

What quality healthcare means to older people: exploring and meeting their needs

Older people's needs do not appear to be at the heart of NHS decision making. A qualitative study identified nine aspirations for better care from the over 80s

AUTHOR Charlotte Potter, MSc, BA, is public services policy programme manager for Age Concern and Help the Aged.

ABSTRACT Potter C (2009) What quality healthcare means to older people: exploring and meeting their needs. *Nursing Times*; 105: 49-50, 14-18.

Background The over 85s is the fastest growing age group in England and a major user of healthcare services. It is vital to understand what quality healthcare means to this group.

Aim To investigate qualitatively what vulnerable older people value in the NHS and whether these aspirations are being met by policy and practice.

Method Face to face interviews were conducted with 20 vulnerable older adults, most of whom were aged over 80, and the findings matched with current policy and practice.

Results Nine aspirations were identified: face to face, personalised and flexible appointments; to retain control in their home; respect for property and belongings; company and the opportunity to be listened to; proactive healthcare and support; choice and control over daily routines; a connected relationship between staff and patients; maintenance of privacy in hospital; and joined-up care.

Discussion Gaps can be identified in each of these areas and the government, healthcare providers and professionals, as well as regulators and professional bodies, need to take steps to ensure policy and practice meet the needs of vulnerable older people.

Conclusion There are two main conclusions from this work: older people are more concerned about their needs being met than about who meets them; and if the NHS is serious about delivering quality it needs to listen to patients about what they want rather than making assumptions about this.

BACKGROUND

More of us are living longer than ever before and the over 85s make up the fastest growing age group in England – a population predicted to double in the next 25 years and expected to treble in the next 35 years (Office for National Statistics, 2008). As such, it is perhaps no surprise that older people make up the largest group of adults regularly using healthcare services. They are more likely to visit their GP (NHS Information Centre for Health and Social Care, 2007) than younger adults. People over 65 occupy almost two thirds of general and acute hospital beds (Audit Commission et al, 2006). Despite this, older people's needs rarely appear to be at the heart of NHS delivery and decision making processes.

The economic downturn has clearly hit all sectors but, despite difficulties, delivering high quality care rightly remains a fundamental organising principle for all NHS services, clearly stated in Lord Darzi's NHS next stage review (Department of Health, 2008a).

Given the expected rise in the number of older people in our society and the changing demands on the NHS, it is essential to understand what quality healthcare means to this group of patients.

AIM

This study was done to investigate qualitatively what vulnerable older people value in the NHS. We also explored whether the aspirations of older people are being met by policy and practice.

METHOD

Age Concern and Help the Aged commissioned Ipsos MORI to explore older people's concept of healthcare quality. The researchers specifically targeted vulnerable older people approaching the last years of their life, who are likely to have multiple and complex health conditions, requiring intense support.

PRACTICE POINTS

- Professionals working with older people need to listen and respect their choices.
- The importance of human interaction and relationship centred care needs to be recognised.
- There is a need to actively point older people in the direction of places of expertise where they can get information and support.
- Micro management of conditions without regard for individuals' wider health circumstances and comorbidities is likely to be ineffective.

In total, 20 in depth, face to face interviews were conducted, mostly with people aged over 80, all of whom had had recent experiences of using health services.

Ipsos MORI (2009) translated the findings into a series of aspirations and Age Concern and Help the Aged carried out detailed analysis on the extent to which each one is being met by policy and practice.

RESULTS

The preferences expressed by this sample of vulnerable older people can be split into nine aspirations listed below, which fall into three categories:

Healthcare in the community

- Face to face, personalised and flexible appointments;
- To retain control in their home;
- Respect for property and belongings;
- Company and the opportunity to be listened to;
- Proactive healthcare and support.

Healthcare in hospital

- Choice and control over daily routines;
- A connected relationship between staff and patients;
- Maintenance of privacy in hospital.

Healthcare across all settings

- Joined up care.

DISCUSSION

Each of these aspirations was evaluated to assess whether health policy and practice are delivering quality to those who use and need NHS services the most. Main recommendations were then identified to ensure the NHS delivers the kind of service older people say they want.

