Do those over 80 years of age seek more or less medical help? A qualitative study of health and illness beliefs and behaviour of the oldest old

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Abstract
Increasing longevity and prevalence of long-term conditions contribute to older adults being the greatest users of health services. However, relatively little is known about the health and illness beliefs of the oldest old or how they decide to seek help in response to symptoms. Through analysis of in-depth interviews with day centre attendees aged 80–93, we find that a moral, hierarchical approach to health problems and help-seeking exists; similar to Cornwell’s (1984) findings among 50–60 year-olds of a similar social group 30 years ago. However, when acting independently, those in their eighties and nineties report modifying their health and illness beliefs and behaviour, in response to their own perceived old age. Some health problems are ‘demedicalised’, being increasingly attributed to age and by being self-managed. Others are perceived as potentially more serious, leading to increased consultation with medical services. When obliged to act outside their moral belief–behaviour framework by others, the participants expressed feelings of disempowerment, yet resisted modifying their moral beliefs. This may represent resistance to adopt the ‘sick role’, while seeking to maintain control over uncertain health as functional dependence and frailty increases. This study furthers theoretical understanding of the health and illness beliefs and behaviour of the oldest old, with important practical implications.

Keywords: older people, health and illness beliefs, health behaviour, health service use, qualitative research

Introduction

Although the mortality rates of the over 65-year olds 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). The use of formal health and social care services and support from lay networks and voluntary carers also increases with age above 50 (ONS 2005), yet only a small proportion of health problems are brought to the attention of medical services (Scambler et al. 1981, Walters et al. 2001) and these are not always those most requiring attention (Morris et al. 2003).

Today’s older adults have lived through significant social, political, cultural and technological change, including the inception and expansion of services and treatments and health
promotion discourse (Pond et al. 2010). All these may influence contemporary health and illness beliefs and behaviour. As populations age globally, a greater understanding of older adults’ perceptions of health and illness is needed to inform theoretical development of how help-seeking behaviour are shaped in old age and ultimately to enable better delivery of appropriate health care to this group.

Classical theory on lay perceptions of health and illness and response to symptoms has predominantly focused on middle-aged adults (for example, Herzlich 1973, Mechanic 1978, Zola 1973). Yet studies exploring older adults’ beliefs have shown there are several differences between them and younger adults. Firstly, older adults often attribute certain health problems to old age rather than disease processes, perceiving health problems and physiological deterioration as a normal part of ageing (Chew-Graham et al. 2012, Gjørup et al. 1987, Walters et al. 2001); for example, with regard to symptoms pertaining to certain body systems, such as the eyes, ears and genitourinary system. In addition, symptoms perceived by older people as vague, such as forgetfulness, tiredness and low mood, are often attributed to age rather than ‘illness’ (Morgan et al. 1997). The attribution of health problems to old age is reinforced when such problems are increasingly observed in contemporaries (Horrocks et al. 2004, Sanders et al. 2002). Older adults may have lower expectations of health than younger individuals (Blaxter and Paterson 1982, Chew-Graham et al. 2012, Walters et al. 2001), often minimising the impact of illness on their lives (Sanders et al. 2002).

Secondly, beliefs of what constitutes good health have been reported to be different among adults over 60 years of age. Health may be conceptualised as functional capability rather than the physical fitness described by younger adults (Blaxter 1990) and symptoms that do not prevent the activities of daily life are not usually attributed to illness (Gjørup et al. 1987). Older adults have also described health as the harmonious interaction between themselves and their environment, with vital components being the ability to master daily life, and feeling validated as worthy and competent (Ebrahimi et al. 2012). However, among the very old, frailty may be a time of great uncertainty with regard to their physical and psychological function, ability to conduct daily routines, and availability of social networks (Nicholson et al. 2012). Maintaining a structure in daily life appears to enable frail individuals to retain some control over an uncertain existence and therefore appears to be important in maintaining positive experiences of health (Ebrahimi et al. 2013, Nicholson et al. 2012).

Thus, it is clear that ideas and beliefs of health and illness may be different at older ages, but how might help-seeking behaviour be affected? It has been suggested that the experience and knowledge accumulated with age provides a unique perspective. Adults aged 65–92 years in rural America were found to evaluate health problems within their individual bricolage of cognitive, emotional and social contexts (Stoller et al. 2011). Yet with regard to consulting a doctor, the relevant symptom characteristics were the same as those reported by Zola (1973) and Mechanic (1978) for adults generally: a symptom’s perceived severity; it being unusual to the individual or of unknown cause; and an individual’s inability to manage the symptom with lay treatments.

