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ENGAGING WITH CARE: A VISION FOR THE HEALTH AND CARE

WORKFORCE OF ENGLAND

Background paper 6:

The Informal Care Workforce

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Preamble

*This is one of 10 web published background papers¹ which provide detailed analysis and support for the Report: **Engaging With Care: A Vision For The Health And Care Workforce Of England**, which will be published in September of 2007. The report together with the set of background papers provides an analysis of current policies and trends and identifies routes for future action. The report identifies trends and challenges that can help define the common ground in health and care policy, while allowing for different policy directions at national and local levels. The intention is that all those involved in health, in their various roles as paid, informal or self carers, patients and clients, educators, service providers and citizens will be able to understand their roles and contributions and, together with the policy makers, feel empowered to influence health and care policy and practice.*

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¹ Available at: <http://www.jbs.cam.ac.uk/research/health/polifutures/restricted>

1. Introduction and Methodology:

This paper begins with a discussion of aims and the methodology used. Section two summarises the trends and issues raised in the preparatory literature search. Section three, the bulk of this paper, is an annotated bibliography of the literature reviewed. The paper concludes with a section detailing conclusions and recommendations that will inform the scenario planning exercise of the broader Health Policy Futures project.

The aim of the literature review was to identify:

- Who provides informal care, in what numbers, and with what intensity
- The future trends in supply and demand of informal care
- How informal care is experienced by those who provide and receive it
- The societal and individual costs of providing informal care
- Motivations to provide informal care despite these costs
- How policy may promote informal caring, and support those who provide it

Keyword searches were performed using Web of Knowledge, culling by title, then by abstract. Keywords used were 'informal care*', 'carer* AND UK' (and United Kingdom), and 'caregiver* AND UK' (and United Kingdom). Citations from selected articles were then mined, and the citations in those articles which met criteria were mined, and so on. 'Cited by' lists were used in this way even more. Articles were selected based on the relevance of their conclusions to thinking about the future and the ease with which policy implications could be drawn from them (or were drawn explicitly by the authors). Newer literature (post-2000) was strongly privileged over older work, in light of the major changes that have taken place in the organisation of formal health and social care, and the recent 'discovery' of carers.

Interest in this topic is shared by many scholars, practitioners and policy-makers. Among practitioners interest is strongest amongst those working with the disabled, the mentally ill, and the elderly, as well as those with terminal illnesses, like cancer. Much of this work appeared in nursing journals, as well as those of medical sociology. While literature from outside the UK has been included, UK-based literature has been strongly favoured. While the purpose of this has been to create as accurate a portrait of UK conditions and resources as possible, an inevitable consequence is that some important international literature has undoubtedly been missed.

One unexpected finding was that while the bulk of this literature focuses on the experience of caring – its hidden costs to health and well-being, what sorts of tasks are involved, how much or little governmental and practitioner support carers receive – relatively little has been written explaining why so many continue to provide care despite the hazards and costs of doing so. Because this question is significant to future trends and to how we may promote and support informal caring, the relevant research that does exist has been highlighted. Even less research exists on the cared-for person's experience of informal care, including a number of closely related questions, such the quality of this care, how to improve it, whether that quality changes over the length of the care relationship, and even how to protect those cared for from potential abuse by their carers. Future research in these areas seems critical to the larger set of policy questions centred around whether and how much carers should be regulated and their quality ensured through training, tests and audits (perhaps via technological advances that may soon be widely available).

Limitations of Study:

For time reasons (a limit of approximately 80 hours), the search focused primarily on academic articles, including both qualitative and quantitative studies. A handful of policy papers were also included. A good proportion of the articles included here were read, and most were skimmed, though those with detailed, straightforward abstracts (and no online viewing privileges) were often simply mined for references and summarised from the abstract. Where possible, earlier reviews of this literature were used to avoid replicating the work of others. Because this literature is so voluminous, and thus varies in quality, scope and ambition, there was insufficient time to appraise methods and data employed. Disagreement in the field has been highlighted, though with sensitivity to the proportional dominance of one side or another of the dispute.

2. Summary of the Literature on the Informal Care Workforce

The Office for National Statistics defines carers as those 'looking after, or providing some regular service for, a sick, disabled or elderly person' (Maher and Green 2002). Carers provide care to people both within their own household and in other households. While the list of activities included as care work is broad (including shopping, cleaning, and supervision, as well as more technically advanced medical tasks), care provided to someone who is also cared for in an institution or care provided to someone with a temporary illness both fall outside this definition, as does care provided for pay or care provided through a voluntary organisation (Maher and Green 2002). Care for healthy children is not considered care work, though care for children with chronic conditions is.

2.1 Trends:

- 70% of all social care in the UK is presently provided by informal carers (Hirsch 2006), and nearly everyone can expect to be a carer at some point in their lives (Hirst 2002). 1 in 20 people in Britain presently provide more than 20 hours of care a week (Maher and Green 2002).
- Demand for informal care will start to accelerate 10 years from now, peaking around 2040 at 30 to 50% above current levels (Karlsson, Mayhew et al. 2006). It is unclear whether formal care is an effective substitute for informal care, and vice versa.
- While over half of carers in 2000 looked after a parent (Maher and Green 2002), care for spouses will become increasingly significant (Pickard, Wittenberg et al. 2000), and in the future carers will be older, frailer, and likely deliver more complex care, just as care appears to have intensified over the 1990s (Hirst 2003). Carers are also disproportionately female, older, more ill, less educated, less likely to be employed, and probably less economically advantaged than the general population (Maher and Green 2002; Doran, Drever et al. 2003; Young, Grundy and Jitlal 2006).
- The supply of informal carers has risen very slightly, and men perform more care now than in the past (Maher and Green 2002). If supply is to meet demand in coming decades, however, rates of male caring will have to trend upward to meet women's present rates, rather than female rates dropping to male rates (Karlsson, Mayhew et al. 2006), which is by no means certain to happen.

- Many carers seem to juggle paid employment and care work simultaneously, and to derive from their paid employment some benefit or insulation from carer strain (Arksey 2002; Glaser, Evandrou et al. 2005). Half of those carers in paid employment, however, change their labour market participation, most commonly by leaving their job altogether. This is particularly true of routine and semi-routine manual workers (Henz 2004).
- While some actively choose to become someone's carer, most appear to 'drift' into the role. This social trend may have implications for the health consequences of care work on the carer.

Current polling data suggests that while today's elderly show a strong preference to receive informal care, the baby-boomer generation may prefer to receive formal care (Brooks et al. 2002).

2.2 Issues:

Who provides care to whom:

While the 2001 Census counted 5.9 million carers across the UK (Doran, Drever et al. 2003), the 2000 General Household Survey estimated there to be 6.8 million carers in Great Britain alone (Maher and Green 2002), showing some disagreement as to how many carers there may in fact be.² This number is even greater if the definition of who constitutes a carer is widened to include those who provide important emotional care to those living in care homes, an activity not normally included in the definition of informal care. Informal care is difficult to measure, which can have significant implications on our ability to predict future supply (van den Berg, Brouwer et al. 2006). Policies to encourage people to work longer risk reducing the pool of informal care, although many carers also work (Carers UK 2004).

While demand for informal care can be expected to remain high, the care one receives for free, even when motivated by duty or love, is not always better than that which is paid for, and the potential for poor quality, neglect, and abuse exists in such an unregulated sphere (McCann and Evans 2002; Newsom and Schulz 1998). Some individuals may simply prefer to pay for their care (Martin, Nancarrow et al. 2005).

The costs of informal care:

Those who provide more hours of care are at greater risk of receiving harm to their health and quality of life, as are women, spouses, and cohabiting carers (Maher and Green 2002; Borg and Hallberg 2006; Hirst 2003; Young, Grundy and Jitlal 2006), even long after they have concluded their care role (Hirst 2005). Indeed, for those with heavy care workloads the strain of caring appears to be strongest at the beginning of the care role and again at its conclusion (Hirst 2005). While there is largely a consensus around the possible negative consequences of being a carer, different aspects of the care role are argued to be the most significant in this relationship, such as a lack of social support (Goldstein, Atkins et al. 2006), long hours of care (Annerstedt, Elmstahl et al. 2000; Hirst 2005; Sherwood, Given et al. 2005), and the erratic or distressing behaviour of the patient (Cameron, Cheung et al. 2006; Croog, Burleson et al. 2006; Sorensen,

² Both numbers are quoted in the literature: Wanless 2006 favours the larger 2000 GHS figure, while the advocacy and support group Carers UK uses the smaller figure. Some of the discrepancy appears related to the self-reported nature of the data.

Duberstein et al. 2006; Venables, Clarkson et al. 2006). The experience of placing someone in a care home can also be a damaging one for carers, leaving the carer feeling guilt, loss, and a lack of control (Davies and Nolan 2003, 2004, 2006; Ryan and Scullion 2000).

Determining the costs of unpaid care to society and the economy is very difficult, and scholars attempt it in many different ways (Wanless 2006). The costs appear to be quite large if they include such things as lost productivity in the paid labour market, interruptions in carers' education or career advancement, the worse health of carers, as well as direct carer support, such as respite and counselling, and what the work done by carers would cost if performed by professional staff.

While the experience of caring appears largely similar between white and ethnic minority carers (Adamson and Donovan 2005), availability of resources (Koffman and Higginson 2003) and coping mechanisms (Milne and Chryssanthopoulou 2005) may be different in ways that should be studied further to find out how support should best be targeted at these groups.

