

Needs assessment in dementia

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SUMMARY

Background Resource allocation and service development traditionally focuses on diagnostic categories and consequent perceived need. Identification of the actual level of need in the elderly with dementia, and the degree to which it is unmet is necessary to plan services both individually and as a group. The aim of this study was to characterise the needs of a sample of community dwelling elderly patients with dementia who were referred to an old age psychiatry service in Ireland between July 2002 and July 2003.

Methodology Eighty-two consecutively referred community dwelling patients with ICD-10 diagnosis of dementia were assessed on The Care Needs Assessment Pack for Dementia (CareNap-D). Data on needs across seven domains (health and mobility, self-care and toileting, social interaction, thinking and memory, behaviour and mental state, housecare, community living) is presented (Reynolds T *et al.*, 1998).

Results Subjects had a mean of 33 (range: 13–56) identified needs. Approximately 1/3 of these were unmet with a mean of 13 (range: 0–37) and a mean of 20 (range: 4–39) were met. High levels of unmet need was identified in the domains of behaviour and mental state (84% of those with agitation) and of social interaction (79% of those with ‘partaking in activities’ need). The specific item of repetitive questioning occurred in 68 individuals and was unmet in 88% of these cases. Increasing age, lower MMSE score, and living alone were associated with greater total levels of unmet need.

Conclusion This data underlines the degree of unmet need in the community dwelling elderly with dementia and the importance of developing a spectrum of services on the basis of the actual needs identified. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS — care needs; dementia; assessment

INTRODUCTION

While research into the aetiology of dementia is significantly and encouragingly on the rise, is unlikely that we will have true disease modifying agents in the next decade. Therefore, a priority for clinicians must be to develop a central co-ordinating role in addressing multiple associated care needs of these patients and their carers (Snyder, 2001).

There is a lack of consensus on the definition of need. The UK Social Services Inspectorate (1991) defines it as a requirement of individuals to enable them to achieve, maintain or restore an acceptable

level of social independence or quality of life. Need can also be defined as a state where help (or more help) with specific difficulties is seen to be required by the care professional, taking into account the views of the person (McWalter *et al.*, 1994). Need has also been defined as the ability to benefit in some way from health care (Audit Commission, 2000).

Traditionally, medical services allocate resources on the basis of symptomatology, diagnosis and disability rather than that of patient need (Slade M, 1994). Thus resources are provided to meet what it is assumed individual’s requirements are and the resulting care plan frequently does not match the actual needs of the patient (Slade *et al.*, 1999; Van os *et al.*, 1999; Walters *et al.*, 2001). Community care reforms in the UK prescribed significant changes in health and social care (Department of Health,

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1989). These reforms emphasise the importance of targeting those with greatest need, interagency working and patient centered care plans. The development of such care plans depends on a needs assessment process.

Needs assessment is a staged process, conducted by a care professional, which begins with the identification of specific difficulties, accounts for the presence and efficacy of current help, recognises perceived need and finally specifies the type of intervention required to meet those needs. It has been recognised that needs in the elderly should be identified, agreed on by patients, carers and professionals, communicated to other professionals and met in order to achieve better co-ordination between leading disciplines and ultimately better patient outcomes (Audit Commission, 2000, 2002). Employing this construct of need not only allows the planning of individual care but also informs service provision.

Thus scales such as the Camberwell Assessment of Need for the Elderly (Phelan *et al.*, 1995; Reynolds *et al.*, 1998), Needs for Care assessment (Brewin *et al.*, 1987) Elderly Psychiatric Need Schedule (Hamid *et al.*, 1995) and the Medical Research Council Needs for Care Schedule (Brewin *et al.*, 1988) have been designed to measure specific social, physical, psychiatric and health needs of elderly individuals. However, less work has been done to assess of the needs of dementia sufferers separately from that of the general elderly population. Gordon *et al.* (1997) demonstrated high levels of need in a local population with dementia known to services, with assistance required more than once a day with mobility by 48%, personal care by 60%, domestic tasks by 75% and behavioural problems by 57%. Assistance was required at night by 59% because of personal care needs and by 54% because of behaviour problems. It is unclear from this study how many of these needs were met/unmet. Hancock *et al.* (2003) found that patients with dementia rated fewer needs (both met and unmet) compared to their carers or relevant staff members, whereas patients with functional disorders rated similar numbers of needs to staff and carers. This under reporting of needs (both met and unmet) by people with dementia may be due to a number of reasons such as memory problems, lack of insight, denial or resignation. This further emphasises our central role in formally identifying the person with dementias' need using carer and professional collateral (Hancock *et al.*, 2003).