1. Face to face, personalised and flexible appointments

Older people value continuity and want to see healthcare professionals they know and trust. However, mobility difficulties and a lack of transport can prevent them from going to a GP surgery. Having a face to face appointment is important to ensure care is tailored to the individual and sometimes this will mean a home visit.

We know that the older patients are, the more likely they are to have a preferred doctor. More than seven in 10 people aged over 85 say they always or almost always see their preferred doctor, compared with 38% of 18-24 year olds (DH, 2009a). At the same time, the percentage of GP consultations undertaken as home visits dropped from 9% in 1995 to 4% in 2008 (PharmaTimes Online, 2009). Older people's experiences of trying to arrange a home visit are mixed and more than one in 10 had found it difficult.

Older people do not necessarily want to shop around for healthcare. They place significant value on the ability to make an appointment to see a trusted individual at a convenient time and place.

The ability to make an informed choice is not available to many. Only 36% of people over 65 have ever used the internet (ONS, 2009) yet, increasingly, the expectation is that patients will become confident consumers of healthcare based on knowledge they have acquired online.

● How to improve appointment access

The drive to promote choice in primary care and general practice should not exclude those who need it most. Older people must be supported to make choices in a way that suits them.

Information and advocacy services will be essential and future reconfigurations of GP services and commitments to remove practice boundaries must preserve continuity of care and the option of care in the home.

There is an urgent need to look at how GPs are remunerated for their services to care homes. It should be PCTs' responsibility to ensure that all individuals in an area receive

their entitlement to be registered with a GP of their choice and for free.

2. To retain control in their home

Many older people receive health services in their own home. Although invaluable, this support should complement rather than crowd out their capacity to retain independence. The home is generally perceived as being the last area over which older people are able to assert control.

More than two thirds of people aged 85 and over in the UK have a disability or limiting long standing illness. For those aged 65-74, the figure is 40%, rising to 55% for people aged 75-84 (Department for Work and Pensions, 2009). Yet more than half of 18-64 year olds expect to be living independently when they are 80 years old.

A recent survey found that 30% of primary care patients were not involved as much as they wanted to be in decisions about their care and treatment (Care Quality Commission, 2008). It is clear that older people want to remain independent and maintain control in later life, even though many will suffer from disability or long term health conditions that require some form of medical or social assistance.

The piloting of personal health budgets takes empowerment to its logical extreme, with the patient as the main focus of decision making. Yet the fact that many patients still feel partially excluded from the decision making process indicates we have not yet broken away from the paternalistic model of healthcare. Treatment and support should start by looking at what older people want to achieve and assisting them to do this, rather than pursuing a disease management model.

On the other hand, the evidence suggests that few older people welcome complete control of the public resources available to meet their needs. The evaluation of individual budgets in social care suggests that, in contrast to other groups, older people do not appear to want the additional burden of planning and managing their own support in this way (Individual Budgets Evaluation Network, 2008).

● How to retain older people's independence

The government must ensure that any rollout of personal health budgets for older people living in the community is deferred until full evaluation has taken place and their impact fully assessed.

Healthcare providers must develop

healthcare professionals' skills and competencies in helping older people to manage their own health wherever possible. This should build on skills developed in preregistration training.

Healthcare professionals must listen to older people when they go into their homes and respect their choices and directions, particularly in relation to how they like things to be done, so they do not feel excluded and powerless.

3. Respect for property and belongings

Any healthcare worker entering an older person's home must respect the way they like things to be done, including the use of their belongings.

In 2008, 61% of clients reported that the care worker always did the things that they wanted done, while 1% said they never did the things they wanted done (NHS Information Centre for Health and Social Care, 2009a).

It is hard to quantify behaviour that is fundamentally about basic respect and politeness when visiting people's homes. It is, however, easy to overlook such courtesies when healthcare professionals have many demands on their time.

Draft regulations and guidance from the government and the Care Quality Commission state that service providers are expected to be considerate and respectful.

