original paper

Carers' views on services for the elderly mentally ill

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Abstract

Background Recent health policy emphasises the involvement of the consumer and carer in health and social care issues. Demographic projections predict a rise in the number of elderly people in Ireland and the number of elderly people with a mental illness. The identification of gaps in service provision should result in appropriate planning for this group in the future.

Objective The aim of the study was to assess carers' opinions of services for the elderly mentally ill in the Limerick area.

Method A questionnaire was sent to the carers of patients referred to the Psychiatry of Old Age service. Information was gathered on satisfaction with existing services for the elderly. Carers were also asked to identify which services they felt they needed.

Results The overall response rate was 51%, but the response rate for individual items varied. Both formal and informal services for the elderly are underused. The need for long-term care places was highlighted and carers wished for more information and emotional support.

Conclusion This study highlighted the aspects of the service that carers value, which should help guide future service development.

Introduction

The number of elderly people in Ireland is increasing. The Department of Health set a target (90%) for those aged 75 years and over that should remain in their own home.[1] It is essential that appropriate services are provided. Informal carers play a major role in enabling elderly people to remain at home.[2-4] The design of services has traditionally been over-influenced by the desires of professionals with very little influence from service users, their families and the community.[5] Involving carers in the planning and evaluation of services improves the credibility of services and results in services that are better suited to local needs.[6] The necessity of orientating services and policies towards the needs of carers, as well as patients, is recommended.[4,7,8] There are no formal arrangements for consulting carers on service planning, although both the Alzheimer's Society and the National Carers Association have a strong advocacy role at a central government level.

The aim of the study was to assess carers' opinions of services for the elderly mentally ill in the Limerick area for use in advocacy on the patient's behalf, and to guide future local service development for this group.

Methods

Study group

The carers of all patients referred to the Psychiatry of Old Age service during the period, 1 April 1995 to 1 June 1996, were targeted for the study. This included both patients with dementia and functional mental illness. A carer was defined as a key person actively involved in a caring/supportive role with the patient during their contact with the service. Patients who were seen only once for consultation/liaison were not included.

Questionnaire

Carers were asked their views on current service provision from the Psychiatry of Old Age service and generic services for the elderly. A questionnaire was designed to gather the appropriate information (see Appendix 1). This covered demographic information on the patients and carers and their contact with the Psychiatry of Old Age service. Carers were asked about other services that they had experience of in their efforts to care for the patient at home and their satisfaction with these. The final section was a list of 10 items that were an amalgam of needs identified in other studies, and divided into those that were patient-based, and those that were carer-based. Respondents were asked to identify the services they felt were necessary.

Psychiatry of Old Age Service

The Mid-Western Health Board established a Psychiatry of Old Age service in 1995 for Limerick city and county. The service accepted referrals of patients with dementia and associated behavioural problems as well as patients over 65 years of age with a first onset of functional mental illness. Resources included six acute psychiatric beds in the general hospital for the treatment of acute functional mental illness, seven acute beds for dementia patients in a non-acute geriatric hospital and a respite care programme operated in a long-term care ward of the same hospital.

Staff included a consultant in the Psychiatry of Old Age, a senior house officer, a part-time secretary and nursing staff. Patients with dementia were seen and treated at home and patients with functional mental illness were mostly seen at an outpatient clinic. Elderly people in the area also have access to a range of community services including public health nurses, home help and meals on wheels.

Data analysis

The questionnaire was piloted on 10 carers and subsequently modified. It was sent with a stamped, addressed envelope and a covering letter requesting consent and explaining the purpose of the study. This was followed a month later with a telephone reminder. The data were analysed using the Statistical Package for the Social

Sciences (SPSS) which provided the descriptive data used below.

Results

Demographic details

One hundred and fifty patients entered a treatment programme during the study period. Two carers did not wish to participate, six were excluded because of failure to identify a carer and 33 questionnaires were returned unanswered. Fifty-six completed questionnaires were returned giving an overall response rate of 39%. Demographic information is given in Table 1. The majority of patients were over 75 years and female. The most common diagnosis was dementia. Fifty-three per cent lived in the city which is in contrast to the 1991 census (33%), but as the service was city-based with limited rural outreach facilities, city patients were over-represented.