Where help-seeking has been compared between older and younger adults, a dichotomy exists in the existing literature. Help-seeking among the over sixties has been observed to be reduced or delayed for particular problems, and this is thought to relate to several beliefs of older adults including: attributing their symptoms to the ‘normal’, inevitable ageing processes that are not considered amenable to medical treatment (Gjørup et al. 1987, Horrocks et al. 2004, Morgan et al. 1997, Sanders et al. 2002); having lower expectations of health and the help available to them (Chew-Graham et al. 2012, Walters et al. 2001); attributing symptoms to another pre-existing condition; and not wanting to waste a doctor’s time (Corner et al. 2006).
Conversely, others argue that older adults seek help more readily (Leventhal et al. 1995) to ‘conserve resources’. By consulting a doctor earlier, it is hypothesised that physical and psychological resources are conserved by minimising the duration of a symptom, reducing uncertainty and waiting time for a diagnosis, and transferring decision-making to the healthcare professional.

The importance to older adults of a moral approach to health and illness beliefs and behaviour has been described (Blaxter and Paterson 1982, Cornwell 1984). Cornwell’s participants, working-class East-Londoners in their fifties, noted that they expected to experience worse health in later life. However, they emphasised the importance of being healthy and standing up to illness, rather than giving into it or complaining about it, and believed strongly in using health services appropriately. A hierarchy of health problems was described: ‘real’ illnesses (those considered to be potentially life-threatening and severe, such as cancer, diabetes and heart conditions), ‘normal’ illnesses (such as common infections, such as colds and flu) and ‘health problems that are not illnesses’ (thought to occur as a result of natural processes, such as ageing or reproductive changes, such as arthritis and menopausal symptoms). Each problem type was believed to have a morally appropriate behavioural response and health service. Real and normal illnesses were deemed to be within the domain of medicine; real illnesses were believed to require hospital services and normal illnesses considered the province of general practitioners (GPs). Health problems that are not illnesses were believed to be the remit of community services.

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 working class, who are now in their eighties and early nineties. While keeping in mind the significant social, political, cultural and technological changes between the 1980s and now, the similarities between Cornwell’s group and ours allow us to contrast our findings with Cornwell’s in order to explore how illness beliefs and behaviour, particularly decisions to consult health services, may be modified in advanced old age. Furthermore, through analysing our findings alongside existing theory on the sick role and health in frailty, we seek to understand the ways in which these beliefs and behaviour might change, or be challenged, as individuals grow older and frailer.

Methods

Participants aged 80–95 years were recruited from two day centres in South-East London. They attended the centres on the suggestion of friends, relatives or their GP, and through doing so, gained an opportunity to socialise with others, have a cooked lunch and play games, for a small charge. The first author spent eight weeks in each centre, conversing informally with attendees 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 a memory impairment that the day centre staff judged to be 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 during the interview period.

Data collection

The participants were interviewed by TE in a private room at their day centre in May to June 2011. Each interview lasted from 29 to 104 minutes (mean 50 minutes) and was

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audio-recorded. The interviews were semi-structured using a topic guide informed by a review of the relevant literature and the clinical experience of the first author as a trainee geriatrician.

Demographic information such as participants’ living arrangements was gathered initially, providing the context for their accounts. The participants were then asked to describe a time in the last 2 weeks when they had ‘not felt right in themselves, physically or psychologically’, although all participants also related instances of such feelings 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 the interviewing progressed, common belief frameworks, attitudes and behaviour 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 the participants greater control in the interviews to increase the richness of information they produced (Cornwell 1984). The first author’s professional background as a medical doctor potentially influenced her beliefs relating to health problems and help-seeking behaviour, and her interviewing style. During the interviews she was therefore careful to reflect the language used by the participants to minimise any power imbalances between participant and interviewer. The language, interview style and content of transcripts were reflected upon after each interview by both authors in order to constantly improve the interview technique and maximise the richness of information obtained. This was important, as Cornwell (1984) found that, if interviewers are perceived as experts, they gain less access to the private, personal accounts of participants, in which they might express thoughts outside what was perceived to be morally expected. Given this, the authors also anticipated that the participants’ awareness that the interviewer was a doctor might alter the nature of information gathered. They therefore decided, with the agreement of the day centre managers, not to disclose this unless the participants directly asked, which they did not.

