

Research on the Costs of Long-Term Care for Older People – Current and Emerging Issues

Alison Bowes

Department of Applied Social Science, University of Stirling
E-mail: a.m.bowes@stir.ac.uk

This review explores debates concerning the costs of long-term care for older people, and aims to give an overview of the recent and current research agenda in this area, referring primarily to work published 2000–2006. The focus of much work is on the identification of costs, their distribution and the contexts of policy and delivery of services in which these operate. Live debates concern future costs, their control and related issues of social justice and equity.

A particular focus of recent work has been potential international lessons. For example, Harrington *et al.* (2002) and Schunk and Estes (2001) consider the transferability of the German long-term care financing model to the USA and a number of cross national surveys have been published (e.g. OECD, 2005). There are of course significant issues attached to comparability of research findings and the potential transferability of policies between different welfare and fiscal regimes. The most fruitful comparisons to date have involved countries more similar in terms of economic development, and this review focuses on OECD countries. In low-income, less developed economies, issues are significantly different (HelpAge International, 2002).

Predicting future costs

Uncertainties in predicting the future costs of long-term care have been a recurrent theme. OECD (2005: 31) describes prediction as an ‘art’, whilst indicating that recent work is increasingly identifying key drivers of changing costs. For example, Comas-Herrera *et al.*’s (2006) projections for Germany, Italy, Spain and the UK suggest that costs may double between 2000 and 2050, but they caution that the figures are sensitive to a number of key factors, including numbers of older people, levels of disability, the availability of informal care, the real costs of services and models of care in operation. Furthermore, they emphasise that calculating the full costs of care is a complex matter. Their study built on earlier work in England (Pickard *et al.*, 2000; Wittenberg *et al.*, 2001) which concluded that the sensitivity of future long-term care expenditure projections to a wide range of factors meant that policy makers needed to ‘plan for uncertainty’ (Wittenberg *et al.* 2001: 15). In addition, it is important to note that researchers have varied in their consideration of total costs as compared with costs to the public purse. Most frequently, the concern is with the latter.

Jagger *et al.* (2006) in background research conducted for the Wanless (2006) review of social care in the UK note a key issue in cost prediction, that of assumptions about

whether current conditions will persist. In the UK, between 1981 and 2001, the gap between life expectancy and healthy life expectancy increased, with greater likelihood of more years of life in poor health (Office for National Statistics, 2004). Jagger *et al.* (2006) predict that without changes in disease prevalence or in the consequences of diseases for disability, the population ageing will result in significant increases in needs for long-term care. If disease rates can be reduced and the impact of disease on rates of disability lessened, needs for long-term care may be moderated. Karlsson *et al.* (2006) also note that future costs are sensitive to factors such as improvements in health and changing patterns of informal care-giving. In the UK, a major new project under the ESRC's Dynamics of Ageing programme 'Modelling needs and resources of Older People to 2030' at the LSE,¹ the LSHTM,² the Universities of Leicester and Essex and the Pensions Policy Institute, will develop modelling capable of incorporating a wider range of factors including services costs and informal care as well as incomes and savings, to 2030. The project will be completed in December 2009 but interim outputs are planned.

Others however see clearer current potential for predicting the future, and in doing so claim ability to respond to the immediate needs of service providers for information to inform planning. For example, Pelletier *et al.* (2005) develop a model which they argue is usable by local authorities to predict future demand, though emphasise that it is realistic only in the short term. Schulz *et al.* (2004) are more confident about their predictions that population ageing will produce demand for hospital care to the extent of necessitating major reorganisations of hospital services.

Difficulties in costing services support a more cautious view. Predictive models clearly need robust costing of services, but there is evidence that governments have difficulties identifying the costs of long-term care, as for example in the case of the Scottish Executive (Bell *et al.*, 2006). The PSSRU annual publication on the costs of care (Curtis and Netten, 2006) draws on a wide range of literature, and continues to identify difficulties with costing particular services.

