Older people's perceptions about symptoms

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SUMMARY

Background. *Little is known of the nature and origins of the attitudes that older people have towards ageing, disease, and medical treatments. Several studies on older people in the community have suggested under-reporting of symptoms. There may be several reasons for this, including the possibility that some older people regard disease processes as a natural feature of ageing and, consequently, feel that medical intervention may have little to offer.*

Aim. *To investigate the perceptions of older people about the significance of symptoms and what action they would take in response to particular symptoms.*

Method. *Thirty-three men and 77 women attending social clubs (median age 78 years) were opportunistically selected and assessed using a supervised questionnaire.*

Results. *Many symptoms classically associated with common diseases were often considered to represent disease as well as to be normal for old people. Most would consult a doctor if they were to experience them. Some important symptoms, such as blackouts or paralysis of a limb, were not considered to be normal. Non-specific symptoms of psychiatric disturbances were also frequently considered normal but were not considered to represent disease. Whether or not a doctor would be consulted was often, but not always, related to whether a symptom was thought to represent a disease. Consulting a pharmacist was seldom considered appropriate.*

Conclusions. *Doctors working with elderly people need to consider how beliefs about health and disease might affect what is reported to them. Specific enquiry needs to be made about symptoms of psychiatric disturbances. These findings suggest that there is a case for increased health education at retirement age.*

Keywords: elderly; perception; symptoms.

Introduction

ILL-HEALTH in old age and its resource implications have become matters of much public policy debate for obvious reasons. Interestingly, older people often rate their health as being good despite the fact that they may carry a substantial 'disease burden',[1] thus suggesting that their views about health and illness differ substantially from those of most health care workers. Much less is known about their understanding of the nature of disease, how the manifestations of disease might be distinguished from the changes attributable to ageing, whether such a distinction is important, and whether much can be done to relieve their symptoms. These are not simply academic questions since the answers to them might well be important contributory factors to independence, well-being, and resource utilization.

Even when old people present with symptoms, diagnosis may be difficult. 'Diseases' often present in an altered fashion in old people, and various patterns have been described, one of which is presentation late in the natural history of a disease.[2] Part of the explanation may well relate to the altered biological substrate that is produced as an individual progresses through his or her lifespan,[3,4] although there are other explanations, such as deliberate concealment and misinterpretation of the significance of symptoms, that are likely to be equally, if not more, important.

The important studies of Williamson *et al*[5] in the 1960s revealed considerable unreported, although symptomatic, illness in older people living in the community. Conditions that fit a traditional disease model (e.g. asthma and ischaemic heart disease) were generally known to the patients' general practitioners (GPs), whereas conditions that do not easily fit this model (e.g. incontinence, locomotor disorders, and falls) were often unrecorded. Later studies[6-8] produced similar findings. These studies suggest that the perceptions of patients about what benefits (if any) might accrue from interventions do not necessarily concur with the beliefs of doctors. Older people have more chronic illness, which may make it difficult to perceive symptoms as disease based, and may lead to them being ascribed to the ageing process instead. If older people regard disease processes as a consequence of ageing, this might deter them from going to their doctor. First, they may feel that the doctor will have little to offer in the way of treatment for something that is inevitable. Secondly, they may want to avoid confirmation as far as they are concerned of a decline due to ageing. There is very little information on people's perceptions of symptoms and disease. We have interviewed 110 community-dwelling older people to determine their beliefs and perceptions about common symptoms and what action they would take in response to each individual symptom.

Subjects and methods

One hundred and eighteen people living in the community and attending social clubs for the elderly were opportunistically selected and invited to participate in this study. Only two people declined to participate and a further six were considered to be ineligible having failed to score >8 on the abbreviated mental test score.[9] One hundred and ten people (median age 78 years, range 67–98 years; 77 women) were interviewed by one of us (RM) using a supervised structured questionnaire. Volunteers were presented with a series of statements, such as 'tiredness is normal in old people', and asked if they agreed with it. Five responses were possible: 1, definitely yes; 2, possibly yes; 3, not sure; 4, probably not; and 5, definitely not. Responses in categories 1 and 2 and categories 4 and 5 were grouped together in the analysis for convenience. The subjects were also asked if they would consult a doctor with this symptom whether they would ignore the symptom, and whether they would get something from the chemist. In the second part of the questionnaire, they were asked whether each of the symptoms they had already been asked about was a symptom of disease. Again, they were presented with a statement, such as 'forgetfulness is a symptom of disease', and asked

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whether they agreed with it. The same five possible responses were offered and they are grouped in the same way for presentation. To assess the reliability of the responses, one of the questions was repeated at random (painful joints). The questionnaire was piloted before the study and, from this, it was clear that the questionnaire would have to be administered on a one-to-one basis in order to ensure its completion.