How people come to care, and whether they may derive value from it:

Many carers do not view themselves as carers at all, but rather as performing a constituent part of their role of spouse, parent, or child (Goberman-Hill and Ebrahim 2006; Henderson 2001; Pickard, Shaw et al. 2000). One hypothesis for women's elevated vulnerability to the harmful effects of caring is that they may have even less choice than their male counterparts in the decision to become carers (Collins and Jones 1997), and thus may feel less control and more resentment.

On the other hand, many carers seem to derive emotional benefits from their care work, even as they simultaneously sacrifice their time and health. Many would not choose to give it up even if the opportunity came along to do so (Brouwer, van Excel et al. 2005), and many carers and families may value the experience of caring for a dying relative despite the work and strain involved (Wolf, Dy et al. 2007). The most important of these benefits of caring for UK carers appears to be the satisfaction of seeing the person who receives care be safe, comfortable, and well looked after (Jarvis, Worth, et al. 2006), though studies from other countries have also identified "enhancement of self" (Halm, Treat-Jacobson et al. 2006), as well as a closer relationship with the person to whom they provide care, feeling needed, and the ability to express one's love through care work as significant benefits as well (Kuuppelomaki, Sasaki et al. 2004). These rewards are difficult to define and quantify, however.

2.3 Summary of Options for Action:

Many carers need more help than they currently receive, but many, particularly carers from minority ethnic groups, do not receive existing sources of support because they do not know about them or how to access them, or because they do not think they will meet their needs (Ingleton, Morgan et al. 2004; Netto 1998; Merrell, Kinsella et al. 2005; Sothill, Morris et al. 2001). Carers from ethnic minorities appear not to enjoy greater familial social support than other carers, and so the perpetuation of this stereotype, along with their relatively more disadvantaged circumstances, may combine to render prospects for minority carers bleaker still (Fazil, Bywaters et al. 2002; Hubert 2006). While women appear to provide more care and be more negatively affected by

performing care work, it has been suggested that male carers may be less able to recognise and voice their own care needs (Thomas, Morris et al. 2002).

Support for informal carers significantly leverages formal care resources, and so a reallocation of resources away from patients and toward carers may be justified. A better prepared, higher skilled and more emotionally supported carer has a more distant 'breaking point', when they must place the person they care for in a care home, and thus formal support for the carer can be viewed as an investment in the capacity of the system.

Professionals should be sensitive to carers' lack of active choice in the matter of whether they are to provide care or not, so that they may maximise their potentially damaged sense of control as well as validate their own needs (Kirk and Glendinning 1998).

One acute early need that often goes unfilled is that for reassurance of carers' competence and abilities (Bereton and Nolan 2002; Kirk and Glendinning 2002). Meanwhile, more support is needed at the conclusion of a carer's 'tour of duty', either in the form of bereavement support (Aoun, Kristjanson et al. 2005; Ingleton, Morgan et al. 2004), or better support in the form of validation, information, and counselling before, during, and after the process of placing the person they care for in a care home (Nolan and Dellasega 1999, 2000).

However, there is no consensus on what may be the best way to support carers. Many interventions have been attempted, ranging from efforts that target carers directly, to ones that target those for whom they care, to those that target the professionals who support them. The programmes which the evidence appears to support the most are respite services (Skilbeck, Payne et al. 2005), family counselling aimed at increasing the social resources of the primary carer (Sorensen, Duberstein et al. 2006), giving the carer practical skills and knowledge that can help improve their perceived ability and competence (Sorensen, Duberstein et al. 2006), peer support groups (Munn-Giddings and McVicar 2007), granting the carer greater control over the care receiver's care plan (Simpson, Wakefield et al. 2006), and professional validation and reassurance (Morris and Thomas 2001). Still others suggest that compensating carers for their work would help to decrease their burden and increase the incentive to care (Wanless 2006), and that educating health and social care professionals to view carers as co-clients whose needs are equal to those to whom they are both providing care would lift a powerful brake on carers' ability and well-being (Guberman, Nicholas et al. 2003).

Evidence that these various interventions had great impact is disappointingly thin (Arksey 2003; Sorensen, Duberstein et al. 2006), though almost all show limited positive results. While some carers are able to access information and support through the internet, older carers, and those of lower socioeconomic status, as well as those who care intensively, are less likely to use the internet, for lack of training, equipment, or time (Read and Blackburn 2005).

Health professionals admit to caring for carers in largely a reactive capacity, reporting that they do not have the time and resources to be more proactive. They also report their own lack of training to identify and treat particularly at-risk carers, who are likely to put the needs of the person they care for ahead of their own (Simon and Kendrick 2001). Another proposal is that rather than training professionals to care for carers, professionals should be trained instead to know what resources and supports the carer

might benefit from best and how to refer them to these, as well as how to convince carers to take advantage of them (Soothill, Morris et al. 2001).

Public health values and methods, which are slowly gaining traction in the professional education of doctors and nurses, may bring new attention to what could be viewed as an epidemic of carer strain. The increased recognition of psychosocial health problems may also lead to better recognition and treatment of carer strain.

Because they are often subject to negative health consequences, we know more about how to decrease the strain on carers in order to keep them performing their role longer and in better health than we do about how to make more informal carers. One option includes paying carers, even small sums, as has proved to be successful in getting more people to provide care in Germany (Beesley 2006).

3. Annotated bibliography

3.1 Who provides informal care, and who will do so in the future?

Who cares for whom and how much? The Office for National Statistics defines carers as those 'looking after, or providing some regular service for, a sick, disabled or elderly person'. Carers provide care to people both within their own household and in other households. While the list of activities included as care work is broad (including shopping, cleaning, and supervision, as well as more technically advanced medical tasks), care provided to someone who is also cared for in an institution or care provided to someone with a temporary illness both fall outside this definition, as does care provided for pay or care provided through a voluntary organisation. Care for healthy children is not considered care work, though care for children with chronic conditions is. Much of the information on who provides informal care, to whom they provide it, and with what intensity, comes from a couple of big data sets, like the General Household Survey and the census, as well as many smaller-scale, more qualitative studies.

- **(Doran, Drever et al. 2003)** report data from the 2001 UK census. Out of the entire population of 57.7 million people, 5.9 million (4.9 million residing in England) reported providing some care to a disabled, elderly, or ill person, and only 56% of this caring group reported that they themselves were in good health (compared with 70% of non-carers). 12% of the entire over-65 population provide care, and more than a third of this group provide more than 50 hours a week. Though they report that 114,000 children between 5 and 15 years provided care (and 9,000 of them provided 50 or more hours a week), an equally dramatic statistic is that of the oldest old: 44,000 people over the age of 85 provided care, and over half of these oldest carers provided more than 50 hours per week. More than a quarter of carers over 65 and a third of those over 85 described their health as 'not good'.
- **(Glaser and Grundy 2002)** look at data from the ONS Retirement Survey of 1988/89, and find that, among British 55- to 69-year-olds, socioeconomic status was not a factor in the likelihood that they provided care to a parent in their home, but that a disproportionate number of spousal carers were working-class. The authors believe this can be explained by higher rates of disability amongst working-class people.
- **(Gosman-Hedstrom and Claesson 2005)** studied 94 women and 53 men (average age 81 and 80, respectively) in Sweden who were living at home one year after having a stroke. While 65% of the sample received informal care, only 44% received formal care. Women were much more likely to be in receipt of formal care than men (56% of women received it, compared to only 23% of men), perhaps because women were much more likely to be living alone (80% of women were living alone while this was true of only 28% of the men in the study). In the case of stroke, at least, while women thus appear much more likely to be an informal carer, they are less likely to receive informal care.
- **(Hirsch 2005)** reports data suggesting that carers and residential homes were unevenly distributed across the UK. The people most likely to be carers were older, as well as relatively worse off in both health and financial terms. Unpaid carers provided 70% of all social care in the UK, though only 10% of this number received direct government help. More than 8% of Bangladeshi and Pakistani women devoted at least 20 hours per week to care work. While the poor and rural were more likely to perform informal care, it is a mistake to think that this means that poorer, less urban people had family to take care of them while wealthier

people chose residential care. In fact it was the most deprived groups who were the most likely to receive care in an institutional care setting.