This study aimed to characterise the needs of community dwelling elderly patients with dementia who were referred to an old age psychiatry service between July 2002 and July 2003.

METHODOLOGY

Procedure and instruments

All participants were referred to the psychiatry of old age service at Waterford Regional Hospital for assessment between July 2002 and July 2003. This is a general hospital based, community oriented service for a defined geographical catchment area. Referral to the service occurs through general practitioners (predominately) and through hospital consultant teams, and assessments take place either at the person's place of residence or at an outpatient clinic. Initial psychiatric assessment, conducted by a psychiatrist includes history, mental state, Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975), and physical examination and physical investigations as clinically indicated. All patients with a diagnosis of dementia, according to ICD-10 criteria, and living in the community were referred to the project nurse for participation in the study. The patient and carer were given information with regard to the needs assessment project by telephone and invited to participate. All interviews were conducted in a quiet room in the family home. The project nurse completed training in the application of the Care Needs Assessment Pack for Dementia (CareNap-D) and conducted all the needs assessments (McWalter *et al.*, 1998). The interview can take up to one hour to complete depending on the case complexity and on occasion more than one visit was necessary.

The CareNap-D was developed in 1990 to establish an evidence-based needs led user friendly comprehensive multidisciplinary assessment tool for use in older adults with dementia and their carers in the community setting. The CareNap-D has been shown to be a reliable and valid instrument for multidisciplinary assessment of need for people in the community and their carers. It provides assessors from various disciplines with a common language, thus facilitating interagency collaboration and co-ordination of care for older people with dementia. It comprises of four sections: to obtain basic and referral information, to perform separate assessments for person and carer, and to obtain a personal history. The core elements are the needs assessment schedule for the person with dementia and the carer assessment. The former comprises of seven domains—health and mobility, self-care and toileting, social interaction, thinking and memory, behaviour and mental state, housecare and community living. Domains are further divided into specific items of potential difficulty for people with dementia. For each item the assessor is asked to indicate need status (none, met

or unmet) and for the unmet the type of action required. The need status is ultimately determined by the assessor following consultation with both the subject and the carer. The survey therefore combines the opinions of patient and carer and therefore in later analysis it is not possible to determine whether the need was perceived present by patient or carer or both. A met need is recorded when an identified problem results in a care need but there is sufficient support from either informal sources or community services to meet the need. An unmet need is recorded when a problem is identified which results in a care need for which there is either no or insufficient support from informal sources or services to meet the need. Total need refers to the sum of unmet and met need for each item.

At an individual level this tool assesses problems in different domains and sources of help currently available and sources/types that should be made available. At a community level it provides an initial specification for new services by describing currently unmet needs in terms of caring behaviours required to meet them and a gauge as to how the community services currently are addressing needs of older people with dementia (met needs).

Data was stored in the CareNap-D software package and analysed using SPSS-PC version 10. The results were analysed using descriptive statistics. We looked for correlations between the clinically important variables of age, MMSE score, living alone/not and rural/city dwelling in terms of unmet needs. The *p* value for significance was set at 0.05 for any *t* tests or correlational analysis applied.

RESULTS

Demographic data

Eighty-two ($n = 55$ female and $n = 27$ male) persons with dementia and currently living in the community were identified and all agreed to be interviewed for the study. The mean (SD) age of patients was 76 (7.8) years. Four persons were under 65 years (53, 59, 62 and 64 years). The mean (SD) age of the female group 80 (7) was significantly older than the male group 76 (8) ($t = 2.3$, $p = 0.027$). Twenty two patients lived alone. More females (57%) than males (37%) lived alone ($\chi^2 = 7.7$, $p = 0.005$). The mean MMSE score of the group was 15.9 with no significant gender difference.