Following their interview, the 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 collected in order to minimise the risk of obtaining potentially misremembered information from interviews alone (Bloor 1997) and to give a snapshot of the 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. The diaries were thus used only as a supplementary method of validating interview findings.

Alongside interviews and diaries, the first author made field notes during the eight-week period in the day centre. These included observations on attendees’ comments about health, illness, behaviour and old age, and shaped reflections on interviews both contemporaneously and afterwards. These were used to validate interview findings rather than as a main data source for analysis.

Analysis

The interviews and symptom diaries were transcribed verbatim and anonymised by the first author. The 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. The codes were cross-checked with the second author and then organised into broader categories, such as moral beliefs relating to help-seeking. The 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).
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 ours with Cornwell’s findings, we then explore how participants recounted and modified their beliefs and behaviour in the context of their own perceived advancing age and decreasing independence. Finally, we examine how being forced to act against their beliefs for a health problem could threaten the participants’ sense of empowerment, competence and mastery and reinforce their health beliefs and behaviour. By considering these findings in a wider theoretical context relating to frailty and the sick role, we aim to better understand these consequences for the participants’ moral framework of health and illness beliefs and behaviour in late old age.

Findings

In total, 10 women and five men participated, aged 80–93 (median 86 years). Of these 11 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 the school-leaving age among the remainder was 11–16 (median 14 years). All had worked in manual or clerical employment, except one teacher. Most reported restricted mobility for which they used aids.

A moral framework for health problems and responses

Consistent with the hierarchical approach to health problems described by Cornwell’s (1984) 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 (Table 1).

**Serious illnesses**

This group was termed serious, as the participants referred predominantly to acute and serious symptoms. Cornwell’s (1984) real illnesses referred to medical conditions considered severe

| Table 1 A hierarchical approach to perceived types of health problem, which are defined by their nature, perceived causes and the health-seeking behaviour that is morally appropriate to each |
|---------------------------------|-------------------------------------------------|---------------------------------|---------------------------------|
| Health problem type            | Nature of problem                                | Examples                        | Perceived causes                | Morally appropriate behaviour  |
| Serious illness                 | Frightening, certain body location, long duration, failed self-management | Severe bleeding, pain           | External causes: fate, bad luck, heredity | Urgent GP or hospital treatment |
| Normal illness                  | Cause participant to feel unwell but no serious features | Colds, headache, diarrhoea      | External causes of an everyday nature, for example, food, the weather | Non-urgent GP or allied health professional |
| Non-illness problems            | Functional impairments, chronic, gradual onset    | Muscular aches, giddiness       | Internal causes: old age, natural wearing down | Self-management, tolerance, not complaining |

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enough to be potentially life-threatening; such conditions were not described by our participants since the interview questions focused on their symptoms rather than medical diagnoses. However, the nature, perceived significance and relevant response to both serious and real illnesses were similar.

Our participants determined a health problem to be serious if it displayed a wide range of features. Having concerning or frightening physical characteristics (for example, bleeding or severe pain) is consistent with findings of Stoller et al.’s (2011) qualitative study of older adults. Symptoms associated with concerning features (such as weight loss following mouth pain or loss of appetite after abdominal discomfort) were also reported to be serious. Similar to Gjørup et al.’s (1987) findings, problems relating to particular bodily locations, such as the heart, lungs or abdomen (termed the insides), were considered serious, whereas musculoskeletal aches and pains, giddiness, urinary symptoms or psychiatric problems were often considered to be non-illness health problems; these are described below. Participants’ personally perceived risks and experiences (for example, new or unfamiliar problems, problems perceived to be due to a participant’s own medical history or problems that had caused serious consequences for a participant’s acquaintance) also led some symptoms to be perceived as serious; as did those associated with certain medical conditions, such as cancer, which participants often reported having ‘heard so much about’ as a serious problem. Lastly, duration of more than a certain amount of time or occurring more than once, and failure to respond to self-management, when medical and often hospital treatment in particular were believed necessary, also led to health problems being deemed serious.

As to the cause of 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 perceived to be relevant only to the illnesses of others. The participants presented serious illness as something that might happen to them, but for which they were not responsible; a phenomenon also observed by Cornwell.