Detailed work on costing reveals the extent of some of these difficulties. Dubuc *et al.*'s (2006) Canadian study exploring in detail the development of a disability-based classification for use in planning long-term care services managed to account for 80 per cent of the variance in costs of nursing care but only 57 per cent of that in total care. A significant literature explores how various particular services might be costed, and many examples demonstrate the complexity of this process. For example, Shih *et al.*'s (2003) study of the costs of incontinence care in long-term facilities identifies interactions with other conditions, client mobility, staffing variations linked with the time of day, as well as different types of incontinence which complicate the costing process.

In the past, assumptions about the ageing population tended to adopt a 'downhill all the way' (Wilson, 1991) perspective, assuming links between ageing and increasing disease and disability. However, reconceptualisation of relationships between older age and needs for long-term care has recently occurred. Some have argued (e.g. Crimmins, 2004; Rice and Fineman 2004 for the USA) that the older population is actually much healthier than it has previously been, and needs for care are increasingly concentrated at the end of life. This undermines the case that longevity per se is the best predictor of care needs. Instead, proximity to death is increasingly a focus of research, following the work of Zweifel *et al.* (1999, 2004), Breyer and Felder (2006) and the so-called 'red herring' debate³, which continues. For example, Polder *et al.*'s (2002) Dutch study finds close relationships between age and care needs, whereas Stoker *et al.* (2001) in the

same country find that the last year of life, whenever it occurs, is more significant for understanding costs. However, they identify that these end of life costs are at a lower level than given in many other studies, since they focus on both 'cure' and 'care' costs and on actual final months of people's lives rather than deaths within particular calendar years. McGrail *et al.* (2000) found that whilst the costs of care did rise with age among all decedents in British Columbia during 1987–88 and 1994–95, proximity to death was a more significant predictor of costs, at least in acute care ('cure' costs) and O'Neill *et al.*'s (2000) UK study also supports this. Yang *et al.* (2003) find that for USA data, 'time to death' is of greatest significance in increasing health care costs, and that by paying attention to this it becomes clear that with compression of morbidity in older age actually the costs of long-term care are not as problematic as some projections suggest. Stooker *et al.*'s (2001) more conservative calculations of costs also support this argument.

Seshamani and Gray (2004) are critical of the original work (Zweifel *et al.*, 1999), and on re-applying the analysis to data from Oxfordshire, England, find that in fact age and proximity to death are both influential on the amount of care needed and therefore the costs of care. Salas and Raftery (2001) identify technical flaws in the original analysis. Zweifel *et al.* (2004) revisit their original analysis, and whilst acknowledging the criticisms, argue that 'time to death' now has to be included in calculations of long-term care costs (echoing Stearns and Norton, 2004).

Specific costs attached to certain conditions have also received research attention. Yu *et al.* (2004) consider the significance of chronic conditions in contributing to the costs of care – in their view, these are much more significant than age per se. Two particular concerns are dementia and falls. Researchers have explored the 'costs' of dementia in terms of both formal and informal care-giving. For example Bonin-Guillaume *et al.* (2005) identified dementia as 'the most costly disease' for France, the Netherlands, Sweden and the USA. Their arguments are echoed by De Kosky and Orgogozo (2001) who write of Alzheimers Disease at 'epidemic proportions' by 2020 in the USA and Fox *et al.* (2001) who identify a tripling of costs of caring for people with dementia in California between 2000 and 2040. Scuffham *et al.* (2003) identify considerable health care costs attached to unintentional falls among older people in the UK, with over 40 per cent of the total being consequential long-term care costs. Seematter-Bagnoud *et al.* (2006) in Switzerland found that older people who were uninjured in a fall still had increased likelihood of admission to long-term care within six months, compared with people who had not fallen. Curry (2006) finds evidence that falls prevention can produce costs savings, noting that this is one of few areas in which the cost effectiveness of preventive social care is supported by research findings.

