



Funding health and social services for older people – a qualitative study of care recipients in the last year of life

Barbara Hanratty^{1,2} • Elizabeth Lowson³ • Louise Holmes¹ • Gunn Grande⁴ • Julia Addington-Hall³ • Sheila Payne⁵ • Jane Seymour⁶

¹Department of Public Health and Policy, University of Liverpool, Liverpool L69 3GB, UK

²Hull York Medical School/Department of Health Sciences, University of York, York YO10 5DD, UK

³Cancer, Palliative and End of Life Care Research Group, Faculty of Health Sciences, University of Southampton, Southampton SO17 1BJ, UK

⁴School of Nursing, Midwifery & Social Work, University of Manchester, Manchester, M13 9PL, UK

⁵Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster LA1 4YT, UK

⁶School of Nursing, Midwifery and Physiotherapy, University of Nottingham, Nottingham NG7 2HA, UK

Correspondence to: Barbara Hanratty. Email: barbara.hanratty@york.ac.uk

DECLARATIONS

Competing interests

None declared

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Summary

Objectives This study explores the views of older adults who are receiving health and social care at the end of their lives, on how services should be funded, and describes their health-related expenditure.

Design Qualitative interview study

Setting North West England

Participants 30 people aged 69–93 years, diagnosed with lung cancer, heart failure or stroke and judged by health professionals to be in their last year of life. Sixteen participants lived in disadvantaged areas.

Main outcome measures Views of older adults on funding of services.

Results Participants expressed a belief in an earned entitlement to services funded from taxation, based on a broad sense of being a good citizen. Irrespective of social background, older people felt that those who could afford to pay for social care, should do so. Sale of assets and use of children's inheritance to fund care was widely perceived as an injustice. The costs of living with illness are a burden, and families are filling many of the gaps left by welfare provision. People who had worked in low-wage occupations were most concerned to justify their current acceptance of services, and distance themselves from what they described as welfare 'spongers' or 'layabouts.'

Conclusions There is a gap between the health and social care system that older adults expect and what may be provided by a reformed welfare state at a time of financial stringencies. The values that underpinned the

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Ethical approval

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Informed written
consent was
obtained from all
participants

Guarantor

BH is the guarantor

Contributorship

BH had the idea for
the study, LH
collected the data,
BH, LH and EL
analysed the data
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views expressed – mutuality, care for the most needy, and the importance of working to contribute to society – are an important contribution to the debate on welfare funding.

Introduction

How to fund health and social care for an increasingly large, older population is a challenge for policymakers in high-income countries. The size of the future financial burden will depend on whether improvement in health can compensate for population ageing.¹ Healthcare spending is concentrated in the last year of life, and a reduction in mortality can lead to lower costs overall.² But, as people live longer, they are more likely to have more complex needs for both health and social care over extended periods.³ In the UK, there is a consensus that existing models of health and social care funding are not sustainable, but despite being a priority for all new governments, acceptable solutions remain elusive. In 1997, the incoming Labour government established a Royal Commission on long term care, chaired by Sir Stewart Sutherland. One of the commission's key recommendations was that personal care costs should be available free, after an assessment of need, and paid for out of taxation.⁴ This was only acted upon in Scotland. In England, free NHS nursing care was introduced, whether the recipient lived at home or in a care home. Hence the current system is complex, with provision varying both within and between constituent countries of the UK. In England, medical and nursing care are universally funded, including nursing home fees for people eligible for NHS continuing care. Personal care at home and in care homes and 'hotel' costs for care home residents are means-tested in England, but available according to need, not ability to pay in Scotland. The current Coalition government set up their own Commission on Funding of Care and Support when they came into office. The 'Dilnot Commission' has recommended a cap on lifetime contributions to social care, raising the means tested threshold above which people are liable for full costs of care, national eligibility criteria and portable assessments.⁵ Government response to the report has been cautious and the White Paper expected in 2012 is unlikely to accept all Dilnot's recommendations. Many other ideas for

