assessing the health promotion needs of informal carers

How do carer support programmes meet the needs of those caring for dependent mentally ill older people? Julie Hall reviews the evidence

Ensuring the assessment of needs and providing effective interventions for informal carers is a significant part of contemporary mental health policy. Literature and policy perspectives suggest that good practice in this area focuses upon carers’ support programmes (Health Education Authority 1997, DoH 1999a). Policy themes, which have driven the move from hospital to community care, have influenced the role of informal carers in society (DoH 1991). However, the assumption that the role of informal carer is supported by an adequate infrastructure has been disputed. Both Working in Partnership (Butterworth 1994) and The Health of the Nation – Key Area Handbook: Mental Illness (DoH 1993) outline the need for assessment involving carers. The Carers (Recognition and Services) Act (DoH 1995) specifically indicates that support for carers and assessment of care needs is a high priority. The scope of the Act suggests that informal carers of all ages are those ‘who provide or intend to provide a substantial amount of care on a regular basis’ (DoH 1995).

Assessment can be undertaken at the carer’s request or as part of a review through professional systems such as discharge/review procedures. It is the responsibility of local authorities to ensure that such systems are in place and that carers are involved from the point where the care process begins. Within the Act there is little acknowledgement of what these systems may entail, omitting reference to the care programme approach (CPA) introduced in 1991. This is a systematic approach towards providing effective community care for people with mental health problems, and has a fundamental relationship with the role of informal carers. Practice guidelines within the Carers Act focus upon assessment, with the scope of support open to local interpretation.

The National Service Framework for Mental Health (DoH 1999a) proposes seven national standards for mental health. Mental health promotion features as Standard One and echoes the suggestion in Saving Lives – Our Healthier Nation (DoH 1999b) that those caring for people with dementia are susceptible to anxiety and stress. Significantly, Standard Six focuses on carers and builds on the previous National Strategy for Carers (DoH 1999c) which suggests an approach to working with carers, offering information, support and care underpinned by extra funding arrangements.

The service models proposed outline needs assessment and carers’ plans underpinned by the CPA, also reviewed in 1999. Service provision and local performance is to be assessed through national assessment and local milestones. Local milestones are measured predominantly through CPA review returns, a process acknowledged within the framework as being administered variably. The recent National Service Framework for Older People (DoH 2001) plays scant attention to the needs of informal carers. Despite claiming to promote independence and health, carers are barely acknowledged within key milestones. Standard Seven of the framework focuses upon mental health provision and leads the way in acknowledging the role of carers, although this is not generalised throughout remaining standards.

informal carers and health promotion

It is widely acknowledged that caring for dependent others can have a detrimental effect upon health and wellbeing (Kennie 1993, Wilford 1996, Turner-Boutle et al 1997). A link between carers and health promotion is established by the potential impact of informal caring upon the determinants of mental health, defined by Tilford et al (1997) as ‘biological/personality, psychological/behavioural, sociocultural and mental health/illness factors’.

The theme of mental health promotion is established in the literature as having the most specific link to informal carers. Turner-Boutle et al (1997) and Armstrong and Sparks (1997) suggest that carers of dependent others are at high risk of experiencing poor mental health or developing mental health problems. Tilford et al (1997) and the Health Education Authority (1997) confirm that carers of highly dependent others are an identified high-risk group. Carers vary in their reactions to their role, but in many cases there is a favourable response to mental health promotion. The Health Education Authority (1997) defined mental health promotion as an integration of the existing fundamentals of health promotion, while acknowledging ‘the importance of psychological processes – how people think, feel, interpret and communicate – and the role the mind and the emotions play in our interactions and experiences at all levels’. Literature on informal caring supports the rationale of adopting a health promotion approach to meeting the needs of informal carers.

