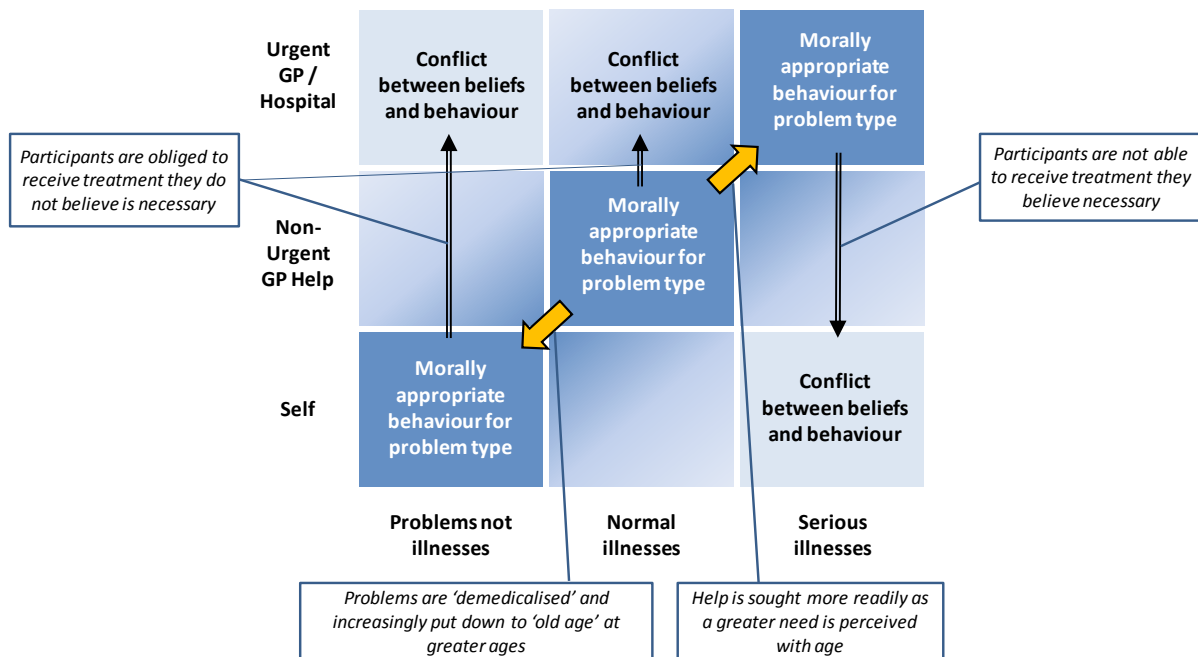


Figure legend: Behaviours considered morally-appropriate are found in the darker three squares.

Thick arrows represent modifications made within the accepted framework with advanced age. Thin arrows suggest the unresolved positions obtained when disempowered actions leave participants outside their moral framework.

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