Results

There was no significant difference between age groups. The answers given by men and women did not differ significantly (overall $\chi^2 = 0$, df = 21, $P = 1.000$). Answers 'definitely yes' and 'probably yes' are shown as 'yes' and answers 'definitely no' and 'possibly no' are shown as 'no'. The response to the repeated question gave a value for the kappa statistic of 0.4 (fair strength of agreement). This is probably the result of choosing a question to which there was a wide spread of answers. A better test of consistency would have been to repeat statements for which the replies showed little scatter, such as 'blackouts are normal in old people'.

Symptoms that might be expected to be clearly indicative of disease (Table 1), such as blackouts and loss of feeling in an arm or leg lasting more than one hour, were generally not thought to be normal in older people, and most subjects stated that they would report such symptoms to the doctor. Interestingly, breathlessness and tightness in the chest when going up hills were often considered normal. Several other symptoms were considered to be normal but were also considered to be symptoms of disease (Tables 1–3), which suggests that they might have interpreted 'normal' to mean 'common' or 'usual'.

Vaguer symptoms, such as tiredness, sleep problems, low mood, and forgetfulness, were generally considered to be normal, and most respondents stated that they would ignore such symptoms (Tables 1–3) and did not consider them to indicate disease. Locomotor problems were also considered to be normal, although frequent falls were not (Table 2). Most respondents thought that these symptoms represented disease (Table 3), although a surprisingly large number stated they would ignore muscle stiffness and painful joints. Interestingly, regardless of beliefs about the origins of symptoms, few people stated that they would go to a pharmacist about them, the only exception being constipation, about which 55% would go to the chemist.

Discussion

Several studies have shown that older people consistently rate their own health as good but, in objective terms, their health is shown to be poor.[10-12] Why is this? The concept of health has been shown to mean many things to many people.[13] In the health and lifestyles survey,[14] health was interpreted by many older women as 'being able to do one's housework'. It is hardly surprising, therefore, that, if health means different things to different people, there will be different ways of measuring health.

In this study, some symptoms, e.g. breathlessness (69%) (out of breath easily while carrying your shopping or walking 100 yards on the flat), were felt to be normal in older people and yet still represented disease (67%). This would suggest that some older people view the process of ageing as one that is inevitably linked with disease. This is supported by a study by Williams *et al*,[15] who discussed the concept of age with elderly correspondents and found that for many 'old' was not a chronological term but was synonymous with ill-health. In another study,[16] older people thought age represented decline and ill-health.

If some older people regard disease as an inevitable sequel or consequence of ageing, could this influence their requests for consultations with their GPs? There may be several reasons why older people may not want to consult their GP. If they can cope with the activities of daily living, they may regard themselves as healthy, despite having what we regard as medical disease.[14] If to have ill-health is to be old and to be in good health is not to be old, then ageism (internal and external) will make older people reluctant to describe themselves as anything but healthy. If some older people also regard normal ageing as a process that inevitably means disease, they may feel that there is no point in disturbing their GP.

Writers on the presentation of disease in old age frequently make unreferenced assertions that important symptoms may be dismissed as 'symptoms of old age'. For example, Freedman[17] makes such a claim for anorexia, weight loss, acute confusion, incontinence, and dizziness. In fact, we know very little of what older people think about the significance of symptoms and what action they would consider appropriate. We believe that this is the first study to describe the beliefs held by a group of community-

Table 1. Response of subjects to statements that the listed symptoms are normal in older people and the actions they would take if they were to experience them (n = 110).

	Normal in older people				Action		
Symptom	Yes	No	Don't know	(%)	Go to Doctor	Ignore	Go to Chemist
Flutter chest >5 min	24	47	29		68	31	1
Tightness in chest going uphill	49	40	11		65	35	0
Breathlessness	69	21	10		54	42	4
Ankle swelling	44	42	14		69	30	1
Blackouts	10	84	6		98	0	2
Lightheadedness	20	59	21		84	13	3
Loss of feeling >1 h	9	82	9		95	1	4
Tiredness	81	14	5		14	79	7
Difficulty going to sleep	68	23	9		49	45	6
Early morning awakening	55	24	21		25	70	5
Awakening not going to toilet	69	16	15		15	79	6
Low in spirits	54	28	18		28	66	6
Forgetfulness	91	4	5		15	83	2
Frequent pain top of tummy	6	78	16		87	10	3
Constipation	29	55	16		34	11	55

Table 2. Response of subjects to statements that the listed symptoms are normal in older people and the actions they would take if they were to experience them (n = 110).

