THE ROLE OF FAMILY SOLIDARITY: ETHICAL AND SOCIAL ISSUES

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Health care systems in Europe are usually based on the principles of solidarity and equal access to care. This means that in most European countries there is a strong belief that individuals who need care should be enabled to access relevant medical and social care services and that there should be no limitations on the basis of income, health condition, race, sex, or any other personal characteristics. Though these principles are acted upon in different ways, the basic understanding of solidarity is that everyone is assumed to make a fair financial contribution to a collectively organized insurance system that guarantees equal access to health and social care for all members of society.

The idea of solidarity is associated with mutual respect, personal support and commitment to a common cause. This sense of fellowship with and compassion for the needy is still strong in the area of health care practices, where solidarity has acquired a particular meaning that goes beyond solely transferring income or benefits. In the domain of health and social care, solidarity is first and foremost understood as a moral value and social attitude regarding those in need of support. Solidarity with vulnerable groups in modern societies, in particular people who are chronically ill, disabled people, political refugees and frail older people is taken as an expression of personal concern and responsibility by the care giver, no matter whether she or he is a professional care-worker, a relative or a friend. Solidarity in this sense has an intrinsic value: it means standing for and protecting others not because of any personal interest, but because they need this protection (Ter Meulen and Houtepen, in press).

Solidarity does not only have a moral connotation, it has a sociological meaning, too. The French sociologist Emile Durkheim (1858-1917) described the transition from traditional to modern society as involving a transformation of traditional forms of co-operation and social relationships between individuals. The traditional or pre-industrial societies are characterised by what Durkheim called mechanical solidarity: the solidarity and the social co-operation based on it, is spontaneous, meaning not reflected upon: it is a normal or natural thing to help and support each other. In a situation of mechanical solidarity, there is a uniformity of beliefs and values within the social group of society, which may be enforced by strict mechanisms of authority and social control. As a result of the modernisation of society in general and the division of labour in particular individual relationships became more complex, dynamic and less territorially based. Heterogeneous associations replaced homogeneous groups and cultural interdependence was surpassed correspondingly by structural interdependence. In other words, societal modernisation resulted in a new and modern form of solidarity, in Durkheim's words an organic solidarity. This organic solidarity can be described as "an actual state of interrelations between individuals, groups and the larger society, which enables the collective interest to take priority over the interests of individuals or sub-collectivities" (Van Oorschot 1998). European health care systems can be seen as an example of organic solidarity in so far as the individuals are under the obligation to contribute to the interest of the community as a whole, that is equal access to health care for all who are in need (Ter Meulen, Arts and Muffels 2001).

However, the professional take-over of traditional mechanical solidarity has never been complete. The fact is that even a professional health care delivery system assumes the existence of a traditional solidarity, i.e., group responsibility for informal or family care, either supplementary to available, or in substitution for temporarily non-available professional care. In fact, the official solidarity is strongly dependent on this less visible kind of solidarity which tries to offer help or voluntary assistance to people who are close or near-by, such as family members, friends, neighbours or others. This kind of help and support

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is often called family solidarity or informal care, because it offers care in a non-professional way without restrictions and rules set by a central agency. Family care or informal care can be described as the mutual, self-evident, unpaid, non-organised help within a social network (Hattinga Verschure 1972).

One can wonder whether the solidarity of family care falls within the two categories of solidarity that are distinguished by Durkheim. The solidarity which is fundamental to family care has a personal, concrete meaning that is different than the organic solidarity which tries to organise collective interest in an abstract way. However, this personal solidarity is also different to the mechanical solidarity that is typical for pre-modern societies. The individualisation process has resulted in a change of the family structure as well as in the social structure of neighbourhoods. The care for another dependent person, a family member or a neighbour, is not self-evident any more. In the case of families, this is not only true for the relationship between parent and child, but also between partners. Instead of an economic relationship, family structures are turning into affective relationships (Knipscheer 1992). However, this change of interdependency does not result in a total disappearance of relations of support and assistance and of the willingness to offer this support. In fact, the decline of the compulsory nature of this support has made room for individual initiatives to provide assistance on the basis of free choice and personal autonomy. One may speak here of a new type of solidarity that is not based on compulsion, but on voluntary choices which tries to help individuals who are in need by way of concrete, personal service.