When describing the response believed appropriate for a serious illness, the 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. Once medical help was sought for a serious illness, it was then considered right to accept and adhere to advice and treatment given, as was also described by Cornwell’s (1984) participants. For example, when Elsie, aged 85, was asked whether she took 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’.

Normal illnesses
The term normal illness was used for problems that 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 of an everyday nature: longstanding headaches were attributed to heavy weather; diarrhoea and sickness to eating the wrong thing.

Normal illnesses were manageable by the sufferer, often with the help of lay and over-the-counter (OTC) treatments such as creams or ointments. Alternatively, they may warrant consulting a practice nurse, optician, dentist or GP via a non-urgent appointment. Jean, aged 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.

This concept of normal illnesses, and their appropriate management strategies, was the same as that of Cornwell’s (1984) participants.

Non-illness health problems and health

The remaining health problems described differed in that the participants emphasised that these were related to functional ability rather than being illnesses as such. The participants often termed them ailments and not illnesses and we have therefore conceptualised these as non-illnesses.

Intrinsic to the participants’ beliefs about non-illness health problems were their ideas about health. The participants perceived being able to function as they wished or deemed necessary to be an important feature of good health, as Blaxter (1990) found. When describing their health, the participants tended to mention their functional restrictions, perceiving these limitations and health problems as non-illnesses rather than illnesses. Non-illness problems were chronic, often with a gradual onset, and without any serious features. Examples included aches and pains, sleepiness and problems with balance, mobility, eyesight, hearing and memory.

Rather than believing that the causes of these problems were 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 with age. This is, again, similar to participants in Cornwell’s (1984) study who described diseases such as rheumatism and arthritis as a natural part of growing old and as non-illness health problems.

Our participants described large numbers of non-illness health problems by their consequent functional impairments, attributing them to advanced age. Ethel, aged 93, described how problems she attributed to old age were different from 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’.

Since these problems were not considered illnesses, the participants usually believed that medical science and doctors could not help them, again echoing opinions of Cornwell’s (1984) participants. Rather, the participants believed that they should put up with these problems and not complain about them. Thomas, aged 87, discussing his painful knees, summed up a view that was consistently expressed: ‘There’s nothing much you can do about it, love’, reflecting the belief observed amongst older adults elsewhere with osteoarthritis (Sanders et al. 2002) and urinary incontinence (Horrocks et al. 2004).

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

Overall, a clear, moral, and hierarchical framework of beliefs and behaviour was found in our participants’ accounts, illustrated by the darkly shaded boxes in Figure 1. For each type of health problem, a morally appropriate behaviour was described, intrinsically linked to beliefs about the causes, and nature of that problem (Table 1). This moral framework of beliefs and behaviour of individuals in their eighties and nineties was very similar to those interviewed by Cornwell (1984), suggesting that pervasive cultural influences exist despite the significant
social and political changes of the intervening 30 years. Of note, none of our participants reported using the Internet when deciding what to do about a health problem. However, now they were aged 80–93, the participants here described and explained important modifications to their belief-behaviour framework, which they attributed to their perceived advanced age: health problems (predominantly normal illnesses) could be ‘demedicalised’, a process in which help was sought less, or ‘upgraded’ and presented to medical services more readily.

The demedicalisation of health problems
While 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 intrinsic factors such as personality, believed by Cornwell’s participants to be responsible for certain non-illness health conditions, were not suggested. Furthermore, participants here described their perceived advanced age as the cause of both a greater number and an increasing diversity of health problems, which were thus also considered non-illnesses. Old age became the default cause of health problems, as one octogenarian stated on hearing the aims of the study: ‘You’ll find everything’s down to old age here, dear.’

Underlying this demedicalisation of health problems was a much-reduced expectation of health and functional ability in later life, as described in the literature. The 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 the participants were also certain of the morally appropriate response to these non-illnesses: tolerance and self-management. Jessie, aged 89, describes in the following extract the social unacceptability of complaining about these health problems and highlights the high degree of such problems within her social network, which reinforced her belief that these were due to old age:

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 participants’ belief that a problem was due to old age was also reinforced by perceiving that there was no medical condition causing it and thus it could not be conceptualised as a normal illness, or that there was no medical treatment available because of their age. As Harry, aged 90, says: ‘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’.

The believed importance of not complaining about symptoms was strengthened by the participants’ desire not to burden others: either doctors, who were perceived to be struggling with rising numbers of patients; or their lay networks, especially their offspring. If the participants did report mentioning non-illness health problems to doctors, it was only in passing when consulting for a different problem or if a doctor specifically asked about that problem.

