The care of older people in the United Kingdom: problems, provision and policy.

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'Problems': Growth of the older population

Within fifteen years a quarter or more of the population in many European countries will be aged 65 and over and by 2050 it is highly probable that those aged 80 and over will constitute at least one in ten of the population in all the largest European countries, including Britain, France, Germany, Italy, and Spain. In the UK the first demographic transition involving a shift from relatively high to low fertility was set in motion towards the end of the 19th century resulting in population ageing in the first half of the twentieth century. In England and Wales the proportion of the population aged 65 and over doubled from 5% to 10% between 1901 and 1941. However, it is now improvements in mortality that are driving accelerated population ageing. In developed countries most deaths occur at older ages and reductions in the overall level of mortality are being achieved through improved survival beyond the age of 65. These improvements have been considerable. In England and Wales male life expectancy at age 65 increased by less than two years between 1901 and 1971 (from 10.1 to 11.9 years) but then by over four years between 1971 and 2001 (to 16). For women, gains were more evenly spread over the century with an increase of nearly six years between 1901 and 1971 (from 11.1 to 15.8) and a further gain of just over three years (to 19.1) over the next three decades.[1]

Economic implications and health care costs

The assumption of policy makers is that population ageing will pose challenges to economic, social and perhaps political structures and will mean that younger people will need to make larger contributions of various kinds to provide for the old. Most people aged 65 and over do not have disabling health problems and make important contributions to their families and communities but current patterns of economic activity and strong associations between age, morbidity, disability and use of health services have all raised concerns about the economic implications of population ageing.

In OECD countries health care expenditure is typically three to five times as high for those aged 65 and over as for those aged under 65 and more detailed information available for some countries shows a continuing rise in costs with increasing age.However there is considerable variation in the proportion of GDP devoted to health care spending for older people which bears little obvious relationship to the proportion of older people in the population concerned. Expenditure relative to GDP is much higher in the USA than in European countries, for example, even though the USA has a younger population. Moreover health economists have identified the growing costs of new technological innovations in medicine as a far greater influence than population ageing on past growth in health care expenditures. [2]

Long-term care

Needs for, and expenditure on, *long term* care of various kinds is, however, very clearly associated with demographic changes as in later old age rates of disability and needs for assistance are high. A quarter of women aged 85 and over in Britain are unable to bathe or shower without assistance and half are unable to manage one or more locomotion activities

without help.[1] Even projections which assume falling rates of disability suggest large increases in the number of older people with limitations in Activities of Daily Living (ADLs) –tasks such as bathing, dressing and transferring to and from bed–as a result of growth in the size of the age groups in which the prevalence of disability is greatest and concomitant large increases in costs.[3]

Changes in family and co-residence patterns

Most of the help needed by older people with disabilities is provided by family members (including elderly family members such as spouses) even in countries such as the UK with relatively well established health and social care systems. However, changes in patterns of family related behaviour and in living arrangements have raised concerns among many policy makers that the availability of family support for older people in need of assistance may diminish while the numbers needing such assistance increases. The marriage and baby boom period of the later 1950s and 1960s, during which ages of marriage were lower and family sizes were higher, was followed by a downturn in fertility during the 1970s and by a number of other changes which some analysts have argued are so important that they constitute a 'Second Demographic Transition'.[4] These changes have included a trend towards later ages at marriage, increased non-marital cohabitation and non-marital childbearing, increases in divorce and substantial changes in living arrangements, including the living arrangements of older people. Living alone or just with a spouse has become increasingly prevalent and living with relatives increasingly unusual for older people in the UK, most of Europe, and North America [5]. In England and Wales in 2001, for example, 55% of women aged 85 and over lived alone, 9% lived with a spouse and only 15% lived with other relatives – considerably fewer than the 23% living in some kind of institutional care. This represents a considerable change from just 30 years earlier when the proportion of very old women living with relatives was twice as high as the proportion living in institutional care. Men have the advantage of being far more likely to be married, even in later old age, and the proportions in this age group living alone or in an institution were much lower – 32% and 13% respectively in 2001 - but the former is still high in a historical context.