In Europe there are no legal duties to supply family care, though there may be a duty for families to contribute to the financial costs of care (for example the Unterhaltungspflicht (“duty to sustain”) in Germany. Family care is considered a voluntary decision, though the moral pressure to supply this care can be rather strong, even when there is no legal duty to do so. Family members can be very emotionally involved in the care for their ill or disabled partners or parents, and find it very difficult not to support and help them (Centrum voor Ethiek en Gezondheid 2004, 134). Spouses who provide care for their partner suffering from dementia try to keep doing so as long as possible as they see it as their moral duty to do so. Many of them feel guilty and depressed when their partner needs to be admitted to a care home if family care becomes too difficult and burdensome. So, while a legal duty to care does not exist in any European country, many family care givers feel a moral duty to supply care based on personal solidarity with the person in need. Nonetheless, in the course of time, family care can become a rather compelling and very burdening situation which is difficult to escape from. This is particularly the case in family care for people with long-term progressive conditions like dementia. Some carers may have started caring out of affection or other intrinsic motivation, but are feeling increasingly trapped in the process of care giving, worried about what would happen if they refused further care (Department of Health 1999, 23). The question arises whether the terms free choice and voluntariness are appropriate in such a situation.

In EU countries the incidence of family care ranges from 1–2 percent for 20–39 years old to 10 percent for women over fifty (Viitanen 2007, 3). This may differ by country as in some countries (particularly in Scandinavia) formal care may be more dominant. In these countries (Finland, Denmark) everyone has a right to care, including professional care at home (RMO/RVZ 1999). The number of family care givers in Great Britain is growing: the 2001 Census found that there were 5.2 million carers (approximately 11 percent of the population) in England and Wales only, with over one million people caring for 50 hours or more (HM Government 2008, 33). There will be a projected 1.6 million more adults in England requiring care by 2026 (a 30 percent increase) and 2.9 million more by 2041 (HM Government 2008, 41).

Women are more likely to be carers than men, 58 percent of the carers in Britain are women, compared with 42 per cent who are men. In the Netherlands in 2004, 2 million people were providing informal care (12 percent of the population), 400,000 of them long-term care. In 2000, 32 percent of the population of 50–69 years was involved in informal care for the older generation (NIZW 2004, 2) with middle-aged daughters and daughters-in-law as the largest group. Compared to men, women perform domestic tasks, including those in the area of personal and intimate care, more frequently. Men tend to work around the house, do financial tasks and offer moral support (Duijnstee et al. 1998). Only in cases where their wives are severely and chronically ill do men perform the same domestic and personal care tasks as women. Informal carers live near-by or in the same house as the dependent person; they live in shared households and generally have no income or belong to the lower income groups. They also have a lower level of education. A substantial number of women take care of their dependent elderly parents as well as their children. Moreover, they may have health problems of their own.

Informal or family care comes at a high cost – financially, physically and emotionally. First of all there are financial costs: caregivers are forced to interrupt their careers or retire early in order to facilitate the provision of informal elderly care. Such interruptions not only result in direct short-term costs, but also have long-term effects in terms of lower collected pension entitlements (Viitanen 2007, 3). The physical and emotional burden of informal care can be very high. The most demanding tasks are lifting the dependent person, helping him or her to the toilet or turning over in bed, extra household tasks and travelling to and from the hospital (Kuyper 1993). These burdens are particularly heavy in the informal care for demented patients who not only need personal care, but also need to be guided and sometimes even guarded almost every hour of the day. Apart from physical burdens, the care for a demented partner leads in most cases to strong emotional problems (see the case study below).