- **(Hirst 2002)** analyses data collected by the British Household Panel Survey from 1991 to 1998 (through which 9,000 adults, including around 1,300 carers, were interviewed each year) in order to find out more about carers' transitions in and out of their care roles. He observes that almost every member of the population could expect to be a carer at some point, and that half provided more than 20 hours of care per week. A third of cohabitating carers and 40% of those who provided care to someone outside their own home stepped into these care roles every year, and a similar number concluded them. Thus carers were not a fixed group of people but a more fluid one.
- **(Maher and Green 2002)**, report that the General Household Survey estimated there to be 6.8 million carers in Britain in 2000, approximately 16% of the entire British population (18% of women, 14% of men).³ 5.8 million of these carers resided in England. 24% of British 45-64 year olds provided some amount of informal care (primarily to their parents but also to spouses). A full 30% of married or cohabitating women in this age group were carers. 52% of the 6.8 million carers looked after a parent (or parent-in-law), 18% cared for a spouse, and 8% cared for an ill or disabled child. Two-thirds of these carers cared for women. Half of all carers had been providing care for 5 or more years. Cared-for people living with their carer were far less likely to be visited by health, social, or voluntary services than were those who lived in a different place than their carer (23% vs. 50%). 62% of carers cared for someone who required care primarily because of a physical disability. One in twenty people in Britain (one in four carers) provided more than 20 hours per week of care work, and those who provided more than 20 hours per week were more likely to be women: 5% of all British women vs. 3% of all British men. Of this number, half cared for someone who could not be left alone for even a few hours (though of this half, only 8% reported that they had no one who could provide assistance). 35% of those caring 20 or more hours per week suffered from a longstanding illness of their own severe enough that it limited their own activities.
- **(Pickard, Wittenberg et al. 2000)** inputted the Government Actuary's Department 1996 marital status projections into the PSSRU computer simulation model, and found that because there are likely to be fewer widows in the future and a rise in the number of elderly women living with partners, spousal carers are likely to gain increased importance in meeting the informal care needs of the elderly in future. Those providing this informal care, however, will be increasingly elderly and frail themselves, and thus need more support than carers presently need (and receive).
- **(Karlsson, Mayhew et al. 2006)** report an economic study of future demand for formal and informal care. They estimate that demand for informal care in the UK will rise from today's 2.2 million recipients to 3.0 million in 2050, assuming current provision patterns continue. On the supply side, they predict there will be enough informal carers providing enough care if male patterns converge with female ones. If females converge with male patterns on the other hand, we will be short 10-20 million hours of care per week. This deficit gets much worse if their assumptions about continuing improvements in health and medicine turn out to be too optimistic. Future predictions are very sensitive to assumptions about care-giving

³ This number is curiously higher than the 5.9 carers in the UK reported by the 2001 Census. Both numbers are quoted in the literature: Wanless 2006 favours the larger 2000 GHS figure, while the advocacy and support group Carers UK uses the smaller figure. Some of the discrepancy appears related to the self-reporting nature of the data.

patterns, expectations, and improvements in medicine. They back up Pickard et al.'s prediction that spousal carers will be of greater importance in coming decades.

- **(Schneider, Hallam et al. 2002)** studied the activity levels of 132 carers for people with dementia in South London, and found that carers who lived with the person they cared for performed significantly more care activity, when controlling for the dependency level of the person they cared for.
- **(van Groenou, Glaser et al. 2006)** looked at the relationship between socioeconomic status and the use of informal care from outside the household among older people in Great Britain, Italy, Belgium and the Netherlands. Older people from lower socioeconomic groups in the Netherlands and Great Britain were more likely to use informal care from outside the household, while across all the countries older people from lower socioeconomic groups were more likely to use both formal and informal care.
- **(Wanless 2006)**, in a study of social care provision for older people, cites ONS data showing a small but unsteady increase in informal caring. At the time of the study, 70% of informal care was received by those over 65 years old. This care was most commonly provided by elderly parents' children, followed by neighbours and friends, followed by spouses. The burden of informal care for the elderly fell disproportionately on older people, however, and on women in particular. However, the data also show that men were increasingly likely to provide informal care to an older person, particularly if that person is their spouse. The economically inactive and less well-educated were also more likely to provide informal care to an older person. Carers who lived with the person they provide care for were more likely to provide a substantial amount of it.
- **(Young, Grundy et al. 2006)** analysed data collected by the Longitudinal Study of the ONS (most recent data is from 2001) to fill out the picture of who provides informal care and to whom in England and Wales, focusing particularly on those carers who provide 20 or more hours of care per week, what they call 'extensive' care. They observe that those from rural areas, like the North of England and Wales, were more likely to provide 'extensive' care, as were those less well off financially, those in poor health, and Bangladeshis and Pakistanis. They focus particular attention on 20- to 29-year-old carers who usually care for a chronically ill or disabled young child. Whilst their numbers are relatively small (1.3% of the entire cohort), the reduced opportunities for education and advancement that result have powerful implications for young carers' futures. Carers aged between 35 and 59 were less likely to be employed or to be healthy if providing extensive care.

The difficulties of measuring informal care: Informal care can be difficult to measure, and this may have significant implications on our ability to predict future supply.

- **(van den Berg, Brouwer et al. 2006)** compare two different recommended methods of measuring care. They asked Dutch informal carers what paid, unpaid, or leisure activities they had foregone in order to perform their caring duties, as well as how much time they had spent performing informal care tasks in the previous week. The reported number of care hours differed significantly, with carers reporting higher hours in the second set of questions than the first. The authors conclude that the way care is currently counted and valued is problematic, and that if we hope to make predictions about carer supply more accurate measures of informal care must be developed.
- **(van den Berg and Spauwen 2006)** compare different ways of measuring time

spent by informal carers in their roles: the diary method and the recall method. They had 199 informal carers complete both. They conclude that the recall method likely overestimates time spent providing care, because it includes 'joint production', i.e. normal work around the home that would be done anyway.

The experience of receiving informal care: Demand for informal care remains high, even when formal care is available, but just because this sort of care is unpaid and often based on feelings of reciprocity and love does not ensure its quality.

- **(McCann and Evans 2002)** interviewed 21 males and 24 females who received informal care in Northern Ireland. They find that while most were very satisfied with the quality of the informal care provided them, some reported being the object of their carer's frustration. The subjects of the study were concerned for their own safety when the carer was not around, as well as for the carer's health and the quality of the carer's life. The authors observe that though informal care has become a significant topic of study, most research has focused thus far on the experience of the carer rather than on the one receiving care, and that care receivers should have more involvement in planning their care and support. The authors also suggest that care receivers should participate more with their carer and professionals in planning the care and support that their carer might need.
- **(Newsom and Schulz 1998)** surveyed 276 physically disabled, elderly Americans who were being cared for by their spouses, and found that nearly 40% of those cared for had experienced some emotional distress in response to having been the recipient of care, something the authors call 'helping distress'. Among those most dependant on their carer, lower self-esteem, fatalism about their circumstances, and marital conflict were the elements most likely to lead to feelings of 'helping distress', which in turn predicted depression in those cared for. 'Helping distress' does not necessarily indicate low quality or abusive informal care, but is something to which professionals should be sensitive.
- **(Wolff and Agree 2004)** analysed the data reported by 420 disabled, elderly American women (collected by the Women's Health and Aging Study Caregiving Survey), and found that while disabled women were more likely to be depressed than the non-disabled, they were at much greater risk of depression if they perceived a lack of respect and support accorded them by their carer, controlling for socioeconomic status, health, and psychosocial characteristics.
- **(Martin, Nancarrow et al. 2005)** draw on 45 interviews and focus groups with professionals in the UK practicing in intermediate care environments. While policy-makers and the public appear to want more care to happen in the home (according to the authors), these practitioners reported that patients frequently resented the medicalisation of their homes, and that some older or disabled patients enjoyed health and social care activities that got them out of their own 'four walls'. The authors recommend that what is important in shaping health and social services is not so much to shape them according to the perceived preferences of the majority of the public, but to structure them so that they are able to respond to individual and changing preferences and needs.

3.2 The costs of informal care:

What are the costs for individuals? Informal carers are at high risk of experiencing negative health consequences as a result of their care work. Those at highest risk are

those who provide the most care, women, spouses, as well as those who live with the person for whom they care.

- **(Barrow and Harrison 2005)**, based on the results of a large postal survey sent to patients in two PCTs, observe that the negative health effects are stronger among carers who feel less connected to their neighbourhoods. These negative health effects include obesity and pain, as well as anxiety and depression. They also recommend that we should distinguish between carers who care for someone at their own home and those who travel to fulfil caring duties, as carers who live with the person to whom they provide care are at greater risk of suffering worse health consequences.
- **(Borg and Hallberg 2006)** studied 151 high-intensity carers, 392 lower-intensity carers, and 1258 non-carers in Sweden, in order to get a better sense of the relationship between caring and reported life satisfaction. While there was no difference between those who performed a small amount of care and those who performed no care, high-intensity carers were found to have lower life satisfaction than the other two groups. The factors explaining this lower life satisfaction among high-intensity carers included poorer health and fewer social resources.
- **(Collins and Jones 1997)** studied 48 spousal carers for dementia patients in the UK, dividing them into two closely matched subgroups by sex. The authors conclude that wives felt much more strain and lower morale than husbands did, and that they were more likely to report wanting to leave their care-giving responsibilities to someone else and to give more reasons why they should give it up altogether.
- **(Maher and Green 2002)** report that 39% of all carers believed that their mental or physical health had been affected negatively by their care work. 59% of carers living with the person they cared for reported negative health consequences, as did 61% of those providing more than 20 hours of care per week. These numbers were derived from GHS data.
- **(Gunnell, Coast et al. 2000)** conclude that hospital-at-home programmes do not seem to increase carer strain, which is surprising, given that these programmes support the care of patients in their own homes who are ill enough to be hospitalised. An RCT in Bristol yielded significant differences at 4 weeks or 3 months between the control and intervention group in any of the outcomes measured for the 133 total carers. Hospital-at-home programmes rate highly among policy-makers because of their relatively low cost and freeing up of hospital beds, and they have generally proven positive with patients as well.
- **(Hirst 2003)** analysed data collected through the British Household Panel Survey from 1991-2000 to find out more about the psychological consequences of caring. The data show that carers suffered more distress than non-carers, particularly those who lived with the person they cared for, those who cared for more than 20 hours per week, and female carers. Though care work appears to have intensified over the 1990s, with carers performing more demanding tasks, the distress rate of carers relative to that of non-carers has not changed.
- **(Sorensen, Duberstein et al. 2006)** estimate that there are 750,000 informal carers looking after someone with dementia in the UK, and conclude that these carers appear to be at particularly high risk of poor health. Reviewing several meta-analyses synthesising from the literature on the psychosocial effects of caring for someone with dementia on the carer, they report that this group of carers is more likely than non-carers to suffer from depression, anxiety and stress, and to feel less self-efficacy and life-satisfaction. Considering weaknesses in the