Assessment of needs

Subjects had a mean of 33 (range: 13–56) identified needs. Approximately 1/3 of these were unmet with

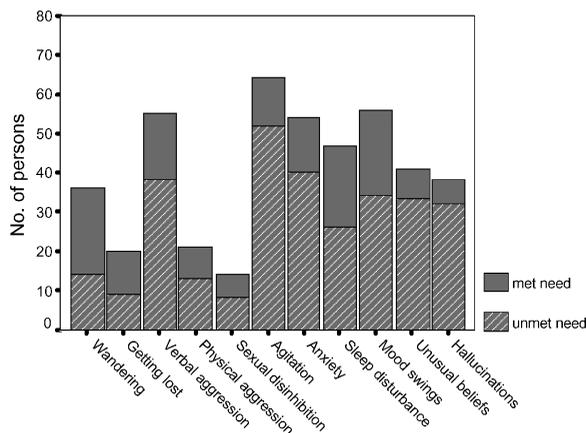


Figure 1. Behaviour and mental state needs

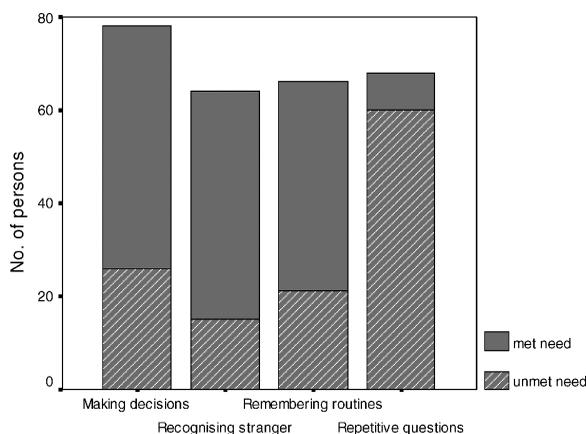


Figure 2. Thinking and memory needs

a mean of 13 (range: 0–37). There was no significant gender difference in the mean number of total, unmet, and met needs.

Figures 1–7 show total needs in each domain and the proportion of needs that are unmet.

Behaviour and mental state needs (Figure 1). The majority of these needs were unmet. Agitation/restlessness, verbal aggression, mood swings and anxiety were the most frequently identified needs ($n = 64$, 56, 56 and 54 respectively). As a high percentage of these needs were unmet they also became the most frequently identified unmet needs ($n = 52$, 38, 34 and 40 respectively). These needs were unmet in 84%, 81%, 74%, and 70% of cases respectively.

Thinking and memory needs (Figure 2). Eighty-eight percent of repetitive questioning needs were unmet

