

Editorial

Private troubles, public issues: the case of family care

Much has been written over the past 30 years about the importance of family care in providing for the needs of people who are chronically ill and dependent. Over a century ago, anthropology described lay care practices and pointed out the vital function of the family for the survival of the ill. For instance, this is recorded in Black's *Folk Medicine*, published in 1883 (Pablo, 1982), and it is shown in a video about the nurse anthropologist Madeline Leininger (Leininger, undated). Today, it is known that about 70–90% of health care takes place within the family and, not surprisingly, it has been described as 'the real site of primary health care' (Helman, 1998:65).

Informal care and caregivers have attracted much research attention, and now constitute a distinctive body of knowledge and a research area. Thus universities throughout the world have centres for examining chronic illness, which touches on family care, and research groups are established around this substantive area. It has clearly become an academic issue. Work in Columbia (de la Cuesta *et al.*, 2000) has shown that family care covers a wide range of conditions and ages, from the frail elderly to the demented adult or the sick child. It confronts terminal, chronic and degenerative conditions, and deals with both essential and high-technology care. Family care is versatile, comprehensive, offers a wide range of services and, most importantly, it is generous. It does not refuse a condition however difficult the carer feels it may be, and yet this service passes either unnoticed or insufficiently supported. Professional help is not a luxury, but something that is much needed. Research has repeatedly found that caring for a relative at home involves suffering and hard work.

Nevertheless, national health care systems and health care insurance schemes are falling short in meeting these needs. In some countries, family care is still very much a private problem. There are

no policies, statutory support or regular community services for the chronically ill and the dependent. An ongoing qualitative study into family care of patients in the final stages of dementia conducted in Medellín, Colombia (de la Cuesta *et al.*, 2000), shows that in this situation caregivers are able to manage highly demanding conditions by mixing insurance schemes, private initiatives and extended family links, and sometimes by relying on community solidarity and even charity. However, there are still few caregivers who have any social network, and many are left alone with their private problems. This study shows that the task they are doing is enormous and usually undertaken under adverse conditions. They have no 'respite' facilities, but they do have good neighbours, friends and relatives who take over their care responsibilities for short periods of time. They are in fact meeting their needs themselves by mobilizing resources, including the setting up of lay associations. Health care professionals are not unresponsive to this arduous situation. For instance, they are running, on a regular basis and *ad honorem*, groups to orient, inform and support caregivers. During the study, caregivers acknowledged the vital role that these groups played, especially during the early stages of the disease.

On the other hand, there are countries where family care is clearly a public issue. For instance, in the UK the Carers Recognition Act of 1995 has put carers' needs into the public eye (Ashworth and Baker, 2000). Nevertheless, being a public issue does not of itself ensure that help needed is received. This has been suggested by a recent published research study conducted in the UK. From a large-scale nation-wide survey of 2000 questionnaires, it provides disturbing evidence. The study found that over 50% of the carers surveyed did not receive enough help with their everyday tasks, and that over 50% needed help and did not know where to obtain it (Anon., 2000). Here, despite policies,

legislation and resources, family care is still for many a private problem – public support does not reach them.

Why is this so? The key clearly lies in primary health care. An important aspect, I believe, is the nature of the relationship that professionals working in the community establish with family caregivers. The literature suggests that professionals ought to regard lay carers as clients with a specific or ‘expert’ knowledge (Nolan *et al.*, 1999), and accordingly they should relate with them in such a way. However, this involves a type of relationship that is new to the health care arena, which has embedded difficulties. On the one hand, it must be borne in mind that professionals and lay carers work under different ‘labour’ rules and draw on different types of ‘expert’ knowledge (Stacey, 1995; Nolan *et al.*, 1999), while on the other hand ‘professionals’ *trained incapacity* to hear what is being said’ (Stacey, 1995: 211) has to be overcome if a true working relationship is to be established. Moreover, it must be recognized that caring professionals often lack a theoretical framework to guide practice when dealing with lay carers (Nolan *et al.*, 1999). If family care is going to receive real support, these issues need to be addressed.

Although policy might well be a necessary condition to give family carers the help that they need, professionals hold the key to making a real difference in this provision. Family care, whether it is regarded as a substitute for state provision (a private problem), its complement, or a ‘client’ (a public issue), is the major concern of primary health care professionals. For some it will imply a need to move professional boundaries, while others will have to strengthen community development schemes, and in some places new services or professional roles in the community will have to be established. Either way, as the trend is towards

more care in the community, primary health care professionals are placed between the public and the family/private health care arena. Therefore they are in a position to make this issue work.

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