While the burden of care is growing, the demographic process is reducing the number of people available to give informal care. The change to the nuclear family has reduced the possibilities for care giving, while many families are now geographically dispersed. Children of dependent elderly have moved away from their parents to other cities or regions, have their own family life, or are divorced and may have started with a new partner or family. According to the HM Government report Carers at the Heart of 21st Century Families and Communities, changes in family life and economic conditions have made it increasingly difficult to supply family care: "More families rely on two incomes, or longer working hours, to maintain an adequate standard of living. Many families find it difficult to balance work with the care needs of friends and relatives without significantly impacting on their own standard of living, esteem and independence – the lifestyle to which the family has been accustomed". The report argues that as a society we need to face up the challenge of family care as we "depend to a large degree on the continuation of the care that carers provide" (HM Government 2008, 36).

The decision to provide informal care is dependent on various social and emotional factors (Knipscheer 1992). One important factor is that there is enough support for the informal carer, not only emotional support from relatives and friends, but also professional support offered by the organised health care system, particularly home care. Duijnstee et al. (1998) mention four categories of support that are especially relevant to informal carers: emotional support, information and advice, practical/instrumental support and material support. Emotional support can be the exchange of information and experience through discussion groups. In the Netherlands there are many such groups specifically aimed at informal carers. Telephone lines are also helpful, for example the Alzheimer line operated by both the Dutch Alzheimer Foundation and the UK Alzheimer's Society.

Professional support is very important for informal carers. This can be practical and instrumental support which can alleviate the physical burden of care. Moreover, instrumental support can safeguard the emotional relationship between partners, which is in many cases the moral basis of the provision of informal care. Professional help for physical care will enable the informal carer to have more time for himself or herself, for the lack of personal free-time is an important part of the burden of informal carers. When family care becomes too stressful and burdensome, it may lead to the physical and emotional abuse of the older person who is supposed to be cared for (Lamura 2008). Temporary breaks from caring may diminish the emotional and physical strain and the personal ties between the patient and the carer can be strengthened or at least kept at an adequate level. Such relief can be realised by respite care and outpatient care offered by nursing homes and community centres.

The most important support of informal carers is the recognition that they are partners in the care for the dependent person (RMO/RVZ 1999). Many informal carers feel that there is little respect and appreciation for their work, which is indispensable to the care system. The institutional home care agencies should recognise the contribution of the informal carers and not create a tension between professional carers on the one hand and the informal carers on the other. The HM Government Report Caring about Carers (1999) states that "recognition of their contribution to the care of someone else and to society more widely is important to many carers. They value involvement in discussions about the help provided to them and the person they are caring for, as well as practical help with the tasks of caring" (Department of Health 1999, 22). Instead of a paternalistic approach, professional home carers (like district nurses) should acknowledge the contribution of the family carer. The family carers should be open to professional advice and not reject the professional care out of hand. Both kinds of care are mutually dependent on each other.

Family care givers are confronted with many ethical problems, like respecting the privacy and autonomy of the cared person, taking care of the best interests of the cared for individual if his or her autonomy has been diminished (for example in the case of dementia), balancing the needs of the person cared for with their own needs, and the relationship with the professional caregiver, especially with regard to confidentiality. These issues are particularly relevant in the case of care for people with dementia as illustrated by the case below.