Carers

The age range for carers was considerable and showed two peaks: between 40-49 years and 70-79 years. The majority were female; 67% of spousal carers were wives and 80% of 'child' carers were daughters of the patient. When asked who helped them in their caring role, 63% of the respondents named a family member, while only 17% had no help. Carers reported that at least 70% of the patient group needed help in the areas of toileting, medication, cooking, visiting and shopping and 50% needed help with feeding.

Table 1. Details of patients and their carers

Patients		
Age	Range	61 - 89 years
Sex	Female	38 (67%)
	Male	18 (33%)
Marital status	Married	25 (45%)
	Widowed	21 (37%)
	Single	9 (16%)
	No information	1 (2%)
Diagnosis	Dementia	35 (62%)
	Functional mental illness	17 (31%)
	- affective disorder	13 (23%)
	- personality disorder	2 (4%)
	- alcohol disorder	1 (2%)
	- psychotic disorder	1 (2%)
	Unknown	4 (7%)
Location	City	28 (50%)
	Town	4 (7%)
	Rural	23 (41%)
	Unknown	1 (2%)
Carers		
Age	Range	32 - 78 years
Sex	Female	41 (73%)
	Male	12 (21%)
	Unknown	3 (6%)
Relationship	Child	22 (39%)
	Spouse	17 (30%)
	Other	12 (22%)
	No relation	4 (7%)
	Unknown	1 (2%)

Carers' experience of services

There is a marked variation in the use of elements of the service (see Figure 1). The three aspects of the service that were experienced most frequently were perceived as the most satisfactory. Counselling is identified as the least satisfactory of the available services. When asked to identify from a list of 10 formal and informal services, which service they had experience of and how they rated, there was a wide variation in response (see Figure 2). Apart from the GP and public health nurse, other services are underused. From the list of patient-based and carer-based needs (Figure 3 and 4), they highlighted long-term care and their need for information and emotional support. Respondents also valued the role of the community psychiatric nurse and the benefit of relief services such as day care services and respite admissions.

Discussion

The response rate to the postal questionnaire was low.[9,10] Personal contact by phone resulted in little improvement. The Health Strategy emphasised the need for the participation of the consumer in the planning and evaluation of services. This low response rate emphasises the difficulty in engaging people in this process. The wide variation in replies to individual questionnaire items highlights a further problem. Focus groups and listening days may be a more efficient method of obtaining contributions and feedback.[11]

The low response rate also precluded a separate analysis of data from the two main groups, patients with dementia and those with a functional mental illness. These groups overlap in their service needs.[12] Patients may not remain exclusively in one category and carers can experience problems with both diagnostic groups.

The majority of carers were related to the patient and received most support from family members. The changing structure of families has implications for elderly, dependent people.[2,13] There will be a greater demand on formal services in the future as the number of families diminish and the number of elderly increase.

Only one carer had experience of long-term care facilities, perhaps reflecting that having placed patients in long-term care facilities the carer no longer feels the service applies to them. Those who replied are probably still actively involved in the caring role and have identified long-term care as a priority need. The limited resources of the Psychiatry of Old Age service are focused on acute care in hospital and in the community, in common with many similar services.[14] The direct role of this service in long-term care is confined to patients with dementia and behaviour problems who cannot be managed in a less specialised setting. However, access is needed to a variety of other long-term care options for patients with dementia who can no longer live in the community. These include welfare accommodation and private nursing homes.

In view of the high dependency levels of this patient group, the use of the respite system is surprisingly low although it is identified as a necessary service. This may reflect ambivalent attitudes of carers, including feelings of guilt and apprehension associated with the patients return home.[15] Professionals need to be sensitive to these issues and realise that removing a patient from the home may not be the best option. More flexible options such as sitting services and night-time relief may be appropriate.

Carers were not satisfied with the counselling service. This may be because at the early stage of the service development there was no formal arrangement for counselling. The use of information packs and putting carers in contact with voluntary bodies such as the Alzheimer's Association, the Carers Association and Aware are easily instituted measures. Carers groups have been shown to reduce psychological distress experienced by carers of patients with dementia.[16,17]