the needs of informal carers

The needs of informal carers of dependent older people with mental illness have been defined succinctly by Naidoo and Wills (1997) as ‘something people can benefit from’. The identified needs of informal carers are analysed based upon Bradshaw’s (1972) taxonomy of needs. The taxonomy examines four types of need – normative, felt, expressed and comparative. This encompasses needs as established by both carers and professionals, in order to achieve a comprehensive analysis.
For the purpose of this article, data is gathered from relevant literature and critically analysed by application of the model of health promotion outlined by Tones et al. (1990). This emphasises how individuals can be enabled to make choices supported by education and information. Running parallel to education is raising public consciousness and pressure, which drives public policy. Age Concern’s influence in the National Service Framework for Older People (NSF) can be seen as an example of the role pressure groups play within policy-making. The rationale behind the choice of this model is its close association with empowerment and healthy public policy. An alliance is established between the model and the psychological/behavioural and socio-economic needs of carers. The model suggests that health promotion is established by a mixture of health education and healthy public policy, which can be defined as policy with a strong evidence-base that embodies the involvement of groups and communities.

- **normative needs** The psychological health of care-givers has emerged as a major focus in professional texts. Studies by Mitchell (1996), Russell et al. (1989) and Juoice et al. (1990) identify the common need for information, emotional support, advice and socialisation. Mitchell (1996) and Russell et al. (1989) further explore the impact of care-giving on self-concept, with its negative effects upon confidence and assertiveness. An absence of decision-making skills results in inadequate coping as outlined by Hunt (1996) and Mackintosh (1993). From this focus, Mackintosh (1993) establishes the importance of empowering carers through health promotion and enabling them to make their own decisions. This may be considered as an attempt to develop an internal locus of control, as many carers find that their role renders them powerless. Building esteem and empowerment enables carers to develop their own control over circumstances and therefore influence their own health choices.

The Health Education Authority (1997) identified the need for social support networks to reduce carers’ levels of isolation and stress. Evidence of carers’ support groups addressing psychological/behavioural needs is commonplace. Critically, the absence of literature regarding the fulfillment of socio-economic needs may be a consequence of the absence of professional intervention associated with social change and relevant health policy. This suggests that where needs assessments are professionally led there is a failure to focus on a wider agenda (Tones 1997). Importantly, this generalisation suggests that often professionals consider all carers to be devastated and unable to cope. This viewpoint shapes health promotion approaches that do not build upon the past, present and drive that can exist within informal carers.

There is an absence of literature celebrating the successes of informal caring and how carers have been successful in empowering communities and influencing public policy. Tones et al.’s (1990) model acknowledges the need for professional education and the promotion of individual as well as group and community autonomy. It may, however, seem ambitious and presumptuous to suggest that all informal carers will wish to pursue public policy through community action. Issues of importance may seem to rest closer to home.

- **felt needs** The felt needs of the target group are expressed in case studies. Mitchell’s study (1996) suggests that, when asked directly, carers express the need for information and emotional support at the top of their hierarchy of needs. This confirms the already suggested normative needs. Case studies by Peace (1995) and Wilford (1996) outline the social needs related to coping with difficult behaviour, help with physical care, respite care and the social isolation related to caring. Professionals less frequently identify these needs, perhaps due to professional agendas and spheres of influence. Professionals are often compromised in expressing the needs of carers due to the scope of existing services. In professional terms advocacy can be difficult and tensions are acknowledged.

In Peace’s study (1995) a carer was deeply distressed by his wife’s behaviour. He said that he felt ‘exhausted, frustrated and embarrassed’ and also ‘that it never went away’. Mawby (1993) describes informal caring as an endless activity with little or no respite. The Department of Health (1991), in the NHS and Community Care Act, acknowledged the vital role of informal carers but outlined little practical assistance. Until recently, critical health policy associated with the long-term care of older people remained neglected. Tones et al. (1990) reinforce the importance of healthy public policy. It is suggested that education should be implemented to raise public consciousness and empower carers to maintain an agenda for increasing pressure to promote healthy public policy. The health promotion model establishes the importance of meeting the socio-cultural needs of carers. Issues of social care, respite care and financial implications are areas of potential influence via this avenue.

