An exploration of help-seeking behaviour in older people with unmet needs

Kate Walters, Steve Iliffe and Martin Orrell*


**Background.** Despite decades of research showing high rates of unmet need in older people, there currently is little understanding of why these needs remain unmet. This study was performed as part of a larger feasibility study of a multidisciplinary needs assessment tool in primary care.

**Objective.** The aim of the present study was to explore patients’ and carers’ help-seeking behaviour and perceived barriers to meeting unmet needs.

**Method.** Four general practices were selected purposively in inner city and suburban London. A random sample of 1 in 20 people aged 75 years and over registered with each practice was selected for a multidisciplinary needs assessment using the ‘Camberwell Assessment of Need for the Elderly’ (CANE) schedule and unmet needs identified by patients and their informal carers. For each unmet need, a further semi-structured interview was used to explore the help-seeking behaviour and perceived barriers to meeting their needs. Responses were recorded verbatim contemporaneously and a thematic analysis performed on perceived barriers following completion of all interviews.

**Results.** A total of 55/84 (65.5%) of patients and 15/17 (88%) of carers completed the initial needs assessment. For 104 unmet needs identified by 31 patients and 11 carers, a further interview was completed on the barriers to meeting that need. Help had been sought for only 25/104 (24%) of unmet needs and it had been offered in only 19/104 (18%). In those not seeking help, withdrawal, resignation and low expectations were dominant themes. In those that had sought help, there were issues of perceived failure of service delivery and rationing, with themes of resignation and withdrawal again emerging in those declining help offered.

**Conclusion.** The majority of older people and their carers do not appear to seek help for their unmet needs for a range of complex reasons, often involving issues of withdrawal, resignation and low expectations. This complexity has implications for the commissioning of services for older people.

**Keywords.** Aged 80 and over, geriatric assessment, needs assessment, self-concept, social perception.

Introduction

Decades of community-based research into the health needs of older people have consistently shown extensive unmet need in older age groups.1,2 It is unclear why these needs are not met; is it because of real or perceived lack of resources and rationing or due to attitudes and perceptions of the worth of older people? In contrast to the large literature on needs assessment, there has been relatively little exploration of these issues.

A number of studies have looked at lay perceptions of health and illness, exploring health-promoting and illness behaviours.3–5 One study reported that older people are less impressed by health education messages and are often condemning of the ‘faddishness’ of current healthy ideas.5 The perception that illness is associated with a lack of ‘moral fibre’ has been reported frequently, particularly in older people.4–6 There consequently is a natural reluctance for older people to describe themselves as ill. It has also been argued that older people tend to
minimize their health problems in order not to fulfill negative images and be labelled in the negative stereotype of old age. One extensive anthropological study exploring the attitudes and beliefs of older people in Aberdeen reported that there was marked inconsistency. It was rare to find unified concepts of health and illness, and older cohorts cannot be seen as one group with common attitudes and beliefs.

There has been little research, however, that has focused on why older people have so many unmet needs. This study is an initial exploration of the perspectives of older people and their carers on perceived barriers to meeting needs.

Method

Subjects

Patients were selected from four general practices representing both larger (three or more principals) and smaller (one or two principals) practices in inner city and suburban areas in northwest London. We selected a systematic random sample of 1 in 20 of registered patients aged 75 years and over from each practice for completion of a structured multidisciplinary needs assessment using the Camberwell Assessment of Need for the Elderly (CANE) schedule, a tool validated in a range of settings and populations. The lists of subjects were reviewed by practice staff and the researcher with reference to their medical records to exclude patients with advanced dementia who had no informal carer to represent their views. For each subject agreeing to participate, a structured needs assessment using CANE was performed in a face to face interview. Their informal carer (relative/friend/neighbour who assisted them in their daily living on one or more occasion per week) also completed a needs assessment using the CANE schedule. The results of the CANE needs assessments and further detail on the recruitment of subjects are reported elsewhere.

Design

Patients and carers who identified an unmet need during the CANE assessment were requested to complete a short semi-structured interview on help-seeking behaviour and barriers to meeting that need (see Box 1). These brief interviews were completed immediately after the CANE assessments. Respondents views on why their needs had not been met were recorded verbatim contemporaneously. In addition, comments that were made during the completion of the CANE assessments on the barriers to meeting needs were recorded in the field notes. All interviews were conducted by the principal researcher (KW). Ethical approval was obtained from local research ethics committees and written consent obtained from patients and carers to participate.