Models of care

One way of controlling the costs of long-term care is to consider the models of care provided and their organisation. Research considering the cost impact of changing models of care has identified a number of features that appear to produce improved cost control and more efficient and effective use of resources. In particular, changes from institutional care towards more home- and community-based models have been explored. Despite early evidence to the contrary (Weissert *et al.* 1988), more recently there is increasing evidence of the cost effectiveness of care at home. In Canada, for example, Chappell *et al.* (2004) compared the costs of care at home and in the community (for a sample

of 222 clients) with costs of care in institutional settings (sample of 198 clients). Their study found that care at home was significantly less costly, even where the contribution of informal care was included at a cost equivalent to minimum wage. Schwab *et al.* (2003) found that care at home was more cost effective than institutional care, studying the service use patterns of 8,229 members of an American Social Health Maintenance Organization (SMHO) who fitted criteria suggesting eligibility for nursing home care. Even Weissert *et al.*'s (1997) more recent work in Arizona has suggested that home care can be more cost effective than institutional care under certain conditions. In modelling the future costs of the Scottish system of free personal care for older people in Scotland, Bell *et al.* (2006) found that care at home tended to moderate costs to the public purse as compared with institutional care.

However, there remains contrary evidence. For example, in Taiwan, Chiu *et al.* (2000) found that care at home was cost effective for people with 'medium' physical disability, but became expensive for people with higher levels of disability when compared with nursing home care. Such findings raise issues *inter alia* about the relationships between need and care received, which are not direct. – e.g. Grando *et al.* (2005) identify a significant proportion of older people in nursing homes (in Missouri) who, they suggest, do not really need the high levels of care that these homes provide, and who could be cared for more economically in community settings. Grabowski's (2006) review of American research evaluating a number of non-institutional care models identifies that, whilst evidence is somewhat limited, home and community-based care appears to be more expensive. Phillips *et al.* (2005) furthermore found that assisted living in the USA had no significant impact on Medicare service use in comparison with community-based, non-assisted living.

Other complicating factors for Italy and other parts of Southern Europe are identified in Bettio *et al.*'s (2006) discussion of changes from a model of care based primarily on the family towards new models which increasingly involve formal caregivers, many of whom are migrant workers. They note that many families are now using a 'foreign minder solution' (2006: 282), employing cheap migrant workers from Eastern Europe to supplement a continuing home-based family care model. Whilst this is economical in the short term and popular with families because it is cheap, Bettio *et al.* (2006) argue that it is inhibiting the development of effective, publicly regulated services.

Across the OECD countries, supplying allowances for older people to buy their own care has been seen by some as promoting choice and independence, as well as having the potential to control costs (OECD, 2005). Ungerson and Yeandle (2006) refer to this as the 'commodification of care'. Dale and Brown's (2006) study in Arkansas examined the impact of giving clients financial allowances to cover the costs of buying their own care compared with the direct provision of care by an agency, and demonstrated that this could produce significant savings. However, there remained concerns about the quality of the care provided. In the Netherlands, researchers (e.g. Kremer, 2006) have cautioned that for many older people, identifying and purchasing appropriate care may be difficult, and echo the concerns about quality. In the UK, take up of 'Direct Payments' by older people has been limited (Riddell *et al.*, 2005), and this has been linked in debate with the possible difficulties of organising one's own care package.

Improved links between services may produce cost efficiencies. The health and social care divide is frequently cited as problematic in terms of producing optimal expenditure on care and support for older people (Lewis, 2001, OECD, 2005) in relation both to

division of budgets and also in relation to the organisation of services. Johri *et al.*'s (2003) survey of integrated or whole systems approaches to long-term and acute services across the OECD countries concluded that community-based care of this kind could control costs and reduce the demand for institutional care. They identify key features of successful systems including (pp. 231–232) case management, effective assessment processes, multidisciplinary teams, a single entry point to the care system and financial arrangements that encourage community-based solutions. They emphasise that effective integrated care involves reviewing the whole system of care rather than making small adjustments, which will not produce the full benefits. Similarly Kodner (2002: 389) identifies central features of effective integrated care, including effective organisational coordination, case management in multidisciplinary teams, effective networks among providers and financial incentives promoting 'downward substitution' (i.e. providing the necessary level of care, rather than a more complex service due to lack of availability of lower level services).