funding have been proposed, from social insurance, partnership or hybrid models in which individual contributions are matched or topped up by a 'care levy' component of national insurance, taxing older adults on income or assets, to enrolling everyone into a National Care Fund at the age of 65 at a cost per person of up to £15,000 (€17,750).^{6–10} The current debates on the proposals have been criticized for focusing on systems rather than the needs, values and socio-cultural contexts of care recipients.^{11,12} At present, families are often negotiating the complex system of financial and care assessments, and taking important decisions at a time of stress, when care is needed urgently, leaving little time for considered decision-making.¹³

Changes to NHS funding or costs to patients are not proposed as part of the forthcoming structural reforms, and public support for the universal nature of the NHS remains strong. Over the last 20 years, the British Social Attitudes Survey has found between 71 and 79% of survey respondents to be in favour of a tax funded health service available to all.¹⁴ There is some enthusiasm for a similar model in social care, though fears have been expressed that individuals underestimate the costs involved.¹⁵ Adult recipients of social care interviewed for the Joseph Rowntree Foundation supported an equitable social care system and expressed concern that users of social services were portrayed as a financial burden, with little consideration of the potential for social care to prevent problems and save money.¹⁶

Health and social care will touch most of the population directly or indirectly at some point in their lives, yet the views of ordinary people are rarely represented in public debates on costs and funding. There is very little research with the people who receive care about the costs they face, and how their care should be funded. Older adults and those from more disadvantaged socioeconomic groups are particularly under-represented. In this study we explored perceptions of a group of older adults, who are receiving care because they are known to have a life limiting illness: lung cancer, heart failure or stroke. As a good understanding of which services are provided by

health or social care cannot be assumed, we encouraged our interviewees to share their perceptions of the costs of care, without restriction.

This study aims to develop understanding of older adults' perspectives about how health and social care services should be funded, and explore their own health-related expenditure.

Methods

In-depth semistructured qualitative interviews were conducted with older adults receiving health and social care services. Individuals were invited to participate through specialist lung cancer, heart failure and stroke services based in secondary care settings. As these interviews form part of a wider study focused on end of life care, clinicians were asked to identify individuals whose death in the following twelve months would not be a surprise. Each interview drew upon a topic guide that also explored their experiences and views on their present illness trajectory, formal and informal care and transitions between places of care.

Approval for the study was granted by the Sefton Research Ethics Committee, the Royal Liverpool and Broadgreen University Hospital NHS Trusts and St Helens and Knowsley Teaching Hospitals. The majority of interviews were conducted in participants' homes (26) with others taking place in a hospice (1), rehabilitation centre (1) or care home (2). Just under half (13) of the participants had a relative or friend present who also contributed to the interview. Written informed consent was obtained from each participant and carers quoted in this paper. Each interview was audio-taped with the participant's agreement, transcribed in full and analysed using the matrix-based Framework approach.¹⁷ Two researchers familiarized themselves with the data, by reading and rereading the transcripts, to develop an idea of the key issues, concepts and themes. A detailed coding index was developed and used independently by two researchers on five transcripts before being applied to the whole dataset. The data were tabulated in a modified Excel spreadsheet, with each major theme allocated a chart, a row for each case and a column for every subtheme or category. A standard process of sifting, sorting and comparing the data (both within and across the cases) was completed to

develop descriptive and explanatory accounts. The themes presented in this paper were identified by three researchers independently, and refined in discussion. They arose from the data, in response to a question about costs of care, and were not part of any *a priori* hypothesis.

Findings

Thirty people participated. They were aged between 69 and 93 years and living with lung cancer (13), heart failure (14) or stroke (3). Their last reported occupations placed sixteen people in the lowest categories (4 and 5) of the National Statistics Social Classification. Four themes relating to the cost of care were identified; welfare being an earned entitlement, the injustice of selling assets to pay for care, people should contribute what they can afford, and the role of family in taking on the financial burden of illness.