Closely related to participants’ desire not to be a burden was their wish to be independent; in line with their perception of good health, this was often described as a functional independence. This explains why, when considering responses to problems attributed to old age or normal illnesses not warranting medical attention, the participants unanimously stated that they would seek medical help only if their function was so impaired that going to the doctor was absolutely necessary. This point is of particular significance for older adults who often experience more functional impairments than younger individuals.

Furthermore, the participants’ ideas of essential function had also contracted, as observed by Ebrahimi et al. (2012). Vera, aged 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, aged 84, compared herself to a friend, deciding to tolerate knee pain that prevented 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’.

In summary, as expectations of health and functional ability in later life diminished, fewer normal illness health problems were conceptualised as such and brought to medical attention. Rather, more were demedicalised and attributed to old age, a process reinforced by comparisons with contemporaries, a desire not to burden social networks or doctors and the perceived lack of available or effective medical treatment. Tolerance, self-management, the desire not to burden others and functional independence in managing problems were highly valued by our sample, correlating with other recent findings that emphasise the importance of these factors and retaining control for positive experiences of health in advanced old age (Ebrahimi et al. 2012, 2013; Nicholson et al. 2012). Responses that were believed to be morally appropriate for demedicalised problems were downgraded (illustrated by the downwards thick arrow in Figure 2), thereby adjusting the moral framework described by Cornwell’s (1984) younger participants.

Upgrading health problems

In contrast to the demedicalisation of health problems, certain normal illnesses were upgraded among our sample. This appeared to occur when the participants believed themselves to be more physically or socially vulnerable to symptoms that were perceived to be potentially more serious in older age, and so in greater need of prompt medical attention and treatment.

Descriptions of physical or bodily vulnerability included a perceived greater susceptibility to illness, greater likelihood of complications, or feared slower recovery with age. The perception
that physical access to the doctor was more difficult due to their age also encouraged medical help-seeking by some. Elsie, aged 85, reported consulting earlier in the course of an illness than she might have when younger, lest she could not reach her GP if she became more unwell. A social vulnerability was described by others when their living arrangements or lack of a lay support network at an older age made them feel more susceptible to illnesses, citing this as a reason for calling a doctor sooner. Thomas, aged 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!’ In this way, illness appeared to be more of a threat to the physically or socially vulnerable older person whose functional independence was precarious than to those who were more functionally independent.

When normal illnesses were upgraded by participants, seeking medical help was viewed as the morally correct response for a problem now believed to be potentially serious in its consequences (illustrated by the upwards thick arrow in Figure 2). This resembles those described by Leventhal et al. (1995) who sought medical help more quickly to conserve their perceived diminishing physical and psychological resources. These participants also appear to be potentially taking control of perceived anxieties or uncertainties over their health by adopting a health-promotion approach, which has been increasingly emphasised throughout society in recent years (Pond et al. 2010). Here, the moral framework described by Cornwell (1984) was again adjusted at perceived older age, but in the opposite direction to demedicalisation, shedding light on the dichotomy observed in the existing literature of responses to health problems among older adults.

Importantly, the demedicalisation and upgrading of problems were adopted readily, as participants were in control of these changes and believed them to be in concordance with both their own views and what they perceived to be the views of health professionals and the wider society with relation to old age. The participants were empowered in modifying their beliefs.
and, in these cases, described their experiences with medical services positively. There were, however, situations when participants felt disempowered, voicing negative attitudes towards medical services or professionals, and it is to these that we now turn.

**Negative accounts and disempowered behaviour**

The participants gave negative accounts when they recounted receiving urgent medical treatment that they did not seek, judge to be necessary or feel had improved their health. These accounts were also voiced when the participants believed that necessary treatment had not been given to them, and these are illustrated by the thin upward and downward arrows in Figure 2. In both scenarios the participants felt disempowered, echoing findings by Cornwell (1984) who noted that negative attitudes towards healthcare professionals often occurred when there was a perceived power imbalance between the participant and doctor.

**Receiving medical treatment against participants’ judgement**

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

Peggy: The nurse that gives me the warfarin tablet every night decided 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 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 20 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?

TE: Do you feel any different?

Peggy: No! I just felt worse.