Case study: the needs of carers for people with dementia

Ethical issues arising in dementia have recently been studied in depth by a Working Party established by the Nuffield Council on Bioethics (Nuffield Council on Bioethics 2009). The ethical framework proposed in the Council's report, *Dementia: Ethical Issues*, places considerable emphasis on the ethical imperative of acting in accordance with solidarity. The report recognises both the "mechanical" and "organic" aspects of solidarity described earlier in this chapter, identifying solidarity as the basis both for the informal family support provided for people with dementia, and for the obligation on wider society to provide appropriate care for those in need. Indeed, it argues that solidarity places such duties not only on the state as a provider of care services, but potentially on all of us, as individuals, families and communities, to ensure that we include people with dementia as equal citizens in our daily lives, and act to support carers in their own expression of solidarity with those for whom they care. Further, the Nuffield Council highlights the ethical importance of considering carers' interests, as well the interests of those with dementia, emphasising that carers have equal value as people in their own right and a strong claim to have their autonomy and well-being considered.

Drawing on this ethical framework, the Nuffield Council report makes the following conclusions and recommendations in respect of those providing unpaid care for people with dementia (quotations taken from the many responses to the Council's public consultation):

- Professionals and care workers should treat families and carers as "partners in care", based on a relationship of trust and mutual respect for each other's role and expertise. Indeed, there is an ethical imperative for professionals and care workers to start from a presumption of trust in the carer, in their good intentions and in their knowledge of the person with dementia. "Carers' skills must be recognised as such, working in partnership with a professional … so that the relationship of trust and honesty is built up."
- Such trust has implications for confidentiality and access to personal information – if carers are truly to be treated as "partners in care", then they should have access to information about the person on the same basis as other members of the care team. In short, carers should be provided with any information that it is necessary for them to know in order to carry out their caring role. "I was stunned that my doctor would not speak about my concerns … I felt frightened about my husband's changes in behaviour …".
- Adequate financial and social support is crucial: carers should not have to "know the system" and assert their rights in order to obtain the support to which they are entitled by law. Support should not be limited to financial matters but should also encompass emotional and practical support such as help in the house, adaptations, access to education about dementia and counselling.
- Carers need to be recognised as individuals with their own needs. In taking on the identity of a carer people often risk losing aspects of what it meant to be themselves. It is therefore crucial that mechanisms are in place in order to allow carers to hold on to their own identity – for example through regular access to respite services in order to give them free space to be themselves and pursue their interests outside their caring role. "I gave up teaching, singing, all things that gave me my identity."
- Carers need to be supported to consider their own interests as well as the interests of those for whom they care. In the UK, decisions for people who are unable to make decisions for themselves must always be made in that person's "best interests". This may seem to imply that once a person with dementia lacks the ability to make their own decisions, their interests must always take precedence over those of others. In practice, this cannot be the case: interests are complex and intertwined and in a family it will rarely be the case that one person's interests always take priority. Professionals have an important role to play in supporting carers explicitly to consider their own needs and interests when difficult decisions have to be made.

Conclusion

Due to the scarcity of resources, many European countries are now discussing the extent and limits of solidarity. Though there is still a large support for weak and vulnerable groups, there is an increasing concern that in the long term equal access to a broad package of health care services cannot be guaranteed. This concern is particularly raised in relation with long-term care of dependent older people, including institutional care, like care homes, nursing homes and professional home care. National governments are trying to deal with this problem in various ways (Ter Meulen, Offermans and Maarse 2004). First of all, they are attempting to reduce the extent of publicly financed long-term care and to make the access to these services dependent on private financial contributions. A second instrument is introducing stricter eligibility requirements for publicly financed long-term care services, including professional home care. A third development is the increasing pressure on families to deliver care for their dependent family members and to take over care previously provided by professionals. An example is the recent policy in the Netherlands, to make a distinction between "real" care (which will be supplied according to need) and "normal" or "usual" domestic care (chores) to be delivered by family members (Morée et al. 2007). Such policies will lead to increased pressure on family care givers, and may threaten the readiness and capacity to supply informal family care.

Family solidarity is an important condition for the adequate functioning of formal, professional health systems, but should be adequately supported by the provision of material, practical, emotional and professional support. Such support is not only important for instrumental reasons, but also from a moral point of view, meaning the importance to maintain the intrinsic value of personal solidarity as a guiding principle in the care of vulnerable people and in our society in general.