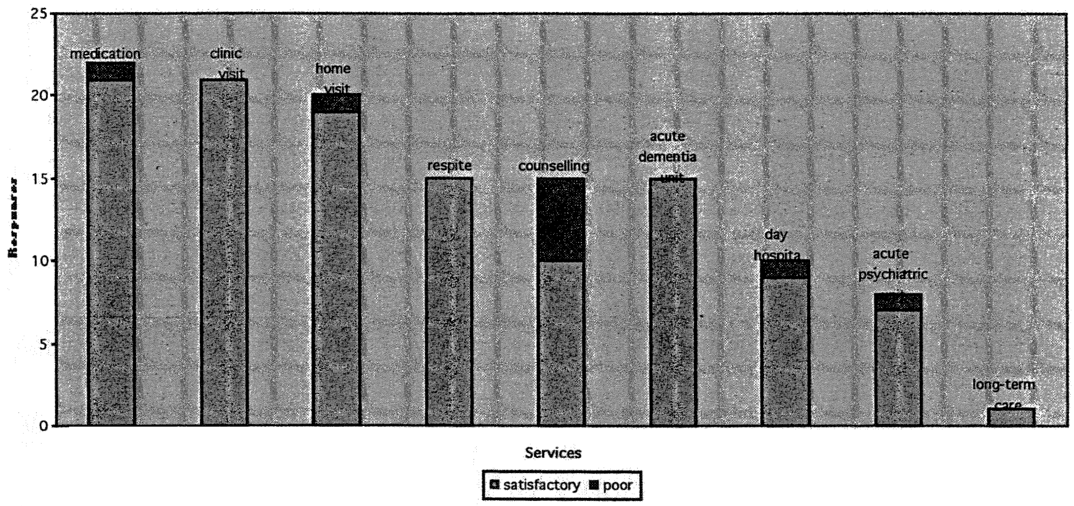

Figure 1. Carers' experience of contact with the Psychiatry of Old Age service

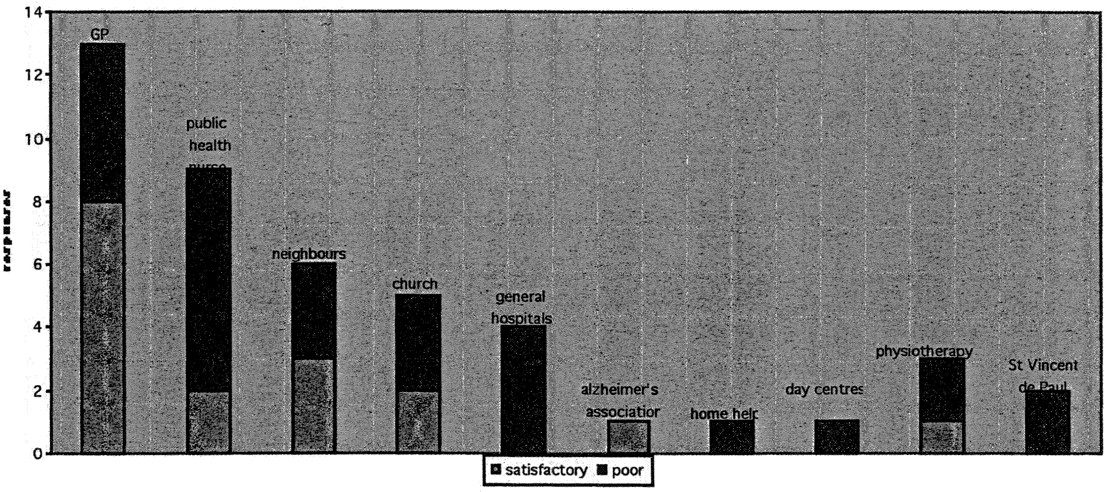

Figure 2. Carers' experience of contact with other agencies

Many studies and reports recognise the important role of the GP in caring for the elderly in the community.[2,18] This study suggests that all respondents do not have contact with the GP. The public health nurse is also acknowledged as a key figure, yet in this study less than half of respondents had availed of the service. These two professionals are the key access to health and social services for the elderly. Elderly people not in contact with them are unlikely to be receiving appropriate assistance. The ratio of public health nurses to population in this study was 1:3,000, which is not unique to this health board area and highlights their difficulties in providing a service. Elderly people have to compete with the demands of other, often more vocal, patient groups. The provision of a dedicated public health nurse for the elderly would have significant impact on this issue. A case management system whereby a key worker is responsible for co-ordinating services for people with dementia in the community has been proposed.[19] Once a diagnosis of dementia is made, an overall co-ordinator would be informed who then assigns a key worker (usually a public health nurse) to the case.