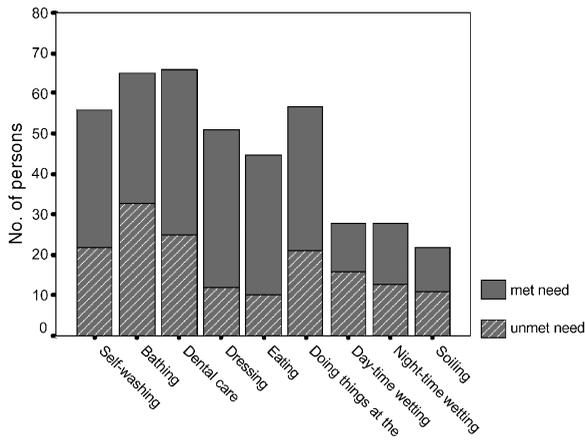


Figure 3. Self care and toileting

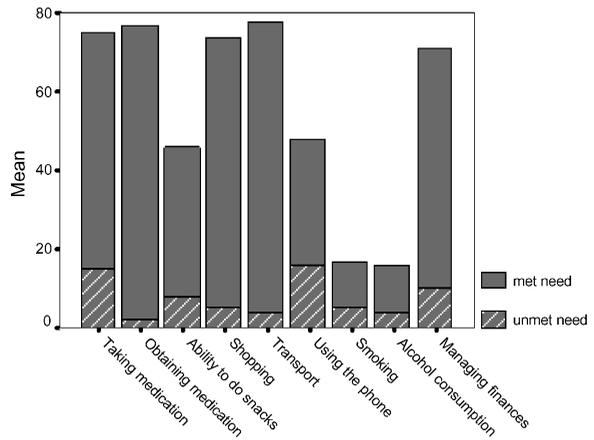


Figure 6. Community living needs

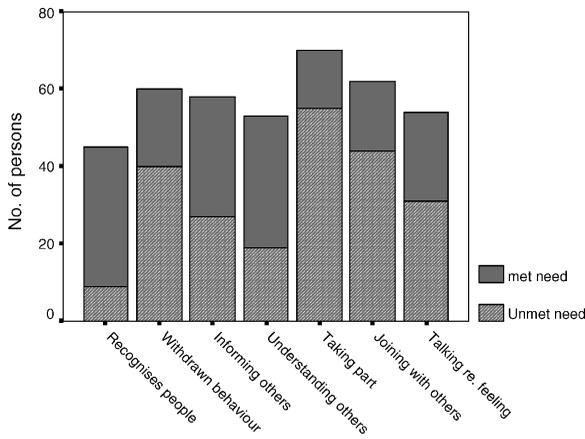


Figure 4. Social interaction needs

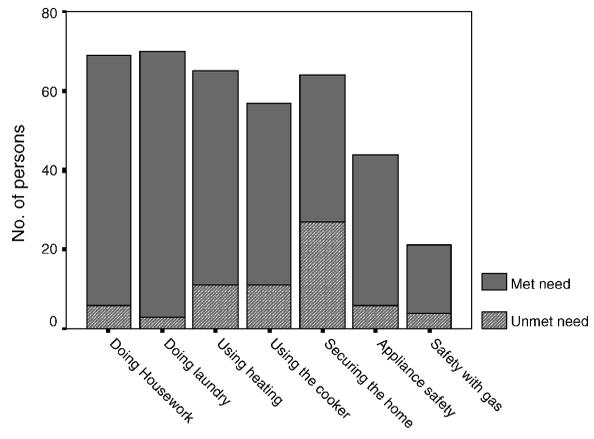


Figure 7. Housecare needs

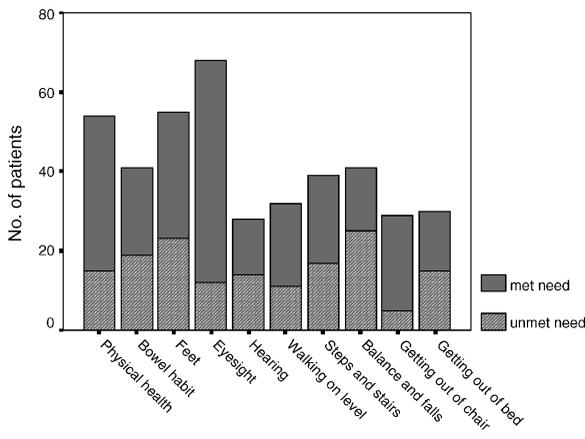


Figure 5. Health and mobility needs

compared to approximately 1/3 of the other thinking and memory needs.

Self care and toileting needs (Figure 3). Dental care, bathing and self-washing needs were the most frequently identified self-care and toileting needs ($n = 66, 65$ and 56 respectively). These were unmet in 39%, 40% and 39% of cases and these remained the most frequently occurring unmet needs ($n = 25, 33$ and 22 respectively). Daytime wetting, soiling and night-time wetting remained unmet in 58%, 46% and 50% of cases where a need was identified.