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

A second instance of negative accounts of healthcare professionals occurred where participants, believing an illness to be normal rather than serious, were obliged by relatives to seek help in opposition to their own moral framework. However, unlike those described above, these participants believed, in retrospect, that the help they received was beneficial. Jean, aged 84, and Ethel, aged 93, 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 a doctor who sent them straight to hospital. This demonstrated a challenge to these participants’ beliefs and independence: 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. Indeed, both repeatedly emphasised in frightened tones how close they had been to death.
However, despite experiencing this sense of vulnerability and potential treatment benefit, 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 this way, Ethel takes back control of her help-seeking decisions and reasserts her independence in decision-making for health problems. Acknowledging her increasing proximity to death and the uncertainty of her health status at this point, she maintains her original beliefs on a condition that she still considers is not serious enough to warrant hospitalisation. A similar desire to remain in control in late old age has been found elsewhere among frail individuals (Nicholson et al. 2012).

In both situations of perceived unnecessary treatment, the participants experienced a sense of disempowerment either by healthcare professionals or their relatives when they were forced into receiving help against their beliefs. When they were forced to act outside their believed morally appropriate belief-behaviour framework, the participants did not alter their beliefs, unlike the empowered modifications of demedicalisation and upgrading of health problems described in positive accounts.

Not receiving medical treatment believed necessary
The second situation where participants expressed negative sentiments about healthcare professionals and services occurred when they experienced reactions from healthcare professionals opposing their beliefs to seek urgent GP or hospital help. Annie, aged 86, who frequently sought help for palpitations that she found frightening, and so perceived them to be a serious illness, reported being repeatedly sent home from the emergency department without treatment. Arthur, aged 82, felt a deep sense of injustice at having only been given ‘half a hip’ replacement, which he believed was due to his age, rather than ‘a full hip’, which he felt he needed after suffering a fracture which he believed to be a serious injury.

In these cases, the participants felt disempowered by their doctors, again describing having to behave differently to what they believed was morally appropriate, by not receiving the treatment they felt was necessary for a serious illness. Similar to those receiving treatment that they believed was unnecessary, these participants did not modify their beliefs. Rather than alter her help-seeking behaviour as she said her doctor advised, Annie reported attending the emergency department 12 times for palpitations. Similarly, Arthur became increasingly certain of his doctor’s negativistic attitude towards interventions for older patients and mentioned this repeatedly; by so doing he both cemented his original beliefs and resisted the negative attitude that he perceived healthcare professionals held towards older people (Conway and Hockey 1998, Higashi et al. 2012).

In all the situations described above, those giving negative accounts of healthcare professionals also expressed their difficulty in adapting to what they believed to be their increasingly threatened independence. These participants were more likely to voice their frustrations or sadness at their perceived loss of function, increasing dependence, and threats to their own control over help-seeking behaviour. The participants who were feeling disempowered became more resolute in their health and illness beliefs and behaviour as a direct response to this perceived threat to their independence. In contrast to the good health and independence they claimed 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.
Discussion

Day centre attendees aged 80–93 in South-East London hold a moral framework of beliefs on health problems and appropriate responses to them. There are many similarities between this framework and that described by Cornwell (1984) among working-class adults in their fifties nearly 30 years ago.

Yet this study also gives an important insight into the modifications that may be made to this moral belief-behaviour framework in advanced old age, shedding light on the conflicting findings in the existing literature. Both the demedicalisation of normal illnesses, where problems are increasingly considered to be non-illnesses and attributed to age, and the upgrading of normal illnesses, which are perceived to be more serious at older ages, occurred. In both situations the participants emphasised making independent decisions and empowered modifications to their beliefs and behaviour. In the first case, the self-management of problems believed to be non-illnesses was emphasised; in the second, help was sought more readily due to their perceived greater vulnerability at an older age. Beliefs regarding a health problem’s nature, cause and appropriate management were reinforced by social comparisons, medical and lay opinion and actions, a desire not to burden one’s lay network or wider society, and the older people’s own beliefs about old age itself. The latter was expected to be a period of worsening health and function, with greater vulnerability.

The participants’ negative accounts of healthcare professionals and services exposed their experiences of disempowerment when they are obliged to behave outside their belief-behaviour framework. Their reactions to this disempowerment reveal that the participants do not modify their beliefs and behaviour after they have been challenged. Rather, at a time of frailty, when life holds many uncertainties, the oldest old may retain and even reinforce their original beliefs as one way of maintaining control (Nicholson et al. 2012).