current literature, they point out that many studies do not consider some other possible factors, and that though the linkage between caring and negative consequences is strong, it could be strengthened further. For example, factors that have not been entirely accounted for are: 1) the roles of particular personality or family characteristics that might have rendered carers more likely to perform their role, 2) financial constraints that forced them into it, 3) the low opportunity cost of leaving paid employment to take on a caring role, or 4) whether those who appear to suffer most from caring would have been unhappy or unhealthy anyway. The authors draw a distinction between primary and secondary stressors, using the example of intense care needs (a primary stressor) cutting in to a carer's social time and increasing social isolation (a secondary stressor), or making them late for work, causing problems there (another secondary stressor). They also observe in the literature that female carers are more likely to report depression than men, partly because they are more likely to report depression in the population at large, but also because female carers are more likely to provide more, and more complete, care than their male counterparts (see **Hirst 2003**), as well as that spousal carers are more likely to experience distress than non-spouse carers.

What are the costs for ethnic minorities? Some have suggested that minority carers experience their care burden differently, while others have observed that the burdens appear quite similar.

- **(Adamson and Donovan 2005)** interviewed 21 African/Caribbean and 15 South Asian carers in the UK, and observe that at least for this group, the experience of informal care is much like that of a chronic illness: a factor that is accepted and adapted to largely without question. For many their care work was simply part of their role as a daughter, husband, nephew, etc, and thus a relatively 'normal and expected thing to do'. That said, younger carers were more likely to view their care work as disruptive, as were those who enjoyed little family support or for whom care work conflicted with other 'moral obligations', like caring for children or earning money. Though the participants often referenced their ethnic or cultural background when describing the nature of their duty to care, the authors overall find 'strikingly similar' their experiences of that care to that of white majority carers observed in the larger literature.
- **(Koffman and Higginson 2003)** interviewed 50 informal carers of first-generation black Caribbean patients in their last year of life and 50 informal carers of native white patients in their last year of life. It is noted that those who cared for black Caribbean patients were more likely to be women in this sample, and to perform the bulk of the patient's care. The personal-care tasks they helped with and the informal resources that both groups of carers used were similar, as were the stress-related symptoms of care. However, carers of black Caribbean patients were more likely to report that care work posed a financial burden (in terms of earnings foregone), and that care work placed more restrictions on their lives. The authors also report that white carers were more likely to visit their GP for help than were black carers.
- **(Milne and Chryssanthopoulou 2005)**, in their review of the research exploring how caring for someone with dementia affects those from Black and Asian communities in the UK, criticise the literature overall for its small scale, relative ignorance of cultural issues, and limited applicability from discipline to discipline. Nevertheless, they report that the research does suggest that though caring for dementia patients presents enormous challenges to both Black and Asian carers as well as to white carers, it is experienced and coped with differently. The

authors suggest that differences stemmed from higher levels of religiosity in Black and Asian communities, different familial expectations, and different cultural conceptions of dementia.

What aspects of caring can be most harmful to those providing the care? Many researchers have attempted to discern which characteristics of the carer, care-receiver, or care role itself may put informal carers at greatest risk of health problems and most significantly lower their quality of life. Despite this, there remains a lack of consensus around what the most significant factors may be.

Some researchers have concluded that it is a lack of social support that is the most significant factor dividing those who suffer the negative consequences of their care work from those who do not.

- **(Goldstein, Atkins et al. 2006)** interviewed 50 English spouses who were the primary carer for someone suffering from ALS, a relatively common neurodegenerative disease (most ALS carers are spouses). The carers rated their partner's behavioural and emotional changes and changes to their everyday activities, as well as rated their own social support and marriage, mood, burden and strain. Finally, an ALS severity scale was completed for their spouse. The researchers found that over time (they interviewed the spouses 3 times, once every 5-6 months) carers' psychological distress increased significantly. At first their distress was explained by the psychosocial impact on their lives of their spouses' condition, as well as their spouses' emotional lability. Later in their spouses' deterioration, carers' distress was most associated with level of social support and satisfaction with social relationships.

Others believe the greatest factor to be the weight of the care burden as measured in time spent providing care.

- **(Annerstedt, Elmstahl et al. 2000)** looked closely at the 'breaking point' at which carers were no longer able to take care of a person with dementia and the patient needed to be institutionalised. They did this by interviewing 79 primary family caregivers of Alzheimer's and vascular dementia patients who were being considered for institutionalisation. They found that a carer's burden was not influenced by their gender or social class, or even by the previous institutionalisation of the patient, or that patient's ability to perform activities of daily living or their level of cognition. What did affect a carer's burden was the closeness of their kinship relation to the person they were caring for, the amount of caring required of them each week, how much the patient's behaviour deteriorated at night, clinical fluctuations, and the severity of impairment of the carer's sense of their own identity.
- **(Hirst 2005)** analysed data on 3,000 carers, 2,900 former carers, and 11,100 non-carers collected by the British Household Panel Survey during the 1990's whose psychological wellbeing was assessed annually. He reports that those who cared most intensively over long periods of time were at higher risk of psychological distress, and that women were at higher risk still. As the number of hours per week spent caring increased, so did the risk of psychological distress. This risk also rose with the length of time one performed care work. Those with heavy care workloads were most likely to feel distress at the beginning and end of their tour of caring. Moreover, even after they had stopped performing their care work, they continued to suffer its ill effects. Male and female spouses, as well as mothers caring for their sick or disabled children, were at the highest risk of suffering

psychological distress.

Still others believe the most significant factor is not social support or time spent, but the behaviour and symptom severity of the person to whom care is provided.

- **(Cameron, Cheung et al. 2006)** found after studying 94 stroke victims' carers that carers were more likely to be depressed if the symptoms of the person they were caring for were more severe. While this may seem an obvious point, it can help health professionals to anticipate who is at greater risk from the effects of providing care and respond to problems earlier.
- **(Croog, Burleson et al. 2006)** observed the burden of care work on 199 spouses of Alzheimer's patients in the US, and found that patients' emotional volatility was a more significant factor than diminishing cognitive function in the strain of caring. A high care burden was most directly associated with a carer's anger and resentment toward the person they cared for. They also found that the greater the impact of caring on the carer's social life, the greater their risk of suffering depression or anxiety.
- **(Sorensen, Duberstein et al. 2006)**, despite observing the shortcomings of the evidence regarding who is most likely to suffer the negative consequences of caring for dementia patients and why, nevertheless report after reviewing the literature that the strongest predictor of depression and burden on the carer is patient behaviour (such as outbursts and night-time wandering).
- **(Venables, Clarkson et al. 2006)** set up an RCT in which 142 dependent older people were assigned to either a control group receiving the usual social services assessment or a group in which they received an additional specialist clinical assessment. They then measured the distress levels of participants' carers. Regression analysis showed that carers' distress levels were most related to changes in the behaviour of those they cared for, rather than services targeted specifically at them as carers. The authors thus recommend that resources spent directly on services for carers might be better spent on services designed to limit the distressing behaviour of those to whom they provide care, and argue based on their results that the most depressed carers will gain the most from this.

Finally, though they make no claims that it is the most significant factor in a carer's health, researchers have also drawn attention to the experience of placing the person to whom one has been providing care in a care home, which can leave the carer feeling guilt, loss, and a lack of control.

- **(Davies and Nolan 2003)** interviewed 48 people in the UK who had recently moved a relative into a care home, in order to find out more about their interactions with social and health professionals leading up to this event. Looking back on the experience, many of their subjects reported feeling unsupported and poorly informed while making their decision. The authors recommend that practitioners furnish carers with more information about their options, as well as help them through the decision-making process itself.
- **(Davies and Nolan 2004)** used the same data set to describe carers' experiences during their relative's move to a care home. The authors recommend that steps be taken to ensure that informal carers feel like partners with practitioners during the transition from informal care to professional care, and believe that this will help the person being cared for as well, as this transition can often be understandably traumatic for them as well. This involves both training staff to engage with carers more productively as well as expanding the ways in which carers can continue to

feel engaged with the person to whom they provided care, as well as their new community.

- **(Davies and Nolan 2006)** used the same interview data of 48 people who had moved a relative into a care home, this time describing the role that carers took on after moving their relative to a care home. Carers' continued activities fell into three categories: maintaining continuity with their relative, as well as helping professional staff learn more about the resident before they came to the care home; monitoring the quality of the care their relative received and providing advocacy when needed; and contributing to the larger care home community through getting to know their relative's neighbours, going to events, and serving other social functions in what can be a very isolating environment. The authors recommend that staff be trained to look for ways to actively engage carers in their relatives' lives and in the life of the community. Staff and carers often distrust and resent one another, making staff-carer partnerships difficult.
- **(Ryan and Scullion 2000)** interviewed 10 family carers in Northern Ireland who had recently made the decision to place the person they were caring for in a nursing home. They found that the family carers often felt considerable anguish and guilt about their decision. They also felt the need to justify it, even though the decision was often precipitated by a crisis, or by the patient's or carer's deteriorating health.