Social interaction needs (Figure 4). Taking part in activities, joining in with others and withdrawn behaviour were the most frequently identified social interaction needs ($n = 70, 62$ and 60). These needs were unmet in

79%, 69% and 77% of cases respectively and remained the most frequently identified unmet needs ($n = 55, 44$ and 40 respectively). There is a high rate of unmet need across the overall social interaction domain.

Health and mobility needs (Figure 5). Eyesight, chiropody and physical health needs were the most frequently identified needs in this domain ($n = 68, 55$ and 54 respectively). Overall, the majority of health and mobility needs were met. However, balance/falls was the most frequently identified unmet needs in this domain ($n = 25$) with 61% being unmet.

Community living needs (Figure 6). Although the frequency of need in this domain was high, a very high proportion was met. Taking medication and using the phone were the two most frequently identified unmet community living needs ($n = 16$ and 15 respectively).

Housecare needs (Figure 7). There was a high prevalence of individual housecare needs, but the majority were met. Maintaining a secure home was the most frequently identified unmet needs ($n = 27$), being unmet in 42%.

Patient variables and unmet needs. Increasing age is correlated with the total number of unmet needs across all domains ($r = 0.31, p = 0.006$) and the level of health/mobility and behaviour/ mental state unmet needs ($r = 0.2, p = 0.009; r = 0.309, p = 0.005$). Lower MMSE scores were correlated with a greater total level of unmet needs across all domains and a greater number of social interaction unmet needs ($r = -2.5, p = 0.015; r = -2.6, p = 0.026$). Those living alone had a higher mean level of total unmet need across domains ($t = -2.5, p = 0.02$). The domains of needs that were unmet significantly more frequently in this group included thinking/ memory ($p = 0.03, t = -2.2$), housework ($t = -2.97, p = 0.004$) and community living ($t = -3.5, p = 0.001$) domains. However a contributory factor may be the fact that the group of persons who were living alone were older ($t = -2.1, p = 0.04$). Rural dwellers had higher levels of unmet joining in social activity needs ($t = 3, p = 0.021$). There is no gender difference in terms of levels of either total unmet needs or levels of unmet needs in specific domains.

DISCUSSION

Methodological issues

This was a survey of subjects living in the community who were referred to the psychiatry of old age service

and hence the results may not be generalisable to all subjects with dementia in the community. There may be a bias towards the needs of those with dementia associated with behavioural and mental state symptoms. However, up to 90% of subjects with dementia experience behavioural symptoms at some stage of their illness (Brodaty *et al.*, 2001). The strength of the study includes the use of a needs assessment instrument designed specifically for use in dementia, and the use of a scale which takes account of both patient and subject perception of need and addresses both met and unmet need.

This survey reports on needs based on information from the patient, one identified principal carer and the assessors own opinion. The quality of the information may be weakened as some carers make better informants than others. The ability of the assessor to use her own judgement in determining the presence/absence of a need and whether or not it is met reduces this weakness somewhat. The use of just one assessor prevents the problem of inter-rater variability.

There may also be domain overlap in terms of specific items in each domain. For example, not recognising faces is a cognitive ('thinking and memory') need but is also a social interaction need. Similarly 'understanding others' is listed as a social interaction need but may also be conceptualised under 'thinking and memory needs'. 'Withdrawn behaviour' is an item under social interaction needs but it could also be conceptualised under 'Behaviour and Mental state needs' as withdrawal can be a feature of a depressive disorder. A recent study, however, classified withdrawal as a 'negative symptom' of dementia and found that negative symptoms are a prominent clinical feature of Alzheimer's disease and are related to memory impairment not mood disturbances (De Jonghe *et al.*, 2003). However, CareNap-D does not attempt to elucidate the aetiology of needs rather it attempts to identify individuals' needs on a very practical level and match these to carer behaviour and resources necessary to meet them.