Some case-study evidence suggests that integrated care systems can assist in controlling costs. For example, in Canada, Beland *et al.*'s (2006a, 2006b) RCT found that clients receiving an integrated, multidisciplinary service were less likely to be admitted to acute hospitals and once there, less likely to become 'bed blockers', that is, to be trapped in acute hospitals waiting for places in nursing home care. In the USA, Lynch *et al.* (2005) discuss case studies of several innovations in addressing chronic health conditions that have the apparent potential to reduce costs, as well as providing better care for older people. They identify a tension between medical approaches, which they characterise as 'disease management', and services provided at home which tend to focus on function, or on supporting ability, and suggest that incentives are needed to promote service integration for such innovations to be successful.

Quality issues and their potential impact on costs have been discussed, especially in relation the issue of whether better quality implies higher costs. However Rantz *et al.*'s (2004) study of 92 Missouri care homes found that higher costs were not correlated with better quality, and some indications that better quality related to lower costs. The key reason for this was that the achievement of high quality care was linked with factors such as effective management of the care home, a general focus on quality and careful work with the staff team to maximise the quality of care. Mukamel and Spector (2000) did not find a linear relationship between quality and costs, rather that in private and public nursing homes in New York State there existed examples where higher quality was associated with lower costs. Bowes, McColgan and Bell (2006) and Bell, Bowes and Dawson (2007) reviewed expenditure on care for older people across 32 Scottish local authorities and found that one of the highest quality providers (West Lothian Council) was actually delivering care at one of the lowest costs. Wiener (2003) argues that actually, there is little clear research evidence which can guide attempts to improve quality of services – in this case in nursing homes. Whilst improved pay for staff might merit additional investment, he argues, the cases for other potentially costly initiatives remain weak.

Changes or potential changes in the role of informal care continue to be debated. Karlsson *et al.* (2006) predict significantly increased demand for informal care in the UK from 2.2 m recipients today to 3.0 m in 2050. This calculation depends on existing forms of care provision continuing and takes account neither of changes in care-giving patterns nor in the activities/availability of informal carers. Changes in informal care are linked significantly with issues of female employment, as Pickard *et al.*'s (this volume)

conclusions make clear. The Chappell *et al.* (2004) Canadian study included a price for informal care work equivalent to a wage, albeit a low one. In Southern Europe, Bettio *et al.*'s (2006) study showed how the availability of cheap female migrant labour could support a family-based care system as female family members were increasingly involved in the labour market – though this was only a temporary solution to a potentially increasing shortage of family caregivers. Speiss and Schneider's (2003) analysis of data from the European Community Household Panel Survey looks at the impact of care-giving on women's hours of employment, and finds in general that care-giving reduces women's capacity to engage in the workforce, more so in Southern than in Northern Europe. As policy developments throughout Europe increasingly promote care at home and thus increasing family involvement in providing care, the potentially negative economic impact of women's non-participation in the labour force will, they suggest, increase. However, Heitmueller and Michaud (2006), using data from the British Household Panel survey, argue that increased employment rates for women do not necessarily impact negatively on informal care.

Improved support for caregivers, in a context in which informal care is increasingly important, may prove important in controlling public costs. For example Gaugler *et al.* (2003) found that the costs of dementia care could be reduced by providing adult day care for people with dementia, as it reduced family caregiver stress and enabled informal care to continue, reducing calls on formal care services. In this example, the emphasis was on reducing costs to the public purse, rather than considering the global costs of care – so, for example, the opportunity costs of informal care were not included. There is evidence of the negative health impacts of caring for informal carers (Hirst, 2005), who may seek additional health care. Furthermore, informal care may be a significant cost for the individuals and families concerned, affecting standards of living (Holzhausen, 2000) as well as pensions (Ginn and Arber, 2000; Evandrou and Glaser, 2003).