Issues of geography and transport should not prevent individuals from receiving the services they require. At the time of the study, the Alzheimer's Association provided the only day centre for patients with dementia. This was located eight miles from the city centre and transport was provided within a restricted radius. For those living at a considerable distance, transport was a limiting factor and is reflected in the low utilisation of the facility seen in the replies. Such issues of inequity must be considered by those responsible for planning and funding services in order to avoid offering only a token service to a minority.

As services for the elderly are developed throughout the country, each area will have unique characteristics, which will shape the design of the service. Seeking the opinion of service users is part of the process of developing a service which 'fits' well with local circumstances. The results of this survey raised several questions and suggested how the service might develop in the coming years. The need for more long-term places and increased support at community level are not unique to this study and will have to be responded to in view of the changing demographic profile of the country.

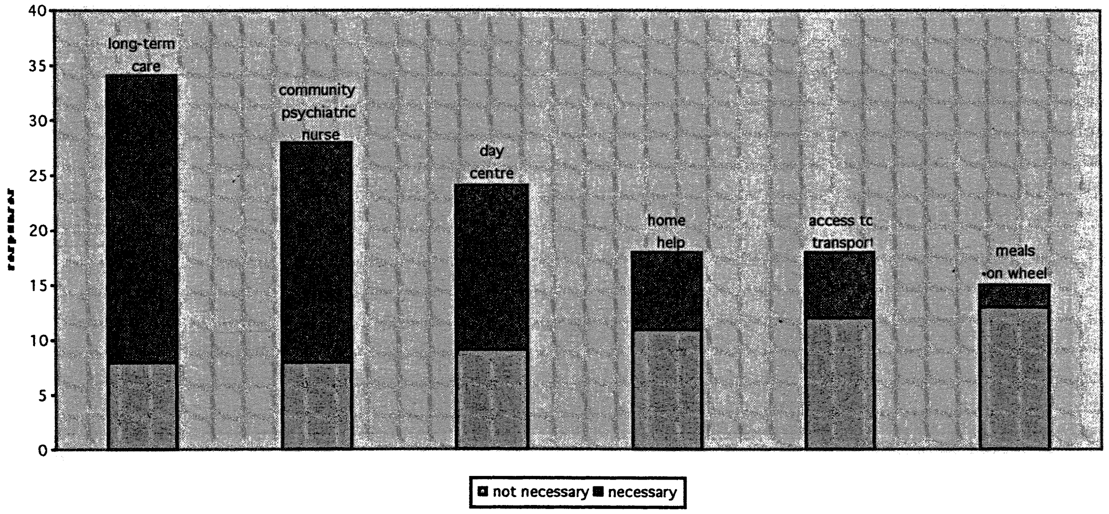

Figure 3. Patient needs expressed by carers

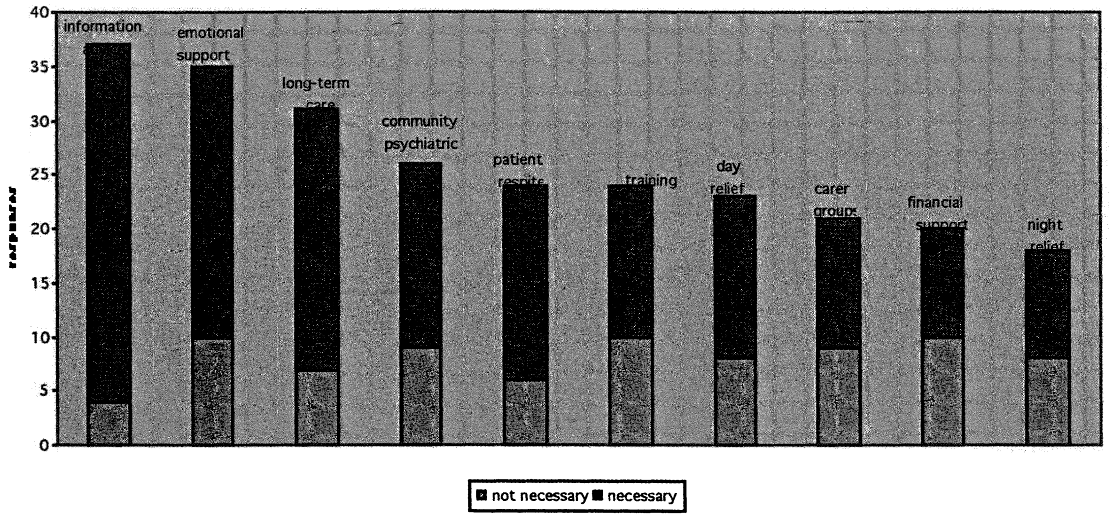

Figure 4. Carer needs

References

1. Shaping a Healthier Future. A strategy for effective healthcare in the 1990s. The Department of Health, Government Publications, Dublin 1994.