- **expressed needs** The expressed needs of carers are rarely established. Those being cared for often dominate the focus of attention and carers’ own needs can go unrecognised. Professionals and pressure groups are suggested as advocates for expressing carers’ needs. Mitchell (1996) suggests that expressed needs span broadly across all of the determinants of mental health. Professionals and pressure groups attempt to adopt the role of expressing carers’ needs. Examples of this may be seen in day-to-day practice when multi-disciplinary teams and families meet to plan aftercare. Professionals advocate on behalf of carers, attempting to define unexpressed needs. Deficiencies in advocacy occur when professionals express purely normative needs. In these circumstances there may be a particular failure to express carers’ socio-economic needs.

- **comparative needs** The comparative needs of many carers are influenced by existing health equalities relating to ageing. This has been examined at length in the literature (Baggot 1994, Benzeval et al. 1997). Hancock and Hancock (1993) established that ageing itself is seen as negative without the impact of the informal caring role. If older carers are compared to a younger group undertaking the same role, alternative agendas and outcomes may be established. Ageist attitudes may suggest that older people have less to lose through the adoption of the caring role.

It should be noted that Alzheimer’s disease is a major area of health-care expenditure in Britain. Mackintosh (1993) estimated that there will be 42 new cases of dementia diagnosed every day between 1993 and 2003. Health and social care implications are phenomenal, reflecting a pessimistic view when the present infrastructure provides no consistent...
method of support for informal carers. The absence of strategic service delivery for carers may itself be viewed as an established health inequality. Healthy public policy is influenced by advocacy. Locally, professionals act as ‘street-level’ bureaucrats, as described by Lipsky (1992). Even if they are not lobbying at national levels they do influence how policy is delivered locally.

The outcomes of healthy public policy are an integral part of health promotion and one potential outcome is a healthy social and physical environment. However, the established needs of carers indicate that a ‘healthy’ environment for carers rarely exists. An intended outcome of healthy public policy is the existence of health-promoting organisations. Again, evidence of this is meagre. The Health of the Nation – Key Area Handbook for Mental Illness (DoH 1993) outlines the need for practical advice and support, but generally this fails to exist as an integral part of NHS trust service specification.

These issues are fundamental to the socio-economic needs of informal carers, as changes in the environment are necessary to maintain positive change in health. Naidoo and Wills (1997) suggest that, within the NHS, comparative needs are met with irregularity. Response is based on service provider attitude, agenda, status and resource. In an arena of overwhelming growth, such an irregular response to need seems inadequate.

**current service provision**

Current approaches are analysed in conjunction with Tones et al’s (1990) model of health promotion. Provision of carer support generally involves the delivery of a carers’ support group in addition to individual supportive interventions by primary and secondary healthcare professionals. Carers’ support groups are described by Mitchell (1996), Russell et al (1989) and Hunt (1996). Such groups focus initially upon information-giving and emotional support. There is a strong emphasis on socialisation and mutual support throughout the six to eight-week closed programmes (Table 1). Critics suggest that this is an expert-led intervention associated with the medical approach to health promotion. However, carers’ support groups offer a strong emphasis towards empowerment and education. Facilitators focus on communication skills, coping strategies and decision-making with a view to empowering. Co-facilitators and voluntary agencies encompass the medical and social aspects of caring. On completion, carers are encouraged to maintain social contact with their peers, although this is the point where service provision often ceases.

The service provision described is limited in meeting the stated needs of long-term informal carers. The carers’ support group focuses upon meeting the normative needs of carers and there is little influence upon the socio-economic needs. Critically, Tones et al’s (1990) model of health promotion would further suggest that this approach to service delivery merely focuses upon health education with no real emphasis on promoting empowerment and healthy public policy. Meeting only the normative health education needs of carers, there is little influence upon socio-economic needs in the absence of a shift from a purely health education emphasis (Tones et al 1990). Further evidence of the limitations of current service delivery is identified by the World Health Organization’s (1996) five key action strategies for health promotion. There is obvious inaction in the areas of healthy public policy, supportive environments, community action and reorienting health services. Despite the development of personal skills and provision of psychological support, lasting impact upon health status may be weak.

**discussion**

The drive towards acknowledging the role of informal carers within health policy has been outlined. Examining the literature has established a relationship between the needs of carers of the dependent older mentally ill person and the aims of health promotion. The adoption of Bradshaw’s (1972) taxonomy enables the identification of carers’ needs across all the determinants of mental health. Application of health promotion model demonstrates the need for a more integrated approach towards addressing the health promotion needs of carers. The model demonstrates that current service provision only influences the psychological/behavioural determinants of mental health.