Possible explanations for these changes in the living arrangements of older people encompass positive developments including higher incomes, better health, and improvements in housing, assistive technology, transport and communications. Such changes may have enabled older people to meet preferences for residential independence and made it easier to provide extra-household help to those who cannot manage unaided. [6-7]. Other interpretations have emphasised constraints, including possible declines in family support. [8] The proportion of older people with a spouse or child alive has increased in recent decades in England and Wales and other European countries because of historic changes in family formation patterns and mortality declines leading to later ages at widowhood. [9-11] However, the ability or willingness of younger generations to provide care, including co-resident care, for disabled older relatives (and older people's care preferences), may have fallen as a result of social changes including increases in the proportions of women working full time and greater individualism. [8,12-13] Policy changes discussed below led to an increase in the use of institutional care during the 1990s. In the short term future, some slowing down in the rate of increase in older people living alone is anticipated for demographic reasons (increases in the proportions of older people who are married reflecting the ageing of the 'marriage boom' cohorts and later widowhood). However, the overall tendency towards more fluid partnership arrangements, changing preferences (considered below) and the ageing of the older population all suggest that the proportion of older people living alone will increase in the

longer term. Family contacts and family care nevertheless remain the bedrock of support for older people, as discussed below.

Provision: Family care

Although co-residence has declined, regular contact and reciprocal exchanges of help with domestic tasks are a normal feature of intergenerational family life in the UK and similar populations, although there are certain sub-groups, such as those without children and divorced men with poor relationships with their children, for whom access to such support is more limited. Numerous surveys demonstrate that much of the care needed by elderly people with disabilities is provided by close relatives, particularly spouses and daughters [14]. Elderly people with heavier support needs usually have a primary carer and this carer is in the majority of cases a family member. Many 'child' carers of elderly people are themselves elderly and this is likely to become even usual if mortality continues to fall. Analysis of the British Retirement Survey showed that in 1994 showed that 9% of married and 18% of unmarried women with a parent still alive were providing co-resident care for a parent, with a further 33% and 31% respectively providing extra- resident care. The 2001 UK Census, which included a question on caregiving, showed that the average age of caregivers providing more than 20 hours per week of care was 54. The proportions providing this level of care were higher among women than men, higher among those with low levels of education, higher among those who themselves had poor health and higher in areas of socio-economic deprivation.[15] Heavy caregiving is thus associated with disadvantage, possibly reflecting both consequences of providing large amounts of care and intra-family associations in health status. Results from the most recent round of the English Longitudinal Study of Ageing [16] showed that a much higher proportion of older people with a limitation in one or more Activities of Daily Living (ADLs) received help from a spouse or child than received formal care, either privately paid for or provided through state services. It is also important to note that 54% of those with paid-for help also received informal help, as did 69% of those receiving state help, suggesting complementary rather than competing provision. This study showed that having a partner and having a child reduced the chances of receiving formal help at home. Other research has shown that non-married and childless women also have higher risks of entry to institutional care. [17]

Provision: Formal Care

Health and social care for older people in the UK: organisational overview

In the UK, health services are provided by the National Health Service (NHS) free at the point of delivery (except for co-payments on medications, eye and dental care from which older people are exempt). The NHS provides primary care (family doctors); acute care in hospitals; intermediate care (a recent priority – designed to prepare people for return from acute hospital care to their own home) ; public health and preventative care (such as screening services), and some long-term care, considered below. The NHS is directly funded by Central Government from general taxation. Other services for older people are mostly the responsibility of local authorities (municipalities). These provide some housing services, including 'sheltered' housing – small flats in grouped developments with a resident warden-; specific housing for older people without warden services; community warden schemes; and various long-term care services described below. To an increasing extent local authorities do not directly provide services but enter into contractual arrangements with voluntary (non profit) and private (for profit) organisations. Local authorities receive most of their income from Central Government but also levy local taxes, subject to central government controls. Apart from these services, older (and younger) people with disabilities are eligible for

additional income supplements (from Central Government) which are not means tested. Younger people who give up work to provide care for a disabled relative are also eligible for some income support and most large employers have schemes which allow people with caregiving responsibilities to adjust their working hours and take some paid carer leave.