● How to ensure respect

The CQC must hold healthcare providers working in the community to account for the behaviour of healthcare professionals working in people's homes. This should be based on patients' experiences.

4. Company and the opportunity to be listened to

Older people can feel lonely or isolated. Contact with health and care workers can offer a much needed form of interaction and friendly conversation is often welcome.

One person households are projected to overtake married couple households by 2030 (ONS, 2007). On top of this, 11% of people aged 65 and over say they are lonely (Age Concern and Help the Aged, 2009). An Age Concern (2007) survey found that 29% of respondents aged 50 and over saw friends, and 36% saw family, a few times a month or less.

The links between social isolation and mental and physical health are well documented (Foresight, 2008) but health services are not well set up to deal with

problems associated with social detachment.

This problem is not the exclusive responsibility of the NHS but services should not exacerbate social isolation. Injecting some humanity into interactions and recognising an individual's identity beyond their ill health can make a big difference. Clearly, many healthcare professionals do go the extra mile and this must be recognised. However, social interaction should not be an optional extra but a core part of ensuring the overall wellbeing of all older users of health services and especially the most frail.

● How to prevent isolation

Healthcare professionals must recognise the importance of human interaction and relationship centred care. Social aspects of healthcare should not be underestimated. Also, providers must ensure health professionals entering older people's homes have readily available information on a range of accessible social opportunities and activities in the local area.

5. Proactive healthcare and support

Older people are often unaware of what is available to them and may need help and support to understand and access services. Information, advice and outreach are the bedrock to making this work.

Research has shown that of those who have a long standing medical condition and need support, 45% said they definitely received enough help from local services or organisations to manage their condition. A further 29% said they had received support to some extent, but over a quarter said they had not received any (CQC, 2008).

As one female participant pointed out: "I would like to have more say about my health, but I don't really know what is available. How can I ask for help if I'm not sure what I need?"

Older people with long term conditions will regularly have to make decisions about their care or will need access to a range of services to live independently. Unfortunately, too often older people and their families experience difficulties in accessing the right information. Internet based information such as that found on NHS Choices excludes the majority of older people as they are not online. Telephone based services can be off putting for those who find it difficult to conduct lengthy and complex calls (Citizens Advice, 2004).

Healthcare professionals should be fully aware of local information and advice services and should signpost older people to

these whenever possible. An Age Concern (2007) survey of local information services suggested the NHS is missing opportunities to connect people with the advice they need. Only 19% of advice service users were referred via a healthcare professional even though 89% of users reported disabilities or long term and multiple health conditions.

● How to ensure older people receive information and advice

The government must provide a clear strategy and sustained funding for the provision of information and advice. In addition, healthcare professionals must proactively direct older people to places of expertise where they can get the information and support networks they need. Healthcare providers should also consider hosting services such as benefits advice (Age Concern, 2008).

6. Choice and control over daily routines

An unfamiliar and busy acute care environment can make someone feel lost and uncomfortable, impeding recovery. Older people should be able to maintain familiar aspects of their daily routine, such as when they take medications or the kind of food they like to eat.

Already busy hospitals are getting busier. Last year, 14.1 million people were admitted to hospital (NHS Information Centre for Health and Social Care, 2009b) – an increase of 600,000 people on the previous year.

Although the average length of hospital stays is falling, many older people can expect to stay a week or more once admitted. A person who has had a fall – one of the top reasons for admission – can expect to stay an average of 8.2 days (Hospital Episode Statistics Online, 2009).

In 2008, 96% of people reported having somewhere to keep their personal belongings on the ward but 65% of respondents could not lock that space, while 22% of people were not always offered a choice of food (CQC, 2009).

One man in Luton explained: "When I was in the ward it was actually quite scary... it's so foreign to me, so having staff there who both respect your routine but also tell you what's going to happen to you, makes all the difference."

Clearly a hospital stay represents a severe disruption to an individual's daily routine. Some participants found it upsetting not to have pills on time or not to be offered food that they could eat. At present, the emphasis in hospitals is very much on throughput and

completing essential clinical tasks, with very little time and space to enable older people to keep hold of familiar aspects of their life or control their experiences. Tolson et al (1999) reported that patients feel better when they can remember and relate to important people, events and things.