Strategies related to community empowerment and promoting healthy public policy remain absent from current service provision. It is appropriate, however, to recognise that carers’ support groups are a successful strategy towards achieving psychological support and individual empowerment (Hunt 1996, Russell et al 1989, Mitchell 1996). The Health Education Authority (1997) further confirms that carers’ support groups are a recommended strategy in targeted programmes of mental health promotion. Robinson and Elkan (1997) confirm that providing information locally and nationally for the purpose of planning health programmes is a core nursing activity. King (1994) discusses the role of nurses within health promotion and suggests that this follows two main strategies. The first is empowerment through interventions such as carers’ support groups. The second is the role of nurses within health reform and political activism. The carers’ support group itself has potential to develop a political agenda, with influence upon the integration of services, and affirming the support of voluntary organisations.

Critically, Mackintosh (1995) says many nurses do not consider themselves as political or in a position to promote empowerment through health promotion. While carers’ support groups influence the emotional states that are fundamental to the theory of empowerment, such a limited educational approach is not sufficient to precipitate health

<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carers’ information group programme</strong></td>
</tr>
<tr>
<td>Session 1: An overview of dementia</td>
</tr>
<tr>
<td>Session 2: Responding to care needs</td>
</tr>
<tr>
<td>Session 3: Legal implications, power of attorney, wills etc</td>
</tr>
<tr>
<td>Session 4: Caring for carers</td>
</tr>
<tr>
<td>Session 5: Helping agencies and social needs</td>
</tr>
<tr>
<td>Session 6: Accessing services</td>
</tr>
</tbody>
</table>

(Dicken et al 2001)
action as described in Tones et al's (1990) model. Use of this model illustrates the need to drive mental health promotion for informal carers towards community participation and promoting health alliances. McCulloch and Boxer (1997) acknowledge the differences between community participation and community-led mental health promotion strategies. Inevitably these differences influence mental health promotion practice and challenge health professionals. This indicates an inevitable shift from professionally-led carers' support groups towards healthcare personnel using facilitative approaches to support community organisation and action. Potentially, this shifts the mental health promotion focus for informal carers away from secondary mental health services to primary care and community alliances.

The interventions of developing coping strategies, stress management, promoting self-esteem and self-identity are acknowledged as activities within carers' support groups (Tudor 1997). It is the areas of changing social support, community action and prevention where the current approach towards mental health promotion is generally weak. It is feasible to suggest that in times of resource constraints a short-acting 'tidy' course is deliverable. However, such individual approaches to health promotion serve to maintain the balance of power largely on the side of professionals. There may be political disincentives to empower carers as their needs are less likely to be voiced with subsequent demands and resource implications. This illustrates that mental health promotion for informal carers would benefit from moving from an individual to a community approach.

Conclusion

Carers' support groups provide an excellent and warranted focus for health education in healthcare service provision. They should be developed and maintained as an integral part of service delivery. However, the limitations of these groups in relation to the aims of health promotion must be acknowledged (Tones et al 1990). Overcoming these constraints involves health providers developing more active alliances (Donaldson 1995). This approach involves service users and carers, long-term planning and commitment, provision of training, dedicated professionals developing links with the community, appropriate resources and evaluation strategies. This alternative involves acknowledging limitations of current provision and establishing a commitment to addressing the health promotion needs of the target group across all the determinants of mental health. If health policy and care provision are to influence the health of informal carers, a planned, comprehensive, measured research-based strategy warrants inclusion in future discussion of contemporary service provision.

Julie Hall RMN, Cert HSM, BSc (Hons) is Health Lecturer, Faculty of Medicine and Health Sciences, University of Nottingham Education Centre, Lincoln County Hospital

References


Mitchell F (1996) Carer support groups: the effects of organisational factors on the character of groups. Health and Social Care in the Community. 4, 2, 113-121.


World Health Organization (1997) WHO Division of Health Promotion, Education and Communication: www.who.ch/