Preventative services may reduce calls on services and hence costs. Elkan *et al.*'s (2001) systematic review of the effectiveness of home-based health promotion interventions for older people identified marked benefits in terms of reduced mortality and reduced admissions to long-term care, though an earlier review (Van Haastregt *et al.*, 2000) was unable to identify positive effects. Taylor and Hoenig's (2006) longitudinal study demonstrated the importance of assistance with walking for people who experienced difficulties. Where people had adequate assistance which supported their mobility, they were significantly less likely to need Medicaid services as time went on. Taylor and Hoenig (2006) describe the potential impact of improved support for mobility on the Medicaid programme as 'large', producing a saving for each person of between \$163 and \$222 per month. Similarly Stewart's (2004) study of income and expenditure of older people in the USA finds (unsurprisingly) that nursing home care has the greatest impact on people's expenditures compared with other expenses in older age. She argues that prevention of health problems and the availability of lower level services could offset some of these potentially heavy personal costs.

Drennan *et al.* (2005) link prevention issues to the development of 'active ageing' policies found across Europe. The promotion of active ageing and the prevention of disability and disease are often seen as ways of reducing need for long-term care. Their case study of an outreach intervention in London however revealed significant delivery problems related to the organisation of the service and problems of effective working in a multidisciplinary team. They identified much enthusiasm for the initiative but little

evidence of its effectiveness. This study supports the arguments identified earlier about the need to review the whole system of care and support, rather than implementing merely incremental changes or experiments. In general, the issue of identifying causal links between preventative (and other) services and beneficial outcomes is inherently complex and requires detailed statistical analysis.

Policy processes

Whilst the organisation and delivery of care and support for older people are key to understanding costs, the policy processes which drive the system are arguably of greater significance. Comparative studies of policies on long-term care are numerous, covering various OECD countries (e.g. Ikegami and Campbell, 2002; OECD, 2005) and the USA (Miller, 2005) among others. Ikegami and Campbell (2002) focus particularly on controlling costs and promote a proactive approach, arguing that policy makers must face issues of efficiency and fairness as well as organisation and costs. Miller's (2005) review of policies across all the 50 states of the USA tries to explain the variation between them. His work identifies some central difficulties of comparison in that studies tend to focus on different variables and to vary methodologically. Nevertheless, he identifies key variables predicting policy variation, amongst the most significant of which is liberal political opinion.

Recent policy debates have frequently focused on costs, alongside recognising the potential pressures of demographic change. In the USA, Weiner *et al.* (2001) discuss the reasons for the ultimate failure of the Clinton administration's attempt to reform long-term care, and see costs as a significant element in this. In England, the recommendation of the 1999 Royal Commission on Long-term Care that personal care should be provided without charge was rejected on cost grounds. In Germany and Japan, systems of long-term care have been adjusted on grounds of increasing costs (Glendinning, Ikegami, this volume). Whilst Scotland took the step of adopting a policy on free personal care, understanding of the costs of this is only now emerging (Bell, Bowes and Dawson, 2007). In all these cases, there is persisting nervousness about costs and the difficulties of predicting them.

Policy decisions about long-term care provision involve questions about public, private and voluntary sector involvement, as well as the extent of informal care. There is increasing interest in the role of the private sector and the impact of markets on costs. For example, Holden (2005) discusses the impact of large, international private sector providers, with particular reference to the twin imperatives to drive down costs, but yet improve quality. Using a business studies approach, he suggests that these may promote standardisation and restrict choice. Government policy and market forces may interact in complex ways. For example, Netten *et al.* (2005) demonstrate that the proposed introduction of higher quality standards in England at a time when homes were already under pressure was significant in causing closures of care homes.

Policy decisions about where the costs of long-term care fall vary significantly. Ikegami and Campbell (2002) identify tax-based and social insurance models as the two main types, with the latter having a more direct impact on the individual. Private insurance models have also been considered (Johnstone, 2005), but the market has largely failed, and appears unlikely to provide a satisfactory means of funding long-term care.

In general, commentators have identified increasing emphasis on individual responsibility for paying for long-term care, including those countries which have

previously had generous public funding regimes (Lundsgard, 2006). The OECD (2005) survey found that many countries are moving towards a cost-sharing or partnership funding (Wanless, 2006) model, with limits on state responsibility. This trend promotes debates about fairness, and researchers have started to explore the outcomes in terms of equity of a range of options. Notable here is the recent work of Hancock *et al.* (2006 and this volume).