References

Centrum voor Ethiek en Gezondheid (2004), "Mantelzorg, kostenbeheersing en eigen verantwoordelijkheid", in *Signalering ethiek en gezondheid*, Den Haag/Zoetermeer, 127–51.

Department of Health (1999), *Caring about Carers. A National Strategy for Carers*, HM Government, Crown Office, London.

Duijnstee, M., A. Van den Dungen, P. Cuijpers and R. Maliepaard (1998), "The Role, the Burden and the Support of Informal Care", in A. J. P. Schrijvers, ed., *Health and Health Care in the Netherlands: A Critical Self-assessment by Dutch Experts in the Medical and Health Sciences*, Elsevier/De Tijdstroom, Maarssen, 20–32.

Hattinga Verschure, J. C. M. (1972), "Ontwikkeling van zorgcriteria voor herstructurering van de gezondheidszorg", Het Ziekenhuis 2(9), 500–04.

HM Government (2008), *Carers at the Heart of 21st-century Families and Communities*, Crown Office, London.

Knipscheer, C. P. M. (1992), "Demografische veranderingen en het zorgvermogen van de samenleving", in N. van Nimwegen and J. de Jong Gierveld, eds., *De demografische uitdaging: Nederland in Europa op weg naar de 21ste eeuw*, Bohn Stafleu Van Loghum, Houten/Zaventem, 89–107.

Kuyper, M. B. (1993), *Op de achtergrond. Een onderzoek naar de problemen van partners met een chronische ziekte*, Katholieke Universiteit Nijmegen, Nijmegen.

Lamura, G., E. Mnich, B. Wojszel, B. Krevers, K. McKee, L. Mesthenos, M. G. Melchiorre, A. Principi, P. Fabietti and H. Döhner (2008), *Elder Abuse and Family Care of Older People in Europe: Some Reflections Based on EUROFAMCARE and Related Findings*, paper presented at the meeting of the FERPA Executive Committee, Brussels, October.

Meulen, R. H. J. ter, W. Arts and R. Muffels (2001), *Solidarity in Health and Social Care in Europe*, Kluwer Academic Publishers, Dordrecht.

Meulen, R. H. J. ter, M. Offermans and H. Maarse (2004), "Ontwikkelingen in de zorg voor ouderen en chronisch zieken" in H. Maarse, R. H. J. ter Meulen, S. Boessen and M. Offermans, eds., *Besluitvorming over het zorgpakket. Politieke, normatieve en internationale aspecten*, Universiteit Maastricht, Maastricht, 133–60.

Meulen, R.H.J. ter and R. Houtepen, "Solidarity", in R. Chadwick, ed., *Encyclopaedia of Applied Ethics*, Elsevier, Oxford.

Morée, M., B. van der Zee and A. Struijs (2007), *Formalisering van informele zorg. Over de rol van 'gebruikelijke zorg' bij toekenning van professionele zorg. Singalering ethiek en gezondheid 2007*, Centrum voor ethiek en gezondheid, Den Haag.

NIZW (Nederlands Instituut voor Zorg en Welzijn 2004), Vergrijzing en informele zorg, Den Haag.

Nuffield Council on Bioethics (2009), *Dementia: Ethical Issues*, London.

Oorschot, W. van (1998), *Shared Identity and Shared Utility. On Solidarity and Its Motive*, Tilburg Institute for Social Sciences, Tilburg.

RMO/RVZ (1999), *Zorgarbeid in de toekomst. Advies over de gevolgen van demografische ontwikkeling van vraag en aanbod zorg(arbeid)*, Raad voor Maatschappelijke Ontwikkeling/Raad voor de Volksgezondheid en Zorg, Den Haag/Zoetermeer.

Viitanen, T. (2007), *Informal and Formal Care in Europe*, Forschungsinstitut für Zukunft der Arbeit IZA DP N0.2648, Bonn.