A contemporary reading of Parsons’ sick role (Williams 2005), allows us to further understand this reinforcement of beliefs and resistance to medical advice when people are disempowered. Classically, patients adopt Parsons’ sick role when they are transiently incapable of their normal level of function due to sickness. In this state, there exists a moral obligation to seek and adhere to medical advice. Both doctor and patient play an active role in their interaction, whereby the former’s technical expertise must be used responsibly, and the patient, albeit with some experiential knowledge, must trust and adhere to professional advice (Williams 2005).

Yet recent analyses by Williams (2005) and others allow us to suggest several reasons why our increasingly frail older participants fail to readily adopt the patient role in their negative accounts. First, the temporary nature of the reduced capacity and dependency intrinsic to Parsons’ sick role is less certain for this cohort, as functional capacity may be less likely to return with increasing frailty. Second, both the frail individual and health professional encounter uncertainties that may prevent a mutually satisfactory doctor–patient relationship. Healthcare professionals may be increasingly unsure how best to care for an older, frailer individual, as the certainty of tools such as evidence-based medicine diminish (Williams 2005). For the older individual who has experienced increasingly widespread health promotion discourse, but now experiences the nearing of death, when health promotion has no role, a conflict of discourses may result in uncertainty as to how to proceed (Pond et al. 2010). Third, the required trust by a patient in their technically expert doctor may be challenged by an older person as experiential knowledge relating to one’s own body increases with age (Stoller et al. 2011). Fourth, the perceived negativistic attitudes of healthcare professionals, potentially denying treatment because of the patient’s age, may provide reasons for older individuals to resist a perceived negative portrayal of old age in modern medicine and wider society (Conway and Hockey © 2014 The Authors
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Finally, given the described uncertainties of their position, frail individuals may aim to maintain as much control as possible over their lives (Ebrahimi et al. 2013, Nicholson et al. 2012); a threat to this from health professionals or others may thus be particularly unwelcome and resisted.

Study limitations

The participants all volunteered and so may have differed from those not wishing to take part, and potential participants who were not fluent English speakers or those with significant memory impairment were excluded due to the methods of data collection. In-depth interviews relied on retrospective interpretations by the participants, however supplementation with symptom diaries supported the interview accounts. The completion rate of the diaries was poor, often due to the participants’ functional limitations; however, this has been shown to be high among older individuals completing structured health diaries with the close support of researchers, suggesting ways in which this technique may be successful among older participants (Stoller et al. 1993). Although our sample was relatively small and most of the participants were of a similar demographic, their similarities allowed their patterns of health beliefs and behaviour, which may be influenced by these characteristics, to be explored more deeply. Furthermore, our findings on the characteristics of serious illnesses support findings among a very different sample of rural-dwelling North American elders (Stoller et al. 2011).

Finally, this study focuses on how individuals conceptualise and respond to health problems. We did not question participants about how wider changes, for example in the National Health Service structure, funding and technology, might have affected their perceptions and behaviour over time. Further research among socially, ethnically and geographically disparate cohorts is therefore warranted to more fully examine how meso-level and macro-level changes influence the oldest old’s health behaviour, as well as to address questions such as why empowered participants demedicalise some problems yet upgrade others.

Conclusion

Adults aged over 85 are the fastest increasing in number and proportion of all age groups in the UK (ONS 2010) and across the world. While they are a heterogeneous group, those becoming physically or psychologically dependent represent a potentially vulnerable group with high medical and social care needs. Understanding how the oldest old people’s health, illness and help-seeking beliefs are formed within their perceived social, emotional and physical contexts, with corresponding behaviour, is essential to advancing theoretical understanding and has significant practical benefits.

Despite the existence of many newer treatments for individuals of all ages, healthcare professionals’ negativistic approaches towards older adults are well-documented (Higashi et al. 2012). 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 in help-seeking. Understanding the process of upgrading certain health problems may allow clinically unnecessary consultations to be reduced. Understanding the importance of maintaining control in frailty in the formation of health beliefs and behaviour by older old adults can also assist in the design of strategies to optimise doctor patient interactions and patterns of health service use. By placing the health and illness beliefs and behaviour of this oldest old group within a theoretical context of a moral approach to health, as well as detecting important changes for the sick role in frailty, this study significantly adds to our theoretical understanding of this increasingly important group.
References


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