Analysis

The data on help-seeking behaviour in the interview schedule were analysed using SPSS 7.0 for Windows. A thematic analysis was performed on the qualitative data after completion of data collection for the whole sample. This involves conceptualizing and reducing data, describing categories and relating these through a series of statements. It enables interpretations to evolve from the data going from the specific case to a more general concept.

The data were reviewed independently by the researcher (KW) and a member of the team not involved in the interviewing process (SI). Each reviewer identified issues and categories that described how or explained why the needs had not been met. A coding framework of themes was developed by consensus and then applied independently by the reviewers (KW and SI) to each verbatim recording in a modified analytic induction process. Modified analytic induction is the search for and review of negative or deviant cases which enable the researcher to refine theoretical statements (in this case, the explanatory categories). The reviewers then met to compare analyses, and a consensus on the content and interpretation of each theme was reached. The themes, their interpretations and examples are given below.

Results

CANE assessments were completed for 55/84 patients (65.5%) and 15/17 carers (88%). There were no significant differences in age, sex and geographical area of abode between participants and non-participants. A carer view alone was taken for 3/55 patients as the patients were unable to complete an interview (two had advanced dementia and one was aphasic). One or more unmet need was identified by 31/52 (60%) of patients and 11/15 (73%) of carers. A total of 104 unmet needs were identified by the 31 patients and 11 carers and explored
in the interviews. Mean age of patients was 82 years (range 75–93 years), 72% were female and 6% spoke English as a second language. Overall, 50% were homeowners, 58% had no income other than the state pension, 44% lived in inner city areas, 44% lived alone, 11% lived in sheltered accommodation and 3% lived in residential care. Interviews took a mean of 40 minutes including the CANE assessments (median 35, range 23–75 minutes) and a mean of 15 minutes (median 15, range 7–24 minutes) excluding the CANE assessments.

Help-seeking behaviour
Help had been sought in only 25/104 (24%) of the unmet needs identified. In 19/104 (18%), help had been offered for the problem. The sources of help (either sought by the patient/carer or offered to the patient/carer) are detailed in Table 1.

The help-seeking behaviour was recorded for each individual variable (see Table 2). Patients and carers appeared more likely to both seek and be offered help for mobility problems than other types of problems such as incontinence, eyesight, psychological distress, memory, accommodation and company.

Barriers to seeking help
Content analysis of the reasons given for not seeking help revealed a number of key concepts. The dominant themes that emerged were the overlapping concepts of withdrawal, resignation and low expectations. Withdrawal was defined as the process of isolating oneself from society, in preparation for dying, and involves an avoidance of social contact with others. It was apparent that many felt ‘resigned’ to their situation and although they identified a problem did not intend to seek help for it. Low expectations were a recurrent theme often linked to resignation. This combination was particularly evident for psychological distress where there appeared to be a belief that there was little point in seeing the doctor because from their viewpoint no action seemed possible. These overlapping themes are illustrated in Box 2.

Other important concepts were of problem minimization and age attribution. Problem minimization occurred particularly with incontinence where it was probably linked to unexpressed embarrassment and consequent denial or minimization of the problem. The simple attribution of the problem to age-related changes was less common than might be thought, except for in relation to memory problems. These are illustrated in Box 3.

Another important concept was that of lack of information, where the respondent reported not knowing where to seek help from or what was available. This was identified with some social and information needs and with incontinence. There was an element of perceived service failure concerning access to services and cost issues regarding services arising as barriers to seeking help.

In others, there arose a fear of the consequences; what might happen if they sought help. Amongst carers, there was a sense of duty and endurance. In some cases, there was action planned that had not yet been taken and with carers a sense that they felt overwhelmed with their responsibilities coupled with isolation, leading to difficulty in seeking help. Lastly, it was on occasion attributed to forgetfulness. These concepts are illustrated in Box 3.

