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# The impact of location on satisfaction with dementia services amongst people with dementia and their informal carers: a comparative evaluation of a community-based and a clinic-based memory service

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## ABSTRACT

**Background:** The development of effective medication for the treatment of Alzheimer's disease led to an expansion in the use of memory clinics and other clinic-based services for the delivery and monitoring of the drugs. In contrast, there is an increased emphasis on providing home and community based service delivery for a range of illnesses including dementia.

**Methods:** This paper reports the findings of an evaluation study comparing a clinic-based and a community service. A convenience sample of 10 service users and carer dyads took part in in-depth qualitative interviews. Service users were diagnosed with mild to moderate dementia of Alzheimer's type. Interviews were recorded, transcribed and subsequently analyzed using template analysis.

**Results:** Service users and carers were satisfied with both services, with determinants of satisfaction differing between the two services. Issues relating to the location and spatial design of services, comfort, familiarity, communication with staff, and ease of use are highlighted as important determinants of satisfaction amongst service users and their carers.

**Conclusion:** This study has implications for person-centred care practices in service delivery and for the future design of mental health services for people with dementia.

**Key words:** Alzheimer's disease, dementia, memory clinic, location, service design

## Introduction

With the ageing of the population within the United Kingdom and many other developed countries, increasing attention is being paid to Alzheimer's disease and other forms of dementia (Lamura, 2003). These are distressing illnesses for both the individual and their family, and effective interventions and care are expensive. Services need to be effective, efficient and meet people's diverse needs. Within the U.K. the introduction and licensing of anticholinesterase drug treatments for Alzheimer's disease, together with the development of national standards for dementia treatment, have led to an increase in the number of specific services available (Department of Health, 2001). While alternative forms of service provision, including community-based nursing services are commonly used, hospital-based memory clinics are often seen as the norm.

This paper draws upon findings from a small-scale qualitative study evaluating the performance of two distinct models for delivering anticholinesterase medications for Alzheimer's disease (Timlin *et al.*, 2005). This paper focuses on the impact of the location of these services upon the experiences and preferences of service users and carers.

### Memory clinics

In the U.K. memory clinics have developed rapidly over the past 20 years (Lindesay *et al.*, 2002). Van Hout *et al.* (2001) identify the main objectives of a memory clinic as providing "an ambulatory diagnostic, treatment and advice service for people with memory impairment and [acting] as a focus of research into dementia." However, the scope and function of memory clinics varies widely, both within the U.K. and internationally (Vernooij-Dassen *et al.*, 2005). With the implementation of National Institute for Clinical Excellence (NICE) guidance (NICE, 2001; 2006) and the National Service Framework (Department of Health, 2001), memory clinics have become particularly focused on providing early diagnosis and treatment using anticholinesterase drugs. These clinics are usually hospital based, although some utilize community service models (Psychologists' Special Interest Group in Elderly People, 1998). A clinic-based service represents a shift away from traditional community-oriented old age psychiatric services (Wattis *et al.*, 1999).

### Alternative service models

Although memory clinics are increasingly common, a variety of other care service models are involved in providing diagnostic and nursing services for people with dementia. Such models include community-based and/or nurse-led services (Woods *et al.*, 2003). However, with some notable exceptions, there has been little evaluative work on alternative forms of service provision.

There is an increasing focus on the development and delivery of community-based care packages. This is particularly true for people with dementia, where providing home- and community-based care is viewed as preferable. A growing literature highlights the importance of home as a location of care among healthy older adults and those with physical difficulties, notably by promoting independent living (Dyck, 1998; Gitlin, 2003; Secker *et al.*, 2003). Despite this, little systematic research in dementia care has examined these issues, although recent years have seen a growth of work in this area (Milligan, 2000; Phinney and Chesla, 2003). The home can play a significant part in the functioning of people with dementia. For example, using the Mini-mental State Examination (MMSE), individuals often perform to a higher level within their own homes than in clinic environments (Shievitz *et al.*, 1998). The physical, emotional and psychological impacts of moving from private dwellings to institutional care environments for people with dementia have also been explored (Reed-Danahay, 2001). Further research on such environments will illustrate how a person's environment can impact upon their cognitive and emotional health, sense of well-being, and quality of life.

## Methods

### Sample

In-depth qualitative interviews took place with a sample of 10 dyads (people with dementia and their main informal carer) receiving treatment either via a hospital-based memory clinic, or via a community-based nursing service. The sample was split equally across the two services. Both sites were located in two distinct urban areas within the county of West Yorkshire in the U.K. Service users were assigned to each site on the basis of their geographical location and which of the two services they were currently using. Sampling was based on a convenience sample: suitable participants already using each service were identified and recruited with the assistance of healthcare professionals and charitable agencies within the study area. In all cases, participants were living together in their own homes. Criteria for inclusion in the study were based upon NICE guidance for the provision of anticholinesterase drugs; including a diagnosis of mild–moderate dementia of Alzheimer's type (NICE, 2001). Sample sizes were small, as the purpose of the qualitative information was to generate sufficient data to assist in the development of a general questionnaire survey to be distributed to all service user-carer dyads in contact with the two services.