Long-term care policy and provision in England and Wales [1]

Long-term care provision for older people in England and Wales still bears the hallmark of the post World War II legislation which established the modern British welfare state. This included a requirement for local authorities to provide residential care for older people and an empowerment to financially support residents in homes provided in the private (for profit) and voluntary (not-for-profit) sectors. Long-term hospital care became the responsibility of the NHS and was free of charge, although local authority provision was from its inception means tested. Subsequent legislation incrementally extended and changed the relative responsibilities of the NHS and local authorities for providing other long-term care services, such as home help, meals, and day care. [18, 19]

The past four decades have seen significant changes in both organisation and availability of long-term care services. After a period of expansion in the immediate post war decades, in the later 1970s and 1980s financial constraints meant that the provision of local authority paid-for residential and domiciliary long-term care services failed to keep pace with increases in the size of the older old population. [20, 21] Long- term hospital provision reduced substantially from the 1980s (associated with reductions in lengths of stay) with further large reductions more recently. [22, 23]Administrative changes in regulations on payment of supplements to those on low incomes introduced in 1980 made 'board and lodging' payments available to low income older people entering private and voluntary residential or nursing homes resulting in a huge expansion in provision; (Central) Government expenditure on these supplements increased ten-fold during the 1980s. [24] It should be noted that the administrative changes introduced in this period were not *designed* to increase access to residential long-term care but were motivated by a wish to increase the role of the private sector – a timely warning of the need to fully consider unintended consequences of policy changes. This increased provision was associated with changes in the balance between institutional care and co-residence with relatives. [25] Subsequently, attempts to rein back escalating costs and re-emphasise community care led to the introduction of the NHS and Community Care Act in 1990 (fully implemented in 1993). This returned to local authorities responsibility for arranging and funding (on a means tested basis) long-term care in residential and nursing homes. This legislation introduced a requirement for an assessment of older people moving into residential or nursing home care (apart from self-funders) and the targeting of home care resources on those most at risk of such a move. These policies appear to have had some effect in that admission rates levelled off during the 1990s [23, 24] and home care services have become focussed on a smaller proportion of older people who receive larger amounts of support. [13] Results of analyses of moves between household types across three decades have shown that in 1991-2001 rates of transition to institutional care were slightly lower than in the previous decade and also that subsequent mortality of those moving to care homes was higher – implying that the requirement for medical assessment led to greater selection of those with the greatest health challenges.[25] This research also demonstrated that the mortality of older people living with relatives was lower than that of those in institutions indicating that the health status of older people living with

[1] There are a number of differences in long-term care policies in the constituent countries of the UK (England & Wales, Scotland, Northern Ireland). Most of this paper relates to E&W which accounts for about 85% of the UK population.

relatives and those in institutions is not equivalent. An overall downward trend in moving to live with relatives was also found. These results illustrate how policy changes may influence, as well as reflect, trends in living arrangements and use of various types of care.

Organisational, staffing and funding issues

In the NHS most staff are still directly employed (although family doctors are independent contractors). To an increasing extent, local authority services, however, have been 'contracted out' with the actual care being provided by someone working for a private company or NGO. A relatively recent innovation, is for 'direct payments' to people assessed as in need of a service who then use the money to arrange their own care (similar to the situation in Germany). Other forms of personalisation of services are also being encouraged, for example service users may be able to choose which services they want from a care package up to a maximum cost. The social care workforce is predominantly female (85%) and includes a large proportion of part-time staff aged 50 and over. Wages are low (slightly higher than for cleaners). About a fifth of care workers and a third of nurses providing care for older people are immigrants (born outside the UK) and this proportion is even higher among recent recruits to the sector and in large cities. Migrant care workers tend to be younger than UK born workers in the sector. [26] Poor levels of pay and training among care staff have been cited in numerous scandals about poor standards of care in residential and nursing homes.

The division of responsibilities between the NHS and local authorities, which has existed in most parts of the UK (not Northern Ireland) since 1974 has meant that at a local level there may be disputes about which organisation is responsible for what and in particular what counts as 'nursing' and what as 'social' care. The fact that NHS care is free at the point of delivery and most local authority services are means tested, has also led to an intense public debate about the funding of institutional long-term care, particularly as (free) long-term hospital bed provision has been very largely replaced by provision in nursing and residential care homes which is means tested on the basis of wealth (including housing wealth) as well as income. Currently anyone with wealth above a level similar to median population income is not entitled to local authority support and many older people entering residential care have to sell their houses. Those with lower incomes/wealth are paid for by local authorities, but the payments made to nursing and residential homes are often below the level of real costs. Proprietors of nursing and residential homes deal with this by charging higher rates to self funders, a form of cross subsidy.