What are the costs to society? Determining the costs of unpaid care to society and the economy is very difficult, and scholars attempt it in many different ways. The costs appear to be quite large if they include such things as lost productivity in the paid labour market, interruptions in carers' education or career advancement, the worse health of carers, as well as direct carer support, such as respite and counselling, and what the work done by carers would cost if performed by professional staff.

- **(Luengo-Fernandez, Leal et al. 2006)** calculate the entire cost of cardiovascular disease in the UK to be £29 billion, and estimate that 17% of this figure comes from costs associated with the informal care of the patient, rather than with the health care or lost productivity of the patient.
- **(Schneider, Hallam et al. 2003)** attempt to form an estimate of what informal care for dementia patients costs in total, based on observation of dementia patients and their carers in England over a 17-month span. What they find through this exercise is that because co-resident carers provide more care than non-resident carers, placing dementia patients in residential homes is actually cheaper than caring for them in their own home.
- **(Wanless 2006)** estimates the entire cost of informal care for the elderly to be approximately £9.4 billion, updating with inflation an estimate made in 1990 by Netten et al that took into account direct carer support, carer's own healthcare needs, and lost revenue to the Treasury resulting from their not working in the paid labour market.
- **(Carers UK 2007)**, an advocacy and support group for carers, reports that to replace unpaid carers with professional staff would cost the UK £57 billion per year.

Combining paid work and unpaid care: Researchers have become interested in what characteristics of the carer or their care burden render them more or less unable to participated in the paid labour market. Researchers are also interested in whether juggling paid work and care work has a beneficial or harmful effect on the carer.

- **(Arksey 2002)** observes from the literature that combining care work and paid work can have a positive or negative effect. While time at work can offer a regular break from care and protection against social isolation (as well as an income), combining the two roles can also be stressful and demanding, so much so that many carers may temporarily or permanently remove themselves from the labour market altogether (or give up their caring role, which the author suspects may occur as just as frequently, if not more so). The author presents the results of two parallel studies done in 1998, one on 51 carers, and one on 13 employers in Yorkshire, to see how employers' policies and practices accommodated carers' needs at work. Based on interviews with carers, the author recommends that for employers to maximise their helpfulness to carers, they need to offer the following: 1) leave policies that allowed for unplanned as well as planned absences, 2) flexible or part-time work, 3) the ability to take longer lunch breaks and to count on being able to leave work on time, 4) the ability to use a telephone in private, 5) supportive managers and co-workers. Turning to the results of the second study, most employers appeared able to meet these criteria for a caring-friendly work environment, based on what their human resource policies and personnel representatives said about themselves. The question remains, then, why so many carers find the two roles impossible to balance. Indeed, out of the 27 carers of working age in the first study, only 12 worked their non-care roles (paid work or schooling) for more than 16 hours a week.
- **(Glaser, Evandrou et al. 2005)** use data from the ONS longitudinal Retirement Survey of 1988/89 and 1994 for the general population to investigate whether carers who also worked paid jobs were in worse health than carers who did not. While replicating the results of other studies showing a positive relationship between paid employment and good health, the authors also find that carers who also worked in paid employment were in no worse health than carers not in the labour market. The results appear to show that performing care and paid roles simultaneously is not more harmful to one's health, however, the authors report that they did not measure mental health, only physical health.
- **(Henz 2004)** analysed the Great Britain 1994/95 Family and Working Lives Survey for data on the relationship between informal caring and labour market attachment. Two thirds of informal carers were in paid employment when they first began their informal care work. One half of these worker/carers reported no change in their paid work due to their care work, but the change most reported by the remaining half was that they exited the labour market altogether for the duration of their care responsibilities. Semi-routine and routine manual workers were those most likely to report that their care work had affected their paid work, and part-time workers were more likely than full-time workers to reduce their hours further because of their care work (perhaps because they had other duties like parenting that had made them work only part-time in the first place.)
- **(Henz 2006)** analysed data from the 1994-95 British Family and Working Lives Survey for 9,139 men and women, and found that women of lower socioeconomic status were particularly likely to leave the labour market as a result of their care work. Part-time women workers were not more likely to either start caring or to give up paid work.

3.3 How people come to care, and whether they may derive value from it:

How individuals become carers: choice or 'drift'? Given the financial, emotional, physical and mental costs involved, one wonders why so many continue to perform informal care roles at all, let alone with such intensity. While many undoubtedly make the active choice to become carers, most appear to 'drift' into the role. Many carers do not particularly self-identify as carers, viewing their care work as a constituent part of their role as daughter, spouse, or parent.

- **(Collins and Jones 1997)** studied 48 spousal carers of dementia patients in the UK, and found that women reported more strain than men. At the same time, however, the wives felt themselves to be under greater obligation to take care of their husbands than the male carers did for their wives, and both groups thought women made better carers than men did.
- **(Gooberman-Hill and Ebrahim 2006)** interviewed 7 men and 8 women in England who were experiencing new difficulty walking, as well as 4 of their spouses. Those interviewed were not prone to describe one another or themselves as a 'carer' or 'cared for', and the researchers point out that for these people caring was embedded in the larger fabric of their relationships. This has implications for the way we talk to carers and those receiving care about informal care provision and its support.
- **(Henderson 2001)** observes that in her interviews with UK couples where one provided care to the other (in this case, mental health patients) many who provided informal care did not self-identify as 'carers', and many in receipt of informal care did not view themselves as 'cared for'.
- **(Kirk and Glendinning 1998)** argue in this meta-analysis of the literature that two trends of modern healthcare—toward patient participation and from the hospital into the home—are reshaping the carer role in the UK. Regarding the first, care needs to be taken that the preferences of the patient do not trump those of the carer: care that is unwillingly or reluctantly provided is unlikely to be of high quality, and is likely to be more damaging to the carer. Many carers do not really make a clear choice at present, partly because they are given so little information on what support will be available to them, what will be required of them, and what the physical, mental, and social costs will potentially be, and partly for lack of attractive alternatives. As more care moves out of the hospital and into the home, the authors suggest that it is important to ensure that the number of carers moving unwillingly into that role does not increase. They suggest training a new generation of community nurses to look after and consider the carers' needs as well as those of the patients they look after.
- **(Pickard, Shaw et al. 2000)** observe that many carers are increasingly performing sophisticated health care tasks normally performed by nurses. Another observation is that although health professionals tend to recognise a carer's right to choose how much care they are able to provide, this assumption may actually conflict with the carer's more complicated 'experience of reciprocity existing within the context of lifetime relationships'. In other words, though carers have a choice in theory, many carers may not actually see themselves as having that choice. The authors argue that if professionals believe that carers have explicitly made the choice to care they risk ignoring carers' continued ambiguity about their role, and risk missing chances to support them.

Does informal caring carry benefits for the carer? More recent research has observed that some carers may derive benefits for their care work, in the form of greater self-enrichment, emotional fulfilment, and a closer relationship with the person to whom

they provide care. These rewards seem to be difficult to define and quantify, however.

- **(Brouwer, van Exel et al. 2005)** studied the benefits 950 Dutch carers derived from their care-giving tasks, and report that overall if the care work carers perform were handed over someone else, the carers' happiness would suffer. In other words, carers derive positives from the process of caring itself, not just the knowledge that the person they are caring for is receiving care. This relationship changes depending on the burden of care and demographics, and thus it is important that practitioners continue to monitor carers' health in order to support their well-being.
- **(Halm, Treat-Jacobson et al. 2006)** studied 166 US spousal carers of coronary artery bypass surgery patients. Analysis of questionnaire responses showed there to be an association between high care burden and poor patient health status, as well as lower mental Health Related Quality of Life scores. However, high care burden was also associated with carers' sense of competence and 'personal gain'. Carers appeared to derive satisfaction and an 'enhancement of self' from their caring role, despite the negative consequences of caring on their health.
- **(Jarvis, Worth et al. 2006)** received 172 completed postal surveys from Scottish carers looking after someone over 75. They described their care work, including what they found particularly difficult or satisfying, and the support they received. According to the authors, the impetus for the article came from the experience of the first author working in a nursing home and observing carers with seemingly impossible care loads surviving or even thriving, while watching others with comparatively lesser loads fall apart. Their data showed that the most stressful aspects of the care role (the 'invisible' aspects, such as emotional activities and consequences, lack of time, family tensions, and 'day-to-day hassles') were less likely to be recognised and supported than physical, practical aspects of the role. Professionals need to learn to recognise and support carers through these invisible stressors, which eventually accumulate to lead to real problems for carers' health and their continued ability to provide care. Co-resident carers were shown to need and to benefit from a break, and so respite services are also endorsed by the authors. Though most respondents found much in their role that brought them satisfaction, they derived the greatest satisfaction from seeing the benefits of their care work for the person they cared for, rather than from feeling that they were going through a period of self growth or enrichment. Rather than concluding that carer strain results from a lack of satisfying elements, therefore, the authors argue instead that carer strain is more likely to result from carers' emotional responses to difficult emotional issues.
- **(Kuuppelomaki, Sasaki et al. 2004)** received 290 completed questionnaires from family carers in Finland designed to help answer the question of why so many carers continue to care when it is so harmful to their mental and physical health. Because other research has shown that those for whom caring is a satisfying, meaningful activity do not suffer the same mental and health consequences as others, they are interested in how to maximise this satisfaction. They report that their Finnish sample derived the most satisfaction from feeling 'needed and wanted', from feeling that their efforts made the person they cared for feel more comfortable, from being able to express their love through their care work, and from the closer relationship with the cared-for person that often resulted from this work. Carers' overall life satisfaction was closely associated with the satisfaction they derived from their care work, and greater satisfaction was inversely related to carer strain. These associations were stronger when the carer was a man caring

for a woman, and younger carers derived the most satisfaction from knowing they had made the person they cared for more comfortable. Research has shown making the person more comfortable to be the greatest source of satisfaction in the UK, while the authors point out that the Finnish carers seem to derive more satisfaction than UK carers from interpersonal dynamics of the care relationship (like being able to express their love in this way) as well as from feeling needed.