Table 1

<table>
<thead>
<tr>
<th>Source of help</th>
<th>Help sought</th>
<th>Help offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>No one</td>
<td>79 (76%)</td>
<td>85 (81.7%)</td>
</tr>
<tr>
<td>GP</td>
<td>10 (9.6%)</td>
<td>10 (9.6%)</td>
</tr>
<tr>
<td>Practice or district nurse</td>
<td>1 (1.0%)</td>
<td>2 (1.9%)</td>
</tr>
<tr>
<td>Hospital</td>
<td>4 (3.8%)</td>
<td>4 (3.8%)</td>
</tr>
<tr>
<td>Social services</td>
<td>9 (8.7%)</td>
<td>3 (2.9%)</td>
</tr>
<tr>
<td>Optician</td>
<td>1 (1.0%)</td>
<td>–</td>
</tr>
</tbody>
</table>

Table 2

<table>
<thead>
<tr>
<th>Variable name</th>
<th>No. of unmet needs</th>
<th>Sought help</th>
<th>Offered help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continence</td>
<td>11</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Accommodation</td>
<td>9</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>9</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Mobility</td>
<td>8</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Eyesight</td>
<td>8</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Company</td>
<td>8</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Memory</td>
<td>8</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Information on condition</td>
<td>7</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Hearing</td>
<td>6</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Looking after the home</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Daytime activities</td>
<td>4</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Self-care</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Physical health</td>
<td>4</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Caring for someone else</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Drugs</td>
<td>3</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Carers’ psychological distress</td>
<td>3</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>Inadvertent self-harm</td>
<td>3</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Benefits</td>
<td>1</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Carers’ need for information</td>
<td>1</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>104</td>
<td>25</td>
<td>19</td>
</tr>
</tbody>
</table>

Concepts occurring when help had been offered or sought
The range of concepts that emerged for those patients who had sought and/or been offered help were broadly similar to those who had not sought help. The main
Perceived service failure, mainly due to a failure of the provision of a service or to inadequacies in the service provided, was a dominant theme that overlapped with concepts of rationing and eligibility for services. It was not clear how many of these perceived needs related to service provision could actually be met. Some of them certainly did not appear to be within the current circumstances. Cost appeared as a prohibitive factor, although again this was not a prominent feature. Information and service issues are illustrated in Box 4.

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**Box 2**  
**Dominant themes: withdrawal, resignation and low expectations**

“*She don’t want to be messed about goin’ up to hospital*”  
(Illustration 49: carer’s view regarding 87-year-old mother’s ‘eyesight’ problems)  
“I’m not really interested. They’d only pop in for a chat and then they’re gone. What’s the use of it?”  
(Illustration 4: 92-year-old man regarding his isolation and need for ‘company’)  
“What can they do? All they can do is listen to me. I don’t want to bother them with my problems”  
(Illustration 26: 79-year-old woman regarding ‘psychological distress’—feeling low and crying all the time)

**Box 3**  
**Examples of other themes**

**Problem minimization, age attribution, fear of consequences**

“I have to hurry and I don’t always get there in time... It’s not a problem really. It’s through the night that’s the bother. I have to get up lots. I wear knickers and I just change them if I leak or dribble. I wouldn’t go to the doctor, it’s not a problem really,”  
(Illustration 41: 78-year-old woman regarding ‘incontinence’)  
“She often locks herself in. We’ve had to have the police break in sometimes. She doesn’t know where she is sometimes... I suppose it’s her age really.”  
(Illustration 17: carer—next door neighbour of 90-year-old woman regarding ‘memory’ problems)  
“Everything you tell them they put it down to old age. ‘You can expect these things at your age’ they say”  
(Illustration 46: 75-year-old woman regarding ‘incontinence’)  
“My husband is so ill I keep putting it off. I don’t want to have an operation”  
(Illustration 55: 75-year-old woman regarding her own problem with ‘incontinence’)

**Carer’s themes: duty and endurance, overwhelmed**

“It’s my husband, it’s my job to look after him”  
(Illustration 12: carer—looking after dependent 93-year-old husband with multiple needs regarding ‘benefits’ and not claiming for attendance allowance)  
“She needs to be watched all the time. My brother said he’d take her sometimes but he’s not been round once. It’s hard, I’m not well myself you know. I’m on the sick. I’ve not told them yet... I’ve just not got round to it yet.”  
(Illustration 30: carer—regarding ‘psychological distress’ while caring for his 84-year-old mother with dementia)