2. The Years Ahead. A policy for the elderly. Report of the working party on services for the elderly. Stationary Office, Dublin 1988.

3. Ruddle H, O'Connor J. Caring without limits. Sufferers of dementia/ Alzheimer's disease; a study of their carers. The Alzheimer's society of Ireland and Policy research centre, Dublin 1994.

4. Jones D, Peters T. Caring for elderly dependants; effects of the carers quality of life. *Age Ageing* 1992; 21: 421-8.

5. Murphy E. A clinical role in service development; what should Geriatric Psychiatrists do? *Int J Ger Psy* 1994; 9: 947-55.

6. Mudge K, Ratcliffe I. Considering the needs of carers; a survey of their views of the services. *Nursing Standard* 1995; 9 (30): 29-31.

7. Philip I, McKee K, Meldrum P et al. Community care for demented and non demented elderly people; a comparison study of financial burden, service use and unmet needs in family supporters. *Br Med J* 1995; 310: 1503-6.

8. O'Connor J, Smythe E, Wheelan B. Caring for the elderly Part 1. A study of carers at home and in the community. National Council for the Aged, report no. 18, Stationary Office, Dublin 1988.

9. Mc Cabe B, Sand B. Availability and utilisation of services by Alzheimer's disease care givers. *J Gerontolog Nursing* 1995; 21 (1): 14-22.

10. Moser CA, Katona G. Survey methods in Social Investigation (2nd edition), Aldershot, Dartmouth 1971.

11. Ageing with confidence; a strategy for the people of Cork and Kerry. Southern Health Board 1999.

12. Arie T. Psychiatric Services. In: Textbook of Geriatric Medicine and Gerontology (4th edition). Eds JC Brocklehurst, RC Tallis. Churchill Livingstone, Edinburgh 1992; 1016-20.

13. Keogh F, Roche A. Mental disorders in older Irish people; Incidence, Prevalence and Treatment. National Council for the Aged. Report No. 45. Stationary Office, Dublin 1996.

14. Godber C, Wilkinson D. Services for dementia: a British view. In: Dementia. Eds A Burns, R Levy. Chapman and Hall,

London 1994; 567-79.
15. Homer A, Gileard C. The effect of in patient respite care on elderly patients and their carers *Age Ageing* 1994; 23: 274-6.
16. Brodaty H, Gresham M. Effect of a training programme to reduce stress in carers of patients with dementia. *Br Med J* 1989; 299: 1375-9.
17. Coen RF, O'Boyle CA, Coakley D, Lawlor BA. Dementia carer education and patient behaviour disturbance. *Int J Geriatr Psy* 1999: 14 (4): 302-6.
18. Livingstone G, Hawkins A, Grahem N et al. The Gospel Oak study; prevalence rates of dementia, depression and activity limitation among elderly residents in Inner London. *Psycholog Med* 1990; 20: 137-46.
19. O'Shea E, O'Reilly S. An Action Plan for Dementia. National Council on Ageing and Older People. Report No. 54. Dublin 1999.

Appendix 1. Summary of study questionnaire

1. Patient details
Age, sex, marital status, occupation, spouse's occupation, medical insurance, transport options, location

2. Carer details
Age, sex, marital status, occupation, spouse's occupation, relationship, transport options, living with patient or distance from patient

3. Carers' experience of Psychiatry of Old Age service
Home visits, clinic visits, day hospital, day centre, respite admission, in-patient treatment, long-term care, medication, counselling

4. Caring role
Rate patient's abilities in activities of daily living. Identify which professionals or services provide support to enable care for the patient at home; GP, home help service, public health nursing, Alzheimer's Association, St Vincent de Paul, day centres, physiotherapy, general hospital services, church, neighbours, others . . . satisfaction rating for these.

5. Identify patient needs from a list — home help, meals on wheels, access to transport, day care centre, home visits from community nurse, long-term care

6. Identify carer needs from a list — information/advice, emotional support, meeting other carers, financial support, relief during the day/night, respite admission, domiciliary nurse visits, long-term advice, training.

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