Deeming and Keen's (2002) survey of 100 older people in England revealed that many were unlikely to be able to pay for long-term care and that, furthermore, many did not realise that they would be called upon to do so. People seemed ill-prepared for a future in which they might need care and be asked to pay for it themselves and there was evidence that they did not understand how long-term care was financed. Wright (2000) identifies some evidence of anger among children who see what they regard as their inheritance being reduced by the costs of long-term care of a parent. Thus at an individual level, a need for long-term care may produce significant unwelcome financial impacts. This contrasts somewhat with governmental concern with controlling calls on the public purse.

Wider social issues – ageism and inequality

Wilson (1991) argued that policy was influenced by the 'assumptive worlds of ageing', that is the value and status attached to older people in society. In general, she argued, in developed countries the status of older people is low and their value seen as limited. Thus services for older people tend to be of lower quality and to be relatively under-resourced. Such a perspective is supported by commentators such as Dalley (1999) and Estes *et al.* (2003) who argue that, since older people are not in the labour market, they are not considered a valued sector of society. It remains the case that in relation to spending on other groups, spending on older people is relatively modest in most countries, especially on social care. The potential costs of long-term care which might be needed by a minority of us as we age have produced what is in some respects a moral panic.

Some researchers have challenged the construction of older people as a problematic group in society when discussing matters of cost. For example, Kildemoes *et al.* (2006) explore the impact on public health care costs of older people's use of prescription drugs in Denmark. They conclude that the issue is not older people's drug use, but more general prescribing practices, and that these could be more cost effective. Their argument is supported by O'Neill *et al.* (2003) who argue for a broader perspective on older people's use of medicines, for example ensuring that older people are included in clinical trials to ensure that prescribing is properly evidence based. Supporting this type of perspective, Knickman and Snell (2002) argue that delivering long-term care for the baby-boomer generation will require a culture change whereby people of all ages are considered active participants in society, and older people are no longer regarded as burdensome.

It is well known that inequalities of earlier life persist into older age, and that disadvantage has adverse health impacts. Matthews *et al.* (2006) demonstrate that socio-economic advantage improves disability-free life expectancy. Systems of provision of long-term care can exacerbate social inequalities. Hellander (2005) identifies increasing social inequality in regard to access to long-term care in USA. A contrasting study by Wright (2003) in England suggested that some care home residents with independent means to pay ('self-funders') were being encouraged by local authorities to admit themselves to

care homes without an assessment of need. Thus, many self-funding care home residents were paying for services they probably did not need. In Scotland, middle income clients were key beneficiaries of the policy of free personal care (Bell and Bowes, 2006).

Some researchers (e.g. Clarke, 2006) have argued that the increasing focus on 'consumerist' models of service delivery may exacerbate social inequalities, as those with more social capital will have better access to services. Furthermore, the impact of such models on the labour market remains to be analysed, as potentially unregulated care workers employed directly by clients may increase in numbers (Kremer, 2006).

Debates about fairness and the distribution of costs are set to continue.

Conclusion

The review has highlighted some key recent concerns, all of which invite further research. First, there is a continuing need to refine and develop improved ways of predicting the costs of care and support for older people who need it, in the context of ageing populations. Second, there are continuing difficulties in the detailed costing of services. Third, better understanding of the relationships between ageing, disability (including specific conditions) and care needs is needed. Fourth, there is further work to be done in understanding the cost implications of different models of care, including 'whole systems' approaches and personal budgets, which are becoming increasingly significant. Fifth, the role of informal care continues to be important, but is changing. A particularly important question here is that of the financial impacts of informal caring for individuals. Sixth, there is a paucity of evidence on the possible impact of preventive services. Seventh, issues of the costs of long-term care are embedded in current policy debates, with particular questions concerning the balance of individual and state responsibilities. And finally, researchers need to contextualise their work within wider analyses of ageism and inequalities.

Notes

- 1 London School of Economics.
- 2 London School of Hygiene and Tropical Medicine.
- 3 The 'red herring' is the notion that increased age and increased costs are positively correlated.

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