NHS policy now, however, recognises that it is no longer satisfactory to treat people as numbers and that a good patient experience is intrinsic to the success of an overall care package. The NHS next stage review (DH, 2008a) included patient experience as one of three key domains of quality. However, the few indications we have suggest that, for many, this vision is far from reality. The rhetoric around quality needs to be made real – especially for those older people who use hospital services most. We need to find new ways of valuing and incentivising behaviour – cutting across all staff, from porters and cleaners, through nurses to consultants.

● How to maintain a familiar routine

Healthcare providers must recognise the importance of going beyond clinical tasks to help people to exercise choice and control. This ranges from choosing treatments to wearing their own clothes. Emphasis needs to be placed on prioritising and reporting quality issues that matter to older people.

7. A connected relationship between staff and patients

Reciprocal communication based on mutual respect and understanding engenders trust and supports good decision making. Taking the time to understand the person behind the patient will further enhance the therapeutic partnership between patient and practitioner.

In 2008, 47% of people said they were not involved as much as they wanted to be (or they were only partly involved) in decisions about their care and treatment in hospital (CQC, 2009). One in five people did not always have trust and confidence in the doctors treating them, a figure that rose to one in four when talking about nurses.

A good relationship extends much further than ticking off standard questions to obtain patients' medical history and carrying out observations while they are passive observers.

Cognitive or sensory impairment can result in behaviour that challenges staff or creates communication difficulties and few healthcare professionals are

appropriately trained to deal with this. Up to half of older people in hospital may have cognitive impairment, including dementia and delirium (Royal College of Psychiatrists, 2005).

Both the end of life care strategy (DH, 2008b) and the national dementia strategy (DH, 2009b) emphasised the need to develop communications skills in the workforce, including involving patients in decisions about care. However, words need to be translated into action.

● How to ensure a therapeutic relationship

Professional regulators, royal colleges and representative bodies must reinforce and promote the importance of relationship centred care throughout health workforce standards. The CQC must reinforce in guidance that service users should be involved throughout the process of making decisions on treatment options and hold providers to account where this has not been the case.

For its part, the government must review the implementation of the Mental Capacity Act across health and social care to ensure steps are taken to improve awareness and to see that the principles are incorporated in everyday practice.

8. Maintenance of privacy in hospital

Older people should never feel embarrassed or humiliated in hospital. Staff attitude is important in imparting reassurance that personal or intimate care is not a burden. The environment should support privacy but not at the expense of interaction. Older people often prefer the company of others on a ward rather than the isolation of a single room. However, this is only the case when sharing accommodation with people of the same sex.

A survey done in 2008 found that 24% of people reported sharing a sleeping area with a member of the opposite sex when they were first admitted to a bed on a ward and 30% of people reported using the same bathroom or shower as patients of the opposite sex. Almost a third of inpatients also said they were not always afforded enough privacy when discussing their condition or treatment and 12% said they weren't always given privacy when they were being examined or treated (CQC, 2009).

After many years of political commitments around privacy and mixed sex accommodation, the NHS needs to get this fundamental principle right. In early 2009,

the government launched a programme to "all but eliminate" mixed sex accommodation. However, maintaining privacy clearly extends much further than the bricks and mortar of mixed sex accommodation. It is also dependent on timely and respectful behaviour from staff. Older people also report feeling humiliated and embarrassed when staff do not respond to calls for assistance in getting to the bathroom on time.

"I was not mobile at all when I was in hospital... I called and called for someone to come and take me to the toilet, but after almost 20 minutes of waiting I embarrassed myself in my bed," one man said.

Although some of this depends on having staffing ratios that enable intimate care to be carried out with privacy and respect, much depends on the approach of individual healthcare professionals. Trust boards need to focus their attention on developing cultures and practices that meet patient expectations around privacy. This demands accepting and responding to feedback from patients – something that the NHS is poor at doing.