**Box 4**  
**Examples of recurrent themes: information and service issues**

“I didn’t know you could ask anybody”  
(Illustration 4: 92-year-old man regarding problems with ‘accommodation’, needing adaptations to assist in mobility)  
“I didn’t know how to get more information”  
(Illustration 13: carer—wife of 88-year-old man with aphasia and hemiparesis following a stroke regarding ‘information on condition’)  
“I’d love to have a cleaner but I can’t afford it dearie... I’d have to pay for it myself and I don’t know how long I’m going to live so I have to make my savings last.”  
(Illustration 2: 88-year-old woman with chronic asthma regarding problems ‘looking after the home’)  
“They come in the morning but it’s only enough time to help me get up. They say I can only have an hour a day but they’re not here that long.”  
(Illustration 3: 81-year-old woman regarding problems in ‘looking after the home’ following a hip replacement)
There was a recurrent theme where it was felt that help had been denied due to age attribution. In other situations, help had been declined and the themes of resignation, withdrawal and low expectations emerged again.

Discussion

The majority of those with unmet needs did not themselves actively seek help for them. A simple needs assessment approach does not take into account the motivational factors to meeting needs which appear to be involved. A strong sense of resignation and withdrawal was a dominant theme which is consistent with the concept of ageing as disengagement. There was also evidence of denial and ‘problem minimization’, which is consistent with previous work on the perceptions of older people.

There were no consistent overarching themes that applied to all cases, and a range of other explanations was given. Some barriers may have simple solutions, such as providing patients and carers with the information on how they can seek help. Low expectations were common, particularly in relation to psychological distress, and this again is something that could be actively addressed. The attribution of the problem to age alone also occurred, particularly in relation to memory problems, and again this is an issue that potentially could be addressed.

In those who had sought help, themes emerged of apparent inadequacies in the service provided to them. In others, the help available was not felt appropriate for them, raising the issue of how meet-able these needs actually were. Rationing also appeared as a problem, particularly in relation to social unmet needs, an issue that has wider policy implications.

This study has limitations, in that it was based on a relatively small sample who had wide ranging unmet needs. Differences were apparent between the unmet needs in the different domains, and a deeper exploration of these is necessary. All subjects who identified an unmet need from a random sample of people aged 75 years and over registered with four general practices in northwest London were included in the sample. It was a community sample that represented both sexes (although the majority were women), different social and economic backgrounds and a range of unmet needs. There was a relatively small proportion from ethnic minorities, as is typical in this age group.

The interviews were performed immediately following a structured needs assessment, and some explanations for barriers to meeting unmet needs were volunteered during the initial CANE assessments. This made tape recording of the interviews difficult and answers were recorded verbatim instead, introducing the possibility of incomplete recording and bias.

This study represents an initial exploration of the perceived barriers to meeting needs amongst older people and their carers. In this study, a range of complex barriers to meeting need were identified, and it was evident that these varied both between individuals and between different types of unmet need. Evidence from previous anthropological research also supports this view, where a wide range of attitudes and beliefs was found among older people. This complexity has implications for the commissioning of services for older people, particularly if a simplistic understanding of unmet need is used to judge the quality of service delivery or to guide service development. Further qualitative study, including concept mapping, would be needed to develop a grounded theory of unmet need.

Conclusion

More than three-quarters of patients and carers had not sought help for the unmet needs they identified. Many had a low motivation to seek help, with a strong sense of resignation, withdrawal and low expectations. For some problems, such as incontinence, there was a tendency to minimize the problem and, in others, such as memory, to attribute it to age-related changes. Sometimes they simply lacked the information on what was available or who to approach. In the minority who had sought help, problems of perceived inadequate or inappropriate services and rationing of services were recurrent themes. Patients and carers had a wide range of often complex reasons for not seeking help for their unmet needs. These reasons often challenge the concept of ‘unmet needs’ which from the patient’s and carer’s lay perspectives may not be considered as ‘need’ as we know it in the medical sense. These issues should be recognized by those involved in undertaking needs assessment and commissioning care for older people, and explored in greater depth in further studies.

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References