

Health and Social Services**Cherry Rowlings**

Rita B. Black, Douglas H. Dornan and John P. Allegrante, Challenges in developing health promotion services for the chronically ill. *Social Work*, 31 (4) (1986), 287–293.

The long-term nature of chronic disorders means that treatment must shift from elimination of disease to maintenance of function. This reflects the challenges facing the individuals concerned, which, for much of the course of their illness, focus on developing coping strategies for daily living. The authors propose that the needs of people with chronic illnesses may best be served through (1) voluntary health agencies and (2) a programme of self-care education, social work and health education.

Voluntary health agencies (such as the American Heart Association, the American Diabetes Association, the Parkinson's Disease Foundation and the Arthritis Foundation) already have developed self-help systems; they are committed to the dissemination of information about treatment and rehabilitative strategies. As organisations whose membership consists of chronically ill people and their families, they are well placed to develop their existing and historical role of addressing the social, educational and medical needs of their members.

The capacity for self-appraisal has been shown to be crucial to the development of coping strategies for chronic illness. Responding to the crisis of the onset of illness and adjusting to an acceptance of chronicity – a stage where individuals move beyond their illness, accepting help where necessary but essentially devoting time and energy to matters unrelated to their illness – represents the development of mastery and of new areas of competence. But for this to be more widely achieved, it is necessary to develop new and expanded programmes of health promotion, and the authors propose that there should be a community, voluntary agency based effort to help individuals understand, manage and cope successfully with the acute episodes and the lasting impairments of their illness.

Such a programme would emphasise the individual's own problem-solving capacities and would therefore focus on time-limited intervention. Self-care education groups, led by a social worker and health educator, would provide support and also aim to deepen individual and group processes of self-appraisal so as to aid self-management of illness and coping strategies. Health education groups would provide information on the specific illness, on methods of care and on general health. Resources would be publicised and attention paid to measures likely

to promote overall physical health. An essential aim of health education would be to enhance the individual's ability to review any controversies over treatment and to debate the options of different approaches to the illness.

The social work element of this health promotion programme would be more likely to be an individualised service, focusing on the needs of a client and his/her family. The social worker would be likely to be dealing with the emotional response to illness, the development of new roles, access to community resources and developing skills in assertiveness or decision-making. A task-centred approach offers an appropriate model for this work.

However, it is essential that the programme is integrated and that social workers, health educators and other community-based health professionals work together to enhance the self-management capacities of those who are chronically ill.

COMMENT

This article is not addressed specifically to the experience of older people but its subject is clearly relevant; many of the chronic disabling conditions (arthritis, heart disease and Parkinsonism, for example) are the diseases predominantly of people who are over pensionable age. Curiously, the authors do not address, or even mention, this fact, yet for many people the onset of their illness is the time at which they confront their ageing. It also means that they are doubly handicapped when seeking to maintain a role and status in society: not only are they sick but they are also old.

The part of this article which addresses the role of voluntary organisations is the less well argued and is probably more location-specific than that which describes the content and purpose of a health promotion programme. But here there is much of interest and relevance to social workers and health care professionals who are committed to services for older people. The authors take a fairly traditional view of the response to chronic illness, adapting the work of Kübler-Ross and others who have described the phases of denial, grief and, finally, acceptance. However, even if one were less inclined to the view that such progression is the norm, the strength of their message is not diminished. They are intent on developing and enhancing strengths for coping, not on creating dependency, and the use of groups and an educational approach is relevant here. Too often, older people are isolated and uninformed about their disability; decisions about treatment (or, sometimes, no treatment), discharge, medication and levels of support

to be provided are made with little involvement from the person concerned. That is why innovations such as allowing elderly patients in hospital to have control of their medication or the contract-making sessions of the Kent Community Care Scheme are important steps towards enabling older people to retain power in determining the way they will live. The authors of this article point out interesting possibilities for the work of, in particular, health visitors and social workers – both individually and collaboratively. Most important, though, is their underlying philosophy which leads them to work for a sharing of power between professionals and those who are ill.

Mona Wasow, Support groups for family caregivers of patients with Alzheimer's disease. *Social Work*, 31 (2) (1986), 93–97.

The author of this paper starts from an acceptance of the value of support groups in educating carers about Alzheimer's disease and in providing opportunities for them to share ideas and common experiences. Nevertheless, drawing on her experience of co-leading a support group, she has identified a number of professional dilemmas and questions which she would like to see explored in practice and in research.

The first of these is whether the leader should be providing therapy or support. Caregivers in her group were sometimes resistant to exploring their negative and painful feelings; they did not always want the group to be stressful since they were under enough stress at home. Yet some were carrying a good deal of anger and despair, and strong negative feelings that are not expressed and understood may cause additional problems for both carer and patient. The author asks, what are the appropriate limits on how much insight and ventilation should be encouraged, given the extremely lonely and difficult circumstances facing many carers, from which they have little hope of relief? If there is little room for change, how far should the leader encourage members to face the pain, however dysfunctional it might be?

A second dilemma concerned the focus of the group. Some members clearly wanted to discuss the disease, coping strategies and so on. Others, however, did not want to dwell on problems and symptomatology, saying they had enough of Alzheimer's disease at home; when they were out, they wanted a change. There were times when the group gave indications of when it wanted to focus 'on' or 'off' Alzheimer's disease, but this was not always the case. Moreover, little evidence exists to help leaders to decide when and under what circumstances focusing on problems is helpful and when it is not.

Thirdly, the author considered the question ‘what is successful coping?’ and linked this with a subsequent dilemma, that of balancing the needs of the caregiver and the cared for. Should caregivers be encouraged and supported to go on caring or is this in fact creating a situation whereby there are *two* victims of the disease?

A final cluster of dilemmas was about the composition of support groups. Is it better to mix spouses, siblings and children together or to run separate groups? The author suggests the latter is preferable. She is less certain, however, about the merits or otherwise of having carers whose relatives are at different stages of the disease or of mixing newcomers and experienced group members.

The author also highlights some more general areas she would like to see addressed in future research. These are (1) a study of the different responses to caring with a view to identifying what may lie behind these differences; (2) an examination of the significance of the family system or, rather, of the three family systems (family of origin, of procreation and spouse’s family) within which the caregiver is functioning; and (3) how carers survive after the death of their spouse.

To conclude, the author describes her ‘dream programme’ for supporting carers. Running over twelve weeks, it would consist of four weeks devoted to education about the disease and a further four weeks where carers could choose between different groups – one focusing on therapy, one on recreation, one continuing the education theme and one run by members on lines similar to Alcoholics Anonymous. In the final block of the programme, carers could switch groups or move back and forth among them.

COMMENTS

The content of this article will be familiar to many who have led carers’ groups and it is a pity that the author, by her own admission, has limited experience of such groups. Thus, whilst the problematic areas are highlighted, there are few suggestions about possible resolutions. Greater depth would have been provided by the inclusion of more practical wisdom or of the literature on carers’ groups. That being said, the value of the article lies in the way in which a number of important practical issues is brought together and the ‘dream programme’ contains useful ideas about the ways in which carers might benefit from a chance to choose the kind of group(s) they attend, instead of being faced with one type that reflects the leader’s interests and skills or none at all.

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