● How to ensure privacy

The government must hold hospitals to account for failing to deliver single sex accommodation and healthcare providers must ensure hospital staffing ratios take into account adequate staff to deliver personal and intimate care in a way that ensures fundamental privacy.

There also need to be steps to improve the collection of feedback from older patients, and use the information to learn from mistakes and change processes and working cultures where necessary.

9. Joined up care

Older people's health and care needs should be assessed holistically. Professionals should work together to ensure the appropriate package of services come together and that patients are informed of every stage of the care process.

In 2008, 8% of patients reported that when they first saw the person to whom they were referred, she or he did not seem to have all the necessary information about them or their condition (CQC, 2008).

Among inpatients, 57% reported they did not receive copies of letters sent between hospital doctors and their family doctor and, although 84% reported being involved in decisions about their discharge from hospital, 30% said they were involved

only to some extent (CQC, 2009).

This is not just patients' views – a survey of doctors by the British Medical Association found that three in five respondents believe there is not appropriate continuity of care for older patients accessing health and social care (BMA, 2008).

Many older people suffer from several health conditions, both physical and mental, that often require the intervention or support of multiple professionals or agencies. However, the system is poorly set up to manage multiple needs at the same time. Healthcare professionals are trained and developed in a way that privileges specialty expertise and specialties can often encourage a blinkered approach to an individual's overall health. Yet our research showed where practitioners took the time to help patients beyond the confines of their particular specialism, this was seen as excellent care.

Older patients' journey through the system is also often poorly managed. This includes transitions between wards in a hospital, between the hospital and home or simply navigating care in the community. Between 1998-99 and 2006-07 there was a 69% rise in emergency readmissions within a month of discharge from hospital in the over 75s (National Centre for Health Outcomes Development, 2009). Good coordination of care at discharge must surely underpin attempts to reverse the trend.

Attempts to better coordinate services have had some success. Providing a person centred and integrated response for older people was one aim of the Partnerships for Older People Projects pilots. The national evaluation has indicated some positive outcomes, including reduced emergency admissions (DH, 2009c). However, there is little sense of how the learning from the pilots will translate into better coordinated practice universally. Our research found that home visits appeared to be well coordinated for those who suffered from one long term condition, such as cancer or a stroke, but for those who had no specifically serious diagnosis but who were nonetheless very frail, barriers appeared to exist in getting the care at home they needed.

The NHS next stage review (DH, 2008a) announced that by June 2010 all people with long term conditions will have been offered a personalised healthcare plan. This could make a big difference as long as the plans are genuinely tailored to older people's multiple and fluctuating needs. Research suggests that care plans, as they are instituted today, are only moderately effective (and, in some

practice research report

cases, ineffective) at achieving gains for patients and that more resources and training for healthcare professionals are needed if the initiative is to be successful (PatientView, 2009).

● How to provide joined up care

The government must disseminate learning from pilot programmes so all areas focus attention on better coordination of care, particularly at hospital discharge.

It must also robustly support the implementation of care plans to ensure healthcare professionals, providers and commissioners are prepared to use them to tailor and coordinate healthcare. This implementation must be carefully monitored

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to ensure progress genuinely reflects need.

Professionals must be aware that comorbidities are a reality for many. Micro-management of conditions without regard for individuals' wider health circumstances is likely to be ineffective – training, development and revalidation of health professionals must reflect this.

CONCLUSION

Two overarching conclusions can be drawn from this work.

First, older people are more concerned about their needs being met, than about who delivers the support. When asked about healthcare at home, interviewees clearly did not always distinguish between health and

social care. This is likely to reflect confusion over how the two systems interact.

In addition, if the NHS is serious about delivering quality, it needs to get to grips with patients' real experiences rather than presumptions over what matters. It needs to focus not only on what is done (and is easily measurable) but how it is delivered and seek ways of valuing this. When asked about waiting times for example, those interviewed reported that waiting times for outpatient appointments and A&E admission were less of a concern than the time waiting for a response to the call button. Often politicians and professionals focus on what they think is important while ignoring those issues by which patients really judge a service. ●

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