	Normal in older people				Action		
Symptom	Yes	No	Don't know	(%)	Go to Doctor	Ignore	Go to Chemist
Deafness	78	9	13		66	29	5
Falls once a week	16	72	12		87	10	3
Unsteadiness	53	31	16		74	26	0
Painful joints	84	8	8		72	21	7
Muscle stiffness	64	22	14		53	36	11

Table 3. Response of subjects to statements that the listed symptoms are indicative of disease (n = 110).

Symptom of disease	Yes	No	Not sure
Flutter in chest >5 min	71	10	19
Tightness in chest going uphill	75	10	15
Breathlessness	68	16	16
Ankle swelling	70	13	17
Blackouts	97	1	2
Lightheadedness	76	6	18
Loss of feeling >1 h	91	4	5
Tiredness	51	32	17
Difficulty going to sleep	11	78	11
Early morning awakening	9	77	14
Frequent awakening not going to toilet	13	69	18
Feeling low in spirits	17	60	23
Forgetfulness	27	57	16
Painful joints	62	18	20
Muscle stiffness	61	18	21
Frequent falls once a week or more often	67	16	17
Unsteadiness	65	13	22
Painful joints	59	22	19
Frequent pain top of tummy	84	4	12
Deafness	29	47	24

dwelling older British people about how symptoms are related to diseases and why patients may not draw the attention of their doctors to the presence of certain symptoms. Our results strongly suggest that most of our subjects are well aware that diseases are common in old people and correctly interpreted symptoms, such as blackouts and loss of feeling in a limb, as indicators of disease, and averred that they would consult a doctor if they had such symptoms. Less concrete symptoms that might indicate psychiatric disorders, such as low mood, disturbed sleep, and forgetfulness, were also recognized as 'common' but were generally not considered to represent disease and seemed not to be thought of as symptoms that required a medical opinion. These results are broadly consistent with the findings of several studies on the patterns of unreported illness among older people,[5-8] and it may well be that one reason for the under-reporting of certain complaints is that they are not perceived as indicative of the presence of disease and thus not something of concern to doctors.

Other investigators[18] have found that older people tend to attribute certain symptoms, particularly those arising from the eyes and ears and those related to psychiatric disturbances, to 'normal ageing' and do not consider them to represent disease. Symptoms representing neurological and cardiovascular disorders tended to be attributed to disease and not to ageing. This contrasts with our own findings, which suggest that our study group considered that a disease could also be a normal occurrence in older people. The difference between our results and theirs may represent a real difference in people's beliefs or may be explicable by how the word 'normal' was interpreted.

Interestingly, some individuals who considered symptom X to be normal in older people would still consult their doctor. There are two possible explanations for this. First, there may have been a difference in interpretation of the word 'normal'. Secondly, there may have been differences of view about the appropriateness of X for visiting a doctor. Thus, although 68% thought that difficulty in going to sleep was normal (78% thought it was not a symptom of disease), 49% would go to their doctor. Presumably, a visit to the doctor is undertaken with the knowledge that treatment can be given, hence the visit is considered worthwhile by some individuals. Older people may not like disturbing their doctor with symptoms that they regard as trivial or normal for their age or for which they think there is no treatment.

Clearly, it is important that doctors who work with elderly people understand how their patients might think about the nature of health and disease. Not to do so will very probably result in the provision of suboptimal medical care. Of course, our results come from a small sample of older people and must be considered as being preliminary. The fact that subjects were recruited from social clubs may have introduced bias, since they may not be typical of the elderly in general, being more mobile, independent, and possibly more extrovert. Nevertheless, they do indicate a problem that might easily be remedied. Instead of relying on self-reporting of illness, opportunistic specific enquiry should be made about symptoms, particularly the vaguer ones that are associated with psychiatric disorders. For the future, it is probably reasonable to promote educational programmes about health and illness in old age, although any such programmes should be properly evaluated for their effectiveness.

Doctors who work with older people must also reconsider their own attitudes and beliefs. We consider that to try to make a clear distinction between ageing and disease is both problematic and unhelpful.[2,3] Diagnostic labelling might have been useful in a clinical practice based on concepts that became established around the turn of the century when infections and other acute illnesses dominated medical practice and when treatment options were extremely limited. However, altered disease patterns in an ageing population have revealed many inadequacies in traditional clinical thought,[19] and advances in medical science and technology should have relegated diagnosis from being a goal to becoming a decision-making tool for the application of intervention strategies. It is now more appropriate to determine how troublesome symptoms come about and what can be done to alleviate them, regardless of whether they arise from ageing or from disease. In other words, to paraphrase Charcot, 'symptoms are merely the cries of the suffering organs',[20] and we need to assume nothing more about their origins to institute appropriate management.

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