- **(Lopez, Lopez-Arrieta et al. 2005)** report that while caring takes a physical and psychological toll on carers, it may carry with it some emotional benefits. They interviewed 111 Spanish carers of elderly patients to find out which factors might best predict the positive emotional aspects of caring to be experienced by carers (what the literature calls 'caring satisfaction'). They found in their interviews that caring had a positive impact on most carers. The best predictors of this caregiving satisfaction were better relationships between carer and cared for before the illness or disability, having made the conscious choice to care rather than being backed into it, not working outside of the home, and being able to maintain some space for leisure time. Thus satisfaction is dependent on mainly individual characteristics, and on those of the carer, rather than the one being cared for.
- **(Wolff, Dy et al. 2007)** analysed data from the Informal Caregivers Survey of the 1999 National Long-Term Care Survey in the US to compare the experiences of carers of patients who had died with those of patients who were still living. They report that though end-of-life carers suffered from greater strain and were required to make greater financial, time, and emotional sacrifices, they nevertheless reported feeling as personally rewarded by the experience as carers of people who had not died. They conclude that families value the experience of taking care of a dying loved one, and that policies and practices should maximise their support for, and support after, this choice.

3.4 Caring for Carers:

Do carers needs go unmet? The consensus appears to be that carers require more support than they currently receive, and that these needs will increase in the future, as the care provided gets still more sophisticated and carers get older and frailer themselves. More services exist than carers are able to access, because they are too difficult to receive, perceived to be of little value, or simply not known about.

- **(Aoun, Kristjanson et al. 2005)** review the literature describing the effects of taking care of a dying person in an informal capacity, and find that this group continues to be given insufficient information and support from health and community services. This is because of both the inaccessibility of help and lack of interventions made toward reducing consequences of caring for the dying.
- **(Brereton and Nolan 2002)** interviewed 14 new carers of recent stroke survivors, and report that during the initial period after being thrust suddenly into their new role the new carers engaged in various 'seeking' activities, attempting to gain assurance from health professionals of their competence. These needs were overlooked by these professionals, however, which increased the carers' sense of isolation and lack of confidence. It is recommended that professionals learn how to identify 'seeking' behaviour and be ready to provide information and reassurance.
- **(Ingleton, Morgan et al. 2004)** report data from 301 postal questionnaires completed by bereaved carers of recently deceased cancer patients in a rural

county in Wales. While satisfaction with the work nurses performed was quite high, almost 40% reported that they and the person they cared for needed more nursing help than they got, and many needs were similarly unmet by social care services. Finally, while four out of five carers described as helpful speaking with someone from health and social services after the death of the person they took care of, only one in five had been given this opportunity.

- **(Kirk and Glendinning 2002)** interviewed parents of children with serious health conditions in the UK that required sophisticated technology and skill for their maintenance to find out more about what support was provided to those parents and what support they needed most. They also interviewed the professionals caring for those children. In total they interviewed 23 mothers and 10 fathers of 24 children, as well as 38 care professionals, including social workers, doctors, and nurses. While a few of these professionals reported feeling threatened by these expert parents, most accepted that the parents were in a primary caring role, and brought much expertise to the table, whereas the professionals were in a more supporting role. Whether professionals communicated their recognition of parents' expertise to them was very important to the parents. Also of importance to parents was the professionals' ability to help with practical tasks not related to their direct care work: things like ordering the right equipment and services, and finding financial resources. Parents were on the whole happy to perform the direct care work themselves. Finally, parents needed much reassurance from professionals, as well as ready and accessible sources of information (and reassurance about the quality of those sources). The authors note in conclusion that parents' expertise will certainly not render that of professionals obsolete, as among other things parents seem to depend on the reassurance and advice of professionals in order to maintain such a sophisticated and stressful role.
- **(Simon and Kendrick 2001)** received completed postal questionnaires from 300 GPs and 272 practice nurses in England, who reported that they rarely operated in anything more than a reactive capacity in their support for informal carers, despite the fact that they are expected by policy-makers to function as many carers' primary support. The GPs and practice nurses said that it was for lack of time, resources, and training that they did not offer more complete, pro-active support to carers.
- **(Soothill, Morris et al. 2001)** report data gathered from questionnaires completed by 195 carers of cancer patients, and interviews with 32 of those carers, concerning their own unmet psychosocial needs. Though most reported satisfaction with their relationships with the health professionals of those for whom they cared, 43% of the 195 carers reported that they had a need which they described as important which had gone unmet, and 28% reported more than three. Spouses or partners, those in relatively better health, those with fewer other caring responsibilities, those with a better social support system, and those caring for patients who had not reached the palliative-only phase of their care were all more likely to report that all of their most significant needs (according to them) had been met. The significant needs that were more likely to be unmet most often related to emotional and social issues, but included more practical issues. The authors suggest, however, that it may be unrealistic to expect health professionals to be able to meet all needs of all carers, and that in many cases the best thing they can do is refer carers to services better equipped to help them, such as counselling or mutual support groups. The authors also recommend that professionals tell carers that their own needs are legitimate and as worthy of their attention as are the needs of the person for whom carers provide care, in order to increase carers to

take advantage of these services.

A related literature assesses the needs of carers placing those they care for in a care home.

- **(Nolan and Dellasega 1999)** interviewed 54 US carers and 48 UK carers who had recently moved the person they cared for into a care home, in order to find out more about the carers' continued stressors and needs. When asked their impressions of the care home and its staff, answers were usually positive, but many interviews also had an undercurrent of concern over the quality of care and attention, as well as of guilt and loss, leading the authors to suggest that interactions and relationships between staff and carers were superficially polite, as staff managed the carers without really identifying and addressing their concerns. The decision to place a relative in a home was a deeply guilt-ridden and ambivalent one, and one way in which staff could help carers is to validate their decision immediately and often. The authors report that staff and family frequently come to see each other as incompetent and demanding, and suggest that ways of explicitly including carers in the continued care of the resident and the larger community should be pursued.
- **(Nolan and Dellasega 2000)** draw on the same data set of 54 US carers and 48 UK carers, this time focusing on carers' experience of placing in a care home the person they provided care to (whereas the previous study focused on carers' experience after placement). These results are not necessarily generalisable, as 41% of the US carers looked after someone with Alzheimer's, while only 19% of the UK sample did so. They observe that carers in the US appeared far better supported than those in the UK, enjoying readier access to support groups and having more involvement in the decision to place the person they cared for in a care home. US participants were much more enthusiastic about the quality of written information presented to them to help them make their choice as well. They conclude that carers receive so little information and support that their decision to place someone in a care home, let alone which one to place them in, can hardly be constituted as a real choice.

Carers who are also members of ethnic minority groups appear to have either more significant or at the least not lesser needs than their white counterparts. Several researchers have observed that they are not likely to make use of what carer resources are available to them, however, either because they do not know about them or how to access them, or because they do not believe those services will meet their particular needs.

- **(Fazil, Bywaters et al. 2002)** interviewed informal carers of disabled children in 20 Pakistani and Bangladeshi families in Birmingham, and report that the families' initial economic and social disadvantage was compounded by their difficulty gaining access to the resources to care for their children. The authors warn that health and social care professionals should not assume that these families are able to rely on deeper and stronger extended family support, as is stereotypically believed, and suggest that this belief further contributes to these families' disadvantage in caring for their children.
- **(Hubert 2006)** interviewed 30 black and minority carers for adults with learning disabilities, and reports that though on the one hand they were satisfied with the quality of the services they had actually received, they had received too few of them. The author also reports that the stereotype that these families enjoyed

stronger extended family resources and commitment turned out to not be the case. It is recommended that more social workers be hired, and trained to help carers draw up care plans and ensure that the most vulnerable carers, and those they care for, receive adequate support.