An earned entitlement

A perception that entitlement to services had been earned was apparent throughout the interviews. A lifetime of working and paying taxes and national insurance was commonly cited, but the sense of entitlement was based on a far broader sense of being a good citizen; working hard, staying in employment, and minimizing their earlier demands on the welfare state (Box 1). One man had brought up six sons with his wife, and he cited his sons' collective contribution to the economy as employees and taxpayers.

The people who were most keen to emphasize their contribution to society through work and taxes, and differentiate themselves from what they termed 'spongers' and 'layabouts that just want everything for nothing' (husband of 73-year-old female with lung cancer), had been in low-income occupations. They described considerable personal efforts to be financially independent, with an implicit sensitivity to the stigma of being a claimant of non-universal benefits.

Assets and savings should not be used to pay for care

Alongside the perception of an earned entitlement to funded care for older adults in this study, was a

Box 1**Feelings about paying for care services****An earned entitlement**

'...we both went to work, and we had a mortgage... that was paid off through our own hard work... I think it's completely unfair that if you have got to go into care that they can confiscate that. ...we get a lot of support off our kids and... I think it's their birthright to have what you have left. ...in the 1970s when in this country we had to go on a 3 day working week... they told me that I was entitled to apply for our free school dinners for my children but I wouldn't do it. I was responsible for those kids. ... we are not a load of spongers. ...', at the same time if she (wife) needed that care I don't see why you should be penalized by having to sacrifice what you worked for to pay for it.' (Husband of 73-year-old female with lung cancer)

'Why should I pay £500 a week if I am that ill for weekly care home fees. The state should be paying, I've paid all my life... From the financial point of view I don't want to go into a home unless I can nip to Scotland and get in free.' (77-year-old male, with heart failure)

Assets and savings should not be used to pay for care

'Because the cost of care is so horrendous, even selling a house, it will keep you for a year or two that's all. I think the care should be as it used to be, you know. Even now if you have no assets, the care is still very good because it's paid for by the local authority. But the thing is, normally you have got to pay it yourself, if it's there, which is wrong. I think society is judged by the way it cares for it's elderly and the sick, and once you start saying I don't care - well it's not a very good society any more.' (74-year-old male, with heart failure)

'Well I don't think they should have to pay really to go in these homes. I mean they have worked hard all their life for their money and I don't see why their savings should be took by somebody else... I mean provided they can get the money to cover it. Which I am sure if they worked things right they could do really. *Do you mean the government?* Yes... I don't think it's fair to take all the money, the savings and everything to pay for it.' (77-year-old female with lung cancer)

People who can afford to, should pay

'Well if they can afford it, why not. Yes, well there was a man on the table here yesterday with us, he went home, and he had just had a stair lift put in: £2,200. Well he must have money, mustn't he, to have that done. So if people have it, they should pay for, it shouldn't they really, obviously didn't have anything else to do with it, yes, he got one put in, £2,200 he said.' (82-year-old male with heart failure)

'I think it's down to the individual, your own conscience, you know... they wanted me to apply for certain things but I said I don't need it... they were amazed that I don't get housing benefit... I get a pension off the post office which takes me over the poverty line, I am quite happy to be that way, I don't owe anybody you know what I mean. I pay income tax believe it or not, not much... but I don't object to that, I think if people can afford to pay it, pay it. If you can and somebody else can't, you should.' (79-year-old male with heart failure)

concern that their homes and savings should not be 'sacrificed' or 'confiscated' to pay for their care. Use of assets and savings to pay for care was framed as an injustice to older adults who had worked hard to accumulate them whilst also paying national insurance contributions; and as denying inheritance to adult children who provide considerable support to their parents. The description of assets and savings as 'took by somebody else' (Box 1) suggests a moral concern about paying for care to which they consider entitlement has already been earned; and that recuperation of this money by statutory authorities is interpreted as contributing to others' care. There is an expectation that with appropriate financial management, contributions should be sufficient to cover costs of care, without additional charges for care recipients.