The funding of long term care has become a major political issue. A Royal Commission for Long term Care was established in the 1990s and issued a report in 1999 in which the majority view was for free personal and nursing care. This recommendation was not implemented, except in Scotland. (Since 2002 the 'nursing' element of long term care in residential settings has been free of charge, but in England and Wales 'personal' care is means tested). There have been several subsequent governmental and non-governmental inquiries and the newly elected Government has now (2010) established a Commission on the Funding of Care and Support.

Conclusions, prospects and policy

Despite variations in level, type and financing of long-term care in Europe, some common threads, and a tendency towards some convergence in levels of provision, have been identified. [14] Thus 'generous' providers such as the Nordic countries and the Netherlands have been trying to reduce levels of provision, particularly of institutional care, while

countries such as Greece and Spain have recognised a need to expand services. The UK Royal Commission on long-term care noted that there was a consensus internationally that long-stay wards in general hospitals were not the most appropriate, or efficient, settings for long-term care. Secondly, in most countries provision of nursing home beds had expanded as an alternative to hospital based care while provision in old-people's homes had been curtailed. The latter are increasingly regarded as no longer necessary because of improvements in housing, advances in home based technologies (both specialist and general) and more targeted home care for people with a high level of disability. Similarly, home care functions have been changing. Thus in the UK traditional 'home helps' who at one time spent much of their time on domestic tasks which are no longer needed or are much less demanding (such as lighting fires, cleaning grates and washing clothes) have now evolved into home carers who spend their time on providing personal care. (Recent budgetary constraints mean that to an increasing extent older people will only receive home care if their needs are assessed as 'critical', although this may prove counter productive if it leads to more rapid deterioration in those not allocated assistance). A third important lesson is that deterioration in function in older people usually does not follow a gradual course but is precipitated by an acute episode of illness or injury or some similar event. As a result admissions to institutions are often from hospital, rather than from home. In some cases better rehabilitative services might enable older people to recover sufficient function to return home and it has been shown that assessment by specialist geriatric teams coupled with post discharge home intervention is associated with shorter hospitals stays, fewer readmissions and fewer nursing home placements. [27]. In the UK one recent response to this has been the establishment of 're-enablement' teams who provide (free of charge) intensive support for older people for six weeks after discharge from hospital. There is considerable scope for extending such methods of management and for providing more enabling interventions, such as physiotherapy and podiatry, rather than prosthetic interventions, such as home delivered meals (in this example, improving function might enable some disabled older people to do their own cooking) .[28[Better co-ordination between agencies and a greater emphasis on preventive services have also been advocated as a way of reducing emergency admissions to hospitals which have increased quite substantially in the UK. [29]

From a policy point of view a further crucial question is whether providing more formal support services 'crowds out' family care or, conversely, whether the provision of supports to family carers enables more to care for longer. As already noted, in England most of those receiving formal care also receive informal care and Penning and Keating [30] in a review of the literature, concluded that formal and informal caregivers worked in partnership without formal care displacing family help. Similarly the introduction of free personal care in Scotland seems to have led to families changing the type of support they provide, rather than withdrawing help. [31] Daatland and Lowenstein [32] in their analysis of variations in intergenerational help in a number of European countries also concluded that easier access to welfare services did not 'crowd out' family care but may contribute to changing how families relate and enable elderly people to maintain more independent relationships with their families.

Looking to the future

The large increase in the number of very old people in many developed societies will inevitably lead to greater requirements for assistance of various kinds. A collaborative group in the UK have been working on Modelling Needs and Resources of the older population to 2030 (MAP2030) taking account of probable changes in the size, structure and marital status distribution of the older population together with projections of disability, household composition and financial resources of older people. [33] Results suggest that even

maintaining current levels of provision (which many think inadequate), would require the proportion of GDP spent on long-term care to double by 2030. Policy makers thus face a challenging, and very important, task when making decisions about care systems for older people. Policies that promote healthy ageing and lead to better co-ordination of services are crucial for meeting these challenges [34].

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