- **(Merrell, Kinsella et al. 2005)** interviewed 20 Bangladeshi carers for dependent adults in South Wales to inquire into their use of caring support resources. Though most viewed their caring experience positively, the authors report that most were also unaware of the health and social services available to them. Those that were known about or provided were criticised for not meeting cultural or religious needs. The authors recommend that health and social care professional receive additional training in order to become more culturally sensitive in assessing need as well as more comfortable working with interpreters. They also recommend that social care service workers pro-actively search vulnerable Bangladeshi carers out (through health services and local facilities such as shops) in order to increase their awareness of available services, as well as simplify the process of their using those services.
- **(Netto 1998)** interviewed 45 ethnic minority carers in Scotland regarding their use of and further need for respite services. The author report that this group of carers had a need for and an interest in respite services, and suggests that their low uptake of currently existing services is a result of their not knowing about the services available or concerns that their particular needs or preferences will not be met by those services. These include dietary, linguistic, religious, cultural and gender sensitive needs, and if policy-makers want to maximise use of these services by minority carers they should ensure that the services are designed with enough flexibility to hand these needs.
- **(Pearce, McGovern et al. 2006)** tested the utility and accuracy of one tool used by mental health professionals to measure carer distress (the Relatives' Cardinal Needs Schedule) among Asian carers in the UK, because research has shown them to have greater difficulty accessing carer support (just as the people they care for have greater difficulty having their conditions identified and treated). Of the 23 carers in their study, 20 were of Indian descent while 3 were of Pakistani descent. Over half of these carers experienced symptoms resulting from their care work that classified them as at the level of 'psychiatric caseness', compared with 43% of the larger carer population in a Scottish study. The authors also observe that virtually no one in their sample had been offered any sort of professional psychosocial help in the previous year, though the sample also believed themselves to have fewer needs for professional support than did a general sample of UK carers in a 1999 study (Barrowclough et al).

While women appear to provide more care and be more negatively affected by performing care work, it has been suggested that male carers may be less able to recognise and voice their own care needs.

- **(Thomas, Morris et al. 2002)** surveyed 262 male and female carers of cancer patients, interviewing 32 of them. It was observed that though carers had many arduous tasks which can be categorised together as 'care work', carers also performed a lot of 'emotion work', as they sought to keep up the patient's (and their own) spirits. They worked hard to present a 'strong' and 'positive' face to their patient, and to maximise their sense that life was 'carrying on as normal'. Women and carers under 60 years old appeared better able to express emotional needs to the researchers (though women were also more likely to identify specific care

needs than men were). Male carers may thus be particularly vulnerable to slipping through the cracks in carer support, and professions should be particularly vigilant and proactive in identifying the needs of this group.

Some researchers have pointed out that carers may be in some ways more satisfying to work with than patients themselves, from a professional's perspective.

- **(Manthorpe, Iliffe et al. 2003)** report on 24 workshops on dementia issues involving over a thousand professionals in 21 cities in the UK. They observe that the participants in these workshops viewed carers' needs as legitimate, and believed in viewing them as co-clients with the patient, rather than simply as a resource. In fact, professionals sometimes viewed their work with carers as more rewarding, given that they were usually 'easy' to work with, grateful for professionals' help, and did not share the dementia sufferer's inevitable slide toward incoherency and death. Finally, most of the professionals did not find it difficult to think of resources available for carers to which they could be referred, such as carers' support groups and respite services.

Ways to support carers: Many ways of supporting carers have been attempted, based on different assumptions about the causes of carer strain and the type of support most needed. Carers have often been the direct target of these efforts, but sometimes those they care for are targeted as well, as an indirect attempt to improve carers' quality of life. These attempts have been met with varying degrees of success.

- **(Pickard 2001)** reviews the National Strategy for Carers, the Royal Commission's Report on Long Term Care, and the dissent from that second document (all published in 1999). The author reports that while the National Strategy and the Royal Commission's dissent argue that services should be made available to carers (particularly respite services) with the aim of maximising the quantity of informal care in the UK, the Royal Commission's report instead advocates 'carer-blind' support for the cared-for person as an indirect but effective way of supporting the carer. Pickard recommends a path down the middle, where carers receive support directly tailored to their own needs (including respites) as well as indirectly, through increased professional support for the physical and domestic needs of the person they care for.
- **(Sorensen, Duberstein et al. 2006)**, observing the many dozens of intervention studies seeking ways to decrease carer strain, identify nine main types: case management, psychotherapy (mostly cognitive behavioural therapy), dementia education, support groups, respite, training for the patient, pharmacotherapy for either the patient or the carer (or both), or combinations of these strategies. They report that the effects of these interventions overall tended to be small and 'domain-specific', so that for example training patients affected patient symptoms but not the carer's, or the application of case management relieved some of the burden of caring but had no effect on depression. Researchers have recently attempted to isolate the most effective components of these strategies. Some of these lessons are: longer-term interventions work better than shorter-term ones; limiting the intensity of care through respite programmes 'unequivocally' reduces carer distress, reducing social isolation through family counselling and other methods of increasing a carer's social support network works as well; increasing the skills and knowledge related to caring may improve the carer's feelings of competence and mastery, and these can have a powerful effect on how equipped one subjectively feels for the task at hand ('appraisal' is the term they use for this), though knowledge without a ready practical application appears to have no effect

on its own.

Some advocate supporting carers indirectly, through providing better, more specialist care to those they care for, such as behavioural management through patient training or medication.

- **(Dixon, Walker et al. 2006)** studied data from the Health Outcomes Data Repository to understand the relationship between patient quality of life and carer quality of life. They find that there is some evidence to suggest that raising a patient's quality of life may reduce their need for their carer's attention and time, and improve the carer's quality of life. See **(Cameron, Cheung et al. 2006)** for evidence of the strength of the link between stroke victims' symptoms and their carers' depression, **(Croog, Burleson et al. 2006)** for the link between American Alzheimer's patients' emotional volatility and carer strain, and **(Sorensen, Duberstein et al. 2006)**, who in their literature review conclude that patient behaviour is the single strongest predictor of carer depression.

Those who advocate targeting efforts at carers directly recommend increasing access to respite programs, compensating (and thus possibly incentivising) carers financially, allowing them more control over the care plans of those they care for, as well as teaching health and social care professionals to view them as co-clients whose needs are equal to whom they provide care. Others, though, observe that much of the evidence for the effectiveness of these interventions is thin.

- **(Arksey 2003)** reviewed 204 studies to determine how much evidence there was for the effectiveness and cost-effectiveness of interventions directed at carers of people with mental illness (a role perhaps 1.5 million people in the UK may be filling to varying extents). The author reports that there is unfortunately little evidence in this literature to justify mass replication of the interventions attempted, though almost all had some limited positive effects. This may be because for many people processes may matter as much as outcomes; thus participants often rated interventions highly, while showing little evidence that their circumstances or health had changed. This review also reports that few of the studies have an economic component, and that there is a paucity of research on programmes championed in particular by the government, such as IT developments, advice centres (like NHS Direct) or respite care.
- **(Gall, Atkinson et al. 2003)** tested an intervention where nursing lecturers and carers trained 9 mental health nurses to deliver a support programme to 9 carers of schizophrenic patients (all mothers). The researchers interviewed the nurses before and after the training and before they worked with the carers, and interviewed the carers as well. They report that though the intervention yielded positive outcomes in terms of support expressed and received, nurses did face some challenges in shifting their attention to explicitly include the carer as well. Among the difficulties the nurses faced were the depression or anxiety of the carers, as well as carers' sometimes negative past experiences with care professionals. The carers reported positive feelings about their interactions with their nurses, and described them as different from previous experiences. The study has several limitations, however, among them that the data is all self-reported, rather than observed, and outcomes (like diagnosis of depression, etc) are not measured. In most of these interventions, the carers and/or staff report enthusiasm, but outcome measures often fail to back up their self-reporting.
- **(Morris and Thomas 2001)** interviewed 79 carers of cancer patients in the UK,

and report that these carers were often left in a somewhat ambiguous position in terms of how much they should advocate for themselves as well as the person they cared for. The authors suggest that carers' tasks and experience will be made easier if practitioners recognise and legitimise their role as well as their needs, viewing them as co-clients rather than as another tool at their disposal in their professional care for the patient.

- **(Munn-Giddings and McVicar 2007)** interviewed 15 carers who were active members of one of two carers' peer support groups. They report that carers' experiences in these groups to be very positive, and report that carers joined the groups because both their emotional and social needs had been unmet through their 'usual' social support network, and because their needs for information, validation, and empathy had been unmet by professionals. The authors also point out that an additional element that set these groups apart was that they validated and met more than carers' strictly carer-oriented needs: they recognised the depth of carers' relationship with the person they cared for. Rather than recommending that professionals somehow learn how to meet all the needs of carers currently met by these groups, participation in these groups should be encouraged, as this sort of support and understanding can only be offered by peers.
- **(Simpson, Wakefield et al. 2006)** tested an intervention (controlled, but not randomised) where they gave half of 84 carers of dementia patients in England the ability to co-draft, revisit, and hold on to the care plans of those they cared for, in this way attempting to make them true partners in decisions about care. The health, strain, stress, and locus of control of all of the carers were measured initially, at 6 months, and 12 months after the start of the intervention. Though no significant differences in health were picked up between the two groups, for those who experienced the intervention, after a year carer strain levels were significantly lower, as were external control measures (meaning that they believed that they personally had more control over what happened in their lives).
- **(Skilbeck, Payne et al. 2005)** observe that 90% of terminally ill patients now spend most of their final year at home, which means that informal carers are providing the bulk of their end-of-life care. The authors interviewed 25 carers of terminally ill relatives before and after they got a break through placing their relative in a hospice respite centre. Carers rated the respite programme very positively, both in terms of the break it allowed them and the quality of care it provided to their relative. As a common reason for inpatient admission of the terminally ill is their carers' inability to continue to care for them, the authors express the hope that the increased deployment of respite opportunities to carers will increase carers' capacity, and thus prevent avoidable admission.
- **(Wanless 2006)** argues in his social care report that though direct improvements in the care of those they care for have some impact, they are no substitute for improving our support for carers themselves. Resources should be directed toward supporting carers, even if that means redirecting those resources away from those to whom carers are providing care. In thinking about incentives, we should assess the care recipient and their carer or care network together in thinking about what formal services they will need. Interestingly, increasing the supply of formal care does not seem to have much of an impact on informal care, suggesting that people decide to provide informal care for different reasons (like in Scotland for example). This may be less true for filial carers than for spousal carers. Wanless recommends then that if we want to improve outcomes for spousal carers we should develop carer support rather than support for the cared-

for person. He speculated that this may not necessarily be true for filial carers, who may be more likely to return to the workforce if they see that their parent is receiving adequate care from formal care services. Time banks, adult day care, and employee support are all also options that need more exploring. We also need more clarity about the role of the state and individuals in taking care of the elderly, more regular assessment of carers' changing needs, and a robust debate about whether to regulate the abilities and performance of informal carers, or whether the resultant bureaucracy outweighs the benefits.