People who can afford to, should pay

While earned entitlement and protection of assets and savings were strongly held beliefs, older adults felt that individuals with financial

resources available should contribute to or pay for their health and social care (see Box 1). This view was held by those with and without personal financial resources to pay for care, and was rooted in a sense of rights, or entitlement, and responsibilities. Paying for care if you could afford to do so was seen as a way of ensuring the individual's own care needs are met, while releasing resources for the care of people who cannot afford to pay. Rather than imposing charges, it was felt that individuals should consult their 'conscience', taking account of their care needs and any surplus financial resources.

Current costs

Most of the older adults interviewed had received universally funded healthcare provided by GPs, community nurses and at hospital, or voluntary sector hospice care, with few having experience of social care assessments and care homes. Despite this, many of the older adults described the effort and expense involved in meeting

Box 2**Condition-related costs met by older adults****Social Care**

Care home places

Carers at home

Home personal alarms

Meals on wheels and some day centre meals & activities

Mobility scooters

Specialized furniture

Healthcare-related

Transport to access healthcare (taxis, car parking)

Paying for TV and telephone calls in hospital

Care of pets during hospital admissions

Private healthcare to access treatment more rapidly

condition-related incidental costs not provided by the health service (Box 2). Considerable costs were involved in paying for care home places, carers at home, specialized equipment and private health care sought for rapid diagnoses and treatment. Many of the lower value costs such as day centre fees, taxi fares, TV and telephone costs in hospital also represented significant costs for most of the older adults.

Family carers filling in the gaps

In addition to meeting financial condition-related costs of their condition, most of the older adults report that family members and friends invest considerable time and effort in supporting them, and ensuring care needs are met which are not funded by statutory provision (Box 3). This informal care covers a wide range of needs, including guidance or handling of finances and benefit claims, installing equipment to avoid long waiting lists or other delays for statutory provision, and meeting household and personal care needs in the home to delay care home admission. Family carers play an important role in bridging gaps between what they consider to be complex and slowly responsive funded care and the expense of self-funding.

Discussion

Older adults in this study displayed a strong sense of entitlement to services that were tax funded,

Box 3**Family carers filling in the gaps****Providing financial guidance**

'See my daughter does all that for me, she doesn't give me any worries about anything like that, I don't know what goes on about money, I really don't, I don't know what I am entitled to or what I am getting, you know. She sorts all that out, yes.' (82-year-old female with heart failure)

Practical tasks

'Well when he was at the hospital 1, I took a taxi every day... that got expensive, it cost me about 20 quid a day, 10 here and back. When he was at hospital 2, I went in the car, my little car that wasn't so bad. It's still expensive.' (Friend of 81-year-old male who had a stroke)

Home caregiving

'I suppose if we had to pay for it, then we would be a bit stretched then. I think, what I will say is that, when it comes to [it] we made it clear, that in so far as I am able to, and if she goes a lot more ill than she is now, she is going nowhere unless it becomes absolutely necessary you know. I think, as a carer what is missing is a bit of professional help given to me... We all went through a first aid course at work you know... I was responsible for setting it up for some of the workers, so I am not ... stupid you know what I mean, but just a little bit more help you know.' (Husband of 73-year-old female with lung cancer)

after working lifetimes contributing to the state. Alongside this, a sense of social responsibility emerged in views that people should contribute to the costs of their social care if they were able. However, this did not extend to selling assets or using savings to pay for residential care, which was viewed as unjust. Support for universal access to currently available health services was widespread. No participants described barriers in access to care because of lack of funds, but they overwhelmingly felt that the welfare state should look after the most needy. These older people felt that a lifetime of tax contributions should represent an obligation fulfilled, and it is clear that any changes to existing systems will be unpopular with a cohort who have paid taxes and have an expectation of comprehensive services.