Results

Patients with dementia who are referred to psychiatry of old age services present with high levels of need. Two-thirds of this need is considered met, through the support of carers, family and basic community services. However, there is a wide variation in the degree to which different needs are met. Behavioural/mental state and social interaction need categories have particularly high levels of unmet need. The very high proportion of behavioural/mental state

needs which remains unmet is likely to reflect the referral pattern but it also emphasises the difficulty encountered in managing these needs (agitation, affective and psychotic symptoms), as all subjects would have already attended generic medical services, predominantly primary care prior to referral. It is not evident what proportion of these behavioural and mental state needs reflect clinical psychiatric disorders, but they certainly reflect considerable psychological need. A previous Irish based study using the Geriatric Mental State-AGECAT semi-structured interview found that 20% of dementia sufferers had comorbid depressive symptoms and 24% had comorbid anxiety symptoms (Kirby *et al.*, 1997). Anxiety symptoms in dementia, in particular, are poorly understood and may not be part of an anxiety disorder or depressive disorder, but may respond either to non-pharmacological interventions or pharmacological agents including serotonergic antidepressants, mood stabilisers or atypical anti-psychotics, and therefore it is important that they are identified (Lenze *et al.*, 2003).

It is clearly unsurprising to see high levels of 'thinking and memory needs'; however, it is striking that 88% of repetitive questioning needs remains unmet. This is likely to reflect the practical difficulty encountered by a carer in dealing with repetitive questioning, in contrast to other 'thinking and memory needs' such as decision making and remembering routines. Health professionals need to be observant of communication patterns that exist between caregivers and their spouses with dementia and help caregivers develop successful communicative strategies that enhance interactions with their spouses. As many studies highlight such cognitive difficulties as being predictive of institutionalisation this highlights the importance of education for carers in devising effective strategies to cope with repetitive questioning (Severson *et al.*, 1994).

The most frequently occurring unmet 'self care/toileting needs' (dental care, self bathing and self washing) are items that appear amenable to simple health and personal care provision on a population basis. It has been shown that caregiver upset with disruptive behaviour and caregiver use of criticism based strategies worsens self-care performance, whereas higher education of carers often simplifies self care tasks (Gitlin *et al.*, 2002). This data supports the need for further specific task led education of carers. Dental problems associated with dementia are not restricted to a decrease in oral hygiene but is also related to difficulty controlling and retaining dentures, xerostomia (which is often drug associated)

and consequential root caries, recurrent decay and purposeless chewing. Dental providers need to be made aware of the increased needs of dementing individuals (Chiappelli *et al.*, 2002). While day-time wetting, night-time wetting and soiling were the three least frequently occurring self care needs, it was notable that when they occurred, the needs were unmet in the highest proportions of cases. This indicated that these items are very problematic, on an individual basis, when they occur. Continence is often central to the relationship between carer and the person being cared for with the bathroom often becoming the most important room in the house. Incontinence has also often been identified as a factor predictive of institutionalisation (Armstrong, 2000; De Jonghe *et al.*, 2003). In general, carers demonstrate low knowledge levels of strategies to promote and maintain faecal continence, however, it has been shown that education increases knowledge of contributing factors, implications of constipation, effectiveness of specific strategies and awareness of factors unrelated to dementia that can have an impact on faecal continence (Clemesha *et al.*, 2004).

The most commonly occurring 'social interaction needs' and unmet needs (taking part in activities, joining in with others, withdrawn behaviour) are needs that clearly need further assessment. If it is believed that these are not secondary to a psychiatric disorder such as a depressive or anxiety disorder then they could be addressed by improved community social supports, particularly appropriate day centre availability and home respite services.

The majority of 'health and mobility needs' were met in this survey but it is interesting that poor balance as a need remained unmet in the majority of individuals in whom it was identified. Poor balance is an important symptom in the elderly as it is associated with an increased rate of falls and hence hip fractures and increased institutionalisation (Hope *et al.*, 1998). Patients with Alzheimer's disease have a reduced ability to suppress incongruent visual stimuli when trying to maintain balance and hence the dementing process may in itself contribute to poor balance in these individuals (Chang *et al.*, 1999). It may be the case that either this symptom is not identified by medical professionals or is not being recognised as important and therefore not appropriately addressed. In one study non disabled persons with dementia with poor lower extremity performance spent significantly more days in hospital than those with intermediate/higher performance and significantly predicted subsequent hospitalisation and institutionalisation (Penninx BW

et al., 2003). The assessment and management of poor balance and falls requires input from different disciplines such as medical, occupational therapy, physiotherapy and further emphasises the importance of a multi-disciplinary approach to the management of the person with dementia.