Several assessment tools are now in use to help practitioners identify those carers suffering most under the burden of their care work.

- **(Guberman, Nicholas et al. 2003)** used focus groups, interviews, and workshops (in the UK, Sweden, and Canada) to understand practitioners' sense of the benefit of carer assessment tools. The consensus was that the tools are useful and effective in reminding the practitioner to focus on the carer and helpful in highlighting issues that the practitioner would otherwise not have picked up. The tools helped practitioners see the carers as potential partners, to view them as individuals, to gain their expertise, but also to not view them simply as further resources at their disposal.

Other interventions are targeted at improving the carers' knowledge and ability.

- **(Blackburn and Read 2005)** surveyed by postal questionnaire 3,014 UK carers in 2003 (including 788 carers of disabled children) to find out about their internet use for information and advice. 75% of these 788 carers of disabled children had used the internet before, and 63% were frequent users, using it to stay connected to others through email, and to do shopping and look for information related to their caring. The remaining 25% were more likely to be renters rather than homeowners, to be unemployed, and to not own a computer. The author concludes that because of this quarter of the caring population, as well as because of the difficulties reported by many of the remaining internet users in finding the time or the technical know-how to look for information on their own, it cannot be expected that the internet to be the main source of information for everyone, and that information should be made available in other ways.
- **(Blackburn, Read et al. 2005)** use data gathered from the same group of 3,014 carers to learn more about carers' use of the internet. Though the authors acknowledge that their sample appears to under-represent men and younger adults, and to over-represent those who had been caring for a long time or with greater intensity (having built their sample partially from the rolls of Carers UK, as well as several local authorities), of their sample, only 50% had ever used the internet, and of these only 61% reported using the internet more than once a week. Younger carers were more likely to have used the internet, and to use it more often, as were the employed. While those caring for children were more likely to have used the internet before, carers who provided care for 20 or more hours per week were far less likely to have ever used the internet, and those that had were 60% less likely to report using it more than once a week. The authors thus conclude that the one in four carers who provide at least 20 hours of care per week, are considerably less likely to derive any direct benefit from efforts to digitise advice, information, or social networks.
- **(Read and Blackburn 2005)** note that of the half of carers who had never used the internet in their previous studies, only 14% claimed that nothing would get

them to use the internet. They therefore tested an intervention in which 60 carers were given free internet access and training. Though all of these 60 carers reported using the internet for a range of tasks, including caring-related ones, it appears that for a significant number of carers it is time constraints and an inability to repair network or equipment problems rather than availability that prevents the internet from being a more effective tool. The authors thus echo their previous recommendation that virtual information resources should be only one of several kinds available.

- **(Smith, Francis et al. 2003)** interviewed 184 carers of older people and 93 of those for whom they cared in order to learn more about the problems encountered by carers in keeping track of and administering medications. 67% of these carers admitted to at least one 'medication-related activity' with which they had trouble, and those under particular strain or suffering from poorer mental health themselves were even more likely to report trouble with medicines. Difficulties most often included maintaining adequate supply of medicines in the home, remembering to administer medicines and ensuring that the patient takes them, making clinical judgements about when to administer medicines or adjust doses, and communicating with health professionals and those they cared for about the medicines. The authors recommend that the process for reordering repeat prescriptions be streamlined, that instructions and information on side effects (a common concern of carers) be made clearer, and that packaging be clearer and simpler. It is also recommended that pharmacists and other health professionals understand that medications are often administered by someone other than the patient, and adjust their communication methods accordingly.

4. Conclusion and Recommendations

Informal care work is motivated by feelings of love, reciprocity, and duty, rather than pay and professional values, and is often performed in the context of longstanding relationships with their own histories and norms. Many who perform care roles view their care work as another stage in their relationship with the person they care for, and this can make the causes of harm and potential sources of satisfaction significantly harder to pin down in the study of informal carers than for paid carers.

Whether a carer will be more harmed or satisfied as a result of their care experience may have as much to do with their own background and resources as with the behaviour of the person they care for, though the diagnosis of the person they care for has a strong effect also. Little consensus has resulted from carer research, and interventions that work well with some people have little effect for others. It may also be because researchers are not measuring all relevant outcomes; one is struck by how many carers claim an intervention was helpful relative to the more modest outcomes measured. Conceiving of carer support efforts the way we do the treatments of patients, this variation is unsurprising given the number of co-morbidities and contributing factors to carer's psychosocial and physical health. Our potential to support carers likely lies in how flexible we can be in constructing a programme of support that best meets their particular needs, rather than in expecting one or several interventions to solve the problem.

Large questions regarding both the future supply and demand of informal care remain. In the future, we can expect care by spouses to increase, and this carer group stands

squarely at the intersection of many risk factors. They will require higher levels of support than they currently receive if they are expected to provide good care and not work themselves sick providing it. The supply and demand of informal care will have an impact on our future demand for formal care, perhaps more than the other way around, as the example of Scotland may show. Support for informal carers significantly leverages formal care resources, and so a reallocation of resources away from patients and toward carers is justified. A better prepared, higher skilled and more emotionally supported carer has a more distant 'breaking point', when they must place the person they care for in a care home, and thus formal support for the carer can be viewed as an investment in the capacity of the system. Public health values and methods, which are slowly gaining traction in the professional education of doctors and nurses, may bring new attention to what could be viewed as an epidemic of carers' strain. An increased recognition of psychosocial health problems may also lead to better recognition and treatment of carer strain.

Despite the lack of consensus around many issues relating to carers, there are a number of things that we know government can do to better support them:

- Educate professionals to recognise and support carers. That intensity of care increased in the 1990's without a change in carer strain may be evidence that the 'discovery' of carers has resulted in improvements. Professionals still operate in a reactive capacity toward carers however (much as it can be argued they do toward patients in general) and require training to identify and know of resources that can help unhealthy or vulnerable carers perform their roles less harmfully. Perhaps the simplest and most important thing professionals can do for carers is to validate their needs, encourage them to look after themselves, and make it easier for them to do so. Brereton and Nolan (2002) observed 'seeking' behaviour in carers looking for guidance and reassurance from practitioners who ignored these cues.
- Take steps that encourage practitioners to seek out carers who may not be engaged with health and social services. Even very dependent people who require substantial care, and thus place a large burden on their carers, may not be in regular contact with health and social care professionals. Maher and Green (2002) report that less than a quarter of those whose carer lived with them received regular visits from a social or health professional or voluntary worker. Hubert (2006) suggests hiring more social workers or district nurses with the mandate of going into the community looking for ways to lend support, rather than waiting for carers to approach practitioners.
- Expand access to respite services, and ensure that these services meet the needs of as many carers as possible through specialisation (palliative or paediatric, for example) and diversifying the amount of respite offered (a weekend, for example, or two weeks).
- Gain a stronger understanding of what elements of the care role can be most beneficial to carers. It is possible that increasing the most satisfying aspects of caring may decrease its negative effects by insulating the carer against depression and loss of control.
- Increase carers' practical, readily applicable knowledge and skills. This will help to increase their perceptions of their own competence, as well as increase the quality of their care by more objective measures.
- Train practitioners to support carers through the decision to place someone in a care home and afterwards. Practitioners must make more information available

- on care home options without simply increasing the information burden on the carer. Better ways of partnering formal and informal care must be tried out and expanded, particularly in care homes and in individuals own homes, as well as adult day care programmes.
- Legislate or incentivise greater workplace flexibility in order to maximise the number of carers who are able to continue working. One third of all carers change their paid work situation as a result of caring, and the most common change is withdrawal from the labour market altogether for at least the duration of their caring responsibilities (many never go back to work as some older carers instead opt to retire early). Besides severely limiting their financial resources, withdrawal from the labour market can increase social isolation, further destabilise carers' self-identities, and lead to depression and other health problems associated with carer strain. This in turn renders carers less able to care. An inability to balance care and work may also lead individuals with alternatives to the opposite conclusion, that is, to withdraw partially or completely from their care work, particularly if others besides themselves are dependent on their income. For this reason, workplace flexibility, and organisational cultures that invite the use of flexibility policies, will also increase the supply of informal care available.
 - Expand provision of formal social care. Though the relationship between formal and informal care supply is by no means a simple and direct one (Wanless 2006), making more and better care options available might have the indirect effect of increasing the room for choice in carers' decisions to care. There is some evidence which suggests that carer strain is related to the degree to which carers actively choose to be carers, and increasing the options available to those who do not could improve outcomes for carers, as well as the quality of care provided, albeit perhaps among a smaller group of informal care receivers.

5. References

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