Strengths and weaknesses

Few of the participants in this study had moved into care homes, which meant that they had not personally experienced the means testing or difficult decisions over disposing of their homes. Hence our study may underestimate the strength of feeling against charges imposed for care home

places that would be found amongst the general population. More than half of the interviewees were from lower socioeconomic groups, making them more likely than average to be eligible for state support and have assets of lower monetary value. However, support for universal, comprehensive services was apparent throughout our study, so our data provided no reason to believe that relative wealth influenced views on how care should be funded. Our participants did not articulate a clear understanding of which services were provided by health rather than social care, and we did not probe this in the interviews. In common with other service users, they were more interested in individual outcomes, than how the service was provided.¹⁸ A National Health Service, free at the point of use, had been available for most of their lives, whereas experiences of social care were associated with older age. Their views may well have been shaped by their expectations of health services, without reflection on whether funding, contributions and access to social care should be similar.

Comparison with other work

Although co-payments for healthcare in the UK are small by European and US standards, many participants faced costs associated with accessing care, or living with their illness. However, none reported financial barriers to accessing healthcare, which is in line with the findings from a Commonwealth Fund study of healthcare in UK and five other high-income countries.¹⁹ There are few comparable studies of user views of the costs and mechanisms to fund care. The Joseph Rowntree Foundation (JRF) funded a number of empirical studies to inform their response to the consultation on the 2009 UK Green paper on social care funding: 'Shaping the Future of Care Together'.⁷ Eighteen service users were interviewed, representing a broad constituency, including older people, those with physical and sensory impairments, learning difficulties and mental health service needs. They shared a concern for equity with our interviewees and both groups supported the funding of social care through taxation; an option previously ruled out by politicians. The authors of the Joseph Rowntree study suggested that there was a need to develop service user views and ideas.¹⁶ Although consultations on

social care funding have been conducted by local and central authorities in the UK, people who are old, unwell and from disadvantaged areas are the least likely to be heard.^{20,21} The voices of older people with high support needs on what they would want and value in their social care, have been described as 'so quiet as to be practically silent'.²⁰ Our participants were typical recipients of such care; aged, unwell, and many of them from disadvantaged areas. Their contributions suggest that some of the silent voices may be dissenting, and out of line with government or academic proposals.

The costs associated with accessing services, or living with an illness, are far smaller than residential, long-term care costs, but they were particularly significant for older people living on low incomes. Taxi fares to hospital, paying for pet care during hospital admission or telephone calls from hospital, for example, were all common expenditures amongst our participants. Family carers were filling gaps in the support provided by the statutory agencies, as has been reported previously.²² In many cases, they were acting to minimize the extra costs for the older adults. These transactions are largely unseen, but as the proportion of older adults with family carers falls, the consequences for care provision and funding are expected to be significant.²³

Implications

The views of our participants are at odds with the direction of welfare reform in many European countries, where the balance continues to shift from public to private provision. Few of our interviewees are likely to have considered the financial, political and practical arguments that are raised against universal coverage, but the values they expressed – mutual support, care for the most vulnerable and the importance of working to contribute to society – could and should inform the debate. In the search for a financially sustainable solution to care for older adults, it is crucial that social sustainability is also a consideration.¹¹ Any reforms must be palatable to a generation who has cared for their elders, as well as the older adults whose working lives were spent in the expectation of cradle to grave care from the state. At a time when financial stringencies may prompt interest in safety-net welfare provision, our

participants affirmed support for the principle of institutional welfare, provided on a universal basis. Such strong support for tax payer-funded social care grounded in values of mutuality and earned entitlement through long working lives is striking. In Scotland, it has been estimated that free personal care has added around ten per cent to the total expenditure on older people's services, equivalent to approximately 0.2% of Gross Domestic Product.²⁴ We do not know if this level of costs would be acceptable in other countries of the UK. Our findings suggest policymakers should inform the debate with accurate estimates of costs for the widest range of options, and not rule out those expected to be unpalatable to the electorate.

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