A very high proportion of 'community living and house care needs' are met in this sample, which indicate that these needs can, in most instances, be met by carers. The most frequently unmet house care need identified is the ability to maintain a secure home, which may reflect a carer's difficulty in providing the 24-hour observation often necessary. One-fifth of patients continued to have unmet needs relating to use of the cooker and heater. This highlights two service provision implications, firstly the need to provide an occupational therapy assessment of an individual with dementia where safety concerns have been identified (such as a kitchen assessment) and secondly, our need to educate carers specifically with regard to general safety risks and to provide advice and recommendations as to how to limit them (Telerico *et al.*, 2001) Using the telephone was frequently identified as an unmet need, due either to an absence of a telephone in the house or because the carer believed the subject with dementia was unable to use it. Use of a telephone for an elderly patient with dementia is important in terms of safety, communication and participation in society. The results of a Stockholm study to assess telephone use amongst patients with dementia found that it is unrealistic to assume that elderly persons with dementia who live alone are able to satisfactorily use a telephone (indicating that following formal testing the percentage of those with this as an unmet need may in fact be much higher) (Nygard L *et al.*, 2003) and other ways to meet these needs for these patients should be sought.

Older individuals, those with more severely impaired cognitive function and those living alone have higher levels of unmet need and clearly, in terms of service provision, require an increased allocation of resources. The unmet needs that occur most frequently in those living alone vs those cohabiting are those which could be addressed by increased provision of community services such as home help and meals on wheels. Patients in rural areas had greater levels of unmet needs with regard to the specific item of joining in social activities. This clearly highlights a need for the increased availability of day centres and transport to and from or use of other innovative social visiting interventions in rural locations.

CONCLUSION

Person-centred care in dementia derives from an emphasis on the experience of the person with dementia. The person is seen as attempting to manage and cope with their difficulties, through a variety of coping mechanisms and use of a variety of resources (Woods RT, 2001). Person-centred care for people with dementia is an aspiration of both family and professional carers, but what constitutes person-centred care and how it can be achieved is less clear. It seems, however, that an essential component of this care is through the development of the range of services for people with dementia based on the identification of their individual needs (and particularly those remaining unmet).

This survey highlights not only unmet needs in terms of behaviour and mental state needs but also unmet needs in a variety of domains. Strikingly, despite the previous contact that all patients had with the health service, there remains a high level of unmet need in areas such as poor balance, dental needs and informing carers regarding how to effectively cope with repetitive questioning. Self bathing and washing were also identified frequently as unmet needs which may call for adequate services to meet needs for physical assistance with bathing. The study highlights that there is a substantial need for specialist services to address unmet needs including behavioural symptoms and poor balance. Sensitive disclosure of the diagnosis, providing information, education and guidance and appropriate referrals to community resources and specialist services are also identified as essential components of an effective person-centred care plan for the person with dementia.

Caregivers, whether family members or paid workers, require additional support in order to recognise the persons needs and to meet them in ways which enable the persons identity and full human value to be upheld. Needs assessment enhances the patient and carers experience and leads to more accurate information but also should reduce the level of reassessment by other professionals and reduce the incidence of service duplication.

The needs assessment framework would better facilitate the delivery of individualised health and social care on a patient-centred basis appropriate to the particular individual needs of patients with dementia.

Finally, to truly provide person-centred care we may need to address the ethical problem of need vs want. So often we encounter the patient who has a demonstrable need but doesn't want help for a variety

of reasons including privacy, preference and maintenance of personal dignity. At what point can we override their want because of their need? In the future we should not only look at the needs of patients with dementia but also their wants, maybe by using a comparison scale so as to identify if a real difference does exist so as to begin unravelling how to really make the care we provide person (not patient) centred.

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