### Interview process

The semi-structured interviews involved an open-ended agenda relating to personal experiences of using the two services, and to the impact of the services

on health and well-being. Interviews were designed to enable people to discuss areas of importance to them, and for the interviewers to probe and explore emerging issues.

Participants and their carers gave informed consent to nursing staff at first approach and to interviewers prior to being interviewed (Bartlett and Martin, 2002). Interviews lasted between 30 minutes and 1.5 hours, and took place in the person's own home. Interviews were transcribed and coded prior to data analysis.

Transcripts were subsequently analyzed using template analysis (King, 1998). Data were coded into general domains that were highlighted as important during interviews. On subsequent readings, each domain was further expanded into themes and sub-themes. Here we report domains relating to perceptions of treatment location amongst service users and their carers.

### Ethics and data protection

Approval was gained from the NHS Local Research Ethics Committee (LREC) and Research Approval Group. The study was also peer reviewed and approved by the Ethics Committee of the School of Human and Health Sciences at the University of Huddersfield.

## Results

The study was based around a comparison of two distinct forms of service provision for people with dementia. The services were involved in two different geographical areas within a NHS Mental Health Trust in the north of England, with patients within each service living in that area. The first service was community based. As part of its care pathway, initial assessments took place at home, followed by diagnostic assessment within a hospital outpatient's clinic. Service users were subsequently monitored and assessed by community psychiatric nurses at six-monthly intervals within their own homes. Nursing staff were supported by consultant geriatric psychiatrists. In contrast, the second service was a traditional memory clinic based within a hospital outpatients department. Service users initially attended the clinic for a baseline assessment and diagnosis, followed by subsequent six-monthly monitoring and efficacy assessments. In both services, efficacy was monitored using Mini-mental State Examination (MMSE). Each service also used different activities of daily living assessments. The memory clinic provided a more prolonged assessment compared to the community service.

In the following, pseudonyms are used to preserve the identity of participants.

**The community-based nurse-led service**

The community service was highly regarded, with the home focus being thought of as the main advantage of this service. Two general themes were identified relating to the spatial design of the community service: personal reactions to the service, and promoting access to services.

PERSONAL REACTIONS TO THE SERVICE

Home was described as a comfortable environment in which to receive treatment. Being assessed within the home helped to reduce any worry or distress that the person with dementia felt, produced a friendlier environment more conducive to feelings of comfort, removed any anxiety associated with attending hospital, and promoted a greater sense of control over events taking place during a nurse's visit:

> I think it is more friendly if it's in your own home . . . and especially for
> my husband because he is in his own environment, and he will be more
> relaxed, whereas I think if you go to a clinic, you can all be very tensed
> up, [. . .] it is on more of a friendly basis, and that is what I like about
> it. (*Lyn, a carer*)

Carers using this service stated that having appointments at home enabled them to talk more openly about their relative with health professionals, and allowed them and the service user to "be themselves" within their own homes, an experience thought not to be possible within a clinic setting:

> If you are in the hospital you are in a different place altogether; [at
> home] you are sitting on your own settee, with your own carpet and your
> own furniture all around you, you can be yourself . . . But in hospital,
> [. . .] you are not as relaxed, tense, wondering what they are going to say
> next. [. . .] When you are in your home, no matter what the outcome
> is, you feel you can take it better in your own home. (*Maude, a carer*)

The nursing staff also acted as important sources of social interaction for participants. Because of both the personal qualities of the nursing staff, and the home-based nature of the service, many participants noted that talking to the community service nurses was akin to talking to friends, or to members of the family. This informal approach made people feel valued as individuals, rather than being perceived as nondescript "patients":

> *Int:* Would you say there's anything negative about the service you're
> receiving?

> *Michael:* No. no. Well let's put it this way I wouldn't know what to do
> if they weren't there now. (*Michael, a service user*)

Anne, a carer, particularly emphasized the humorous banter between her husband and the attending nurse. To Anne, this not only demonstrated an improvement in her husband's cognitive ability, but also his feelings of ease and comfort with the nurse, making him feel more at ease, and deflecting attention from the clinical assessments taking place:

> The nurse is excellent and she could not be better at the job because she is casual, she is not formal, she is completely informal, and she has a good laugh with you, and makes a joke of it. (*Anne, a carer*)

The emphasis on the contact was based on social rather than professional relations, with the person's own home promoting a more relaxed and informal atmosphere. This was conducive to the provision of emotional support in addition to the treatment aspects of the service.

## PROMOTING ACCESS TO SERVICES

Receiving treatment at home raised important issues in terms of access to services, reinforcing the perception that the community service met the patients' needs. Participants strongly appreciated the fact that they did not need to travel to a clinic in order to access services. Being visited at home by the community nurse eased the burden felt by carers by removing the additional tasks of arranging transport, and removing much of the physical and emotional difficulty of attendance.

Among these participants, attending a hospital clinic appeared to increase levels of anxiety. For some, exposure to others at more severe stages of the illness within the clinic was a potent contributor towards anxiety, illustrating what could be expected as the disease progresses. Appointments at home removed this exposure.

> I think if you went into the hospital you would be sat in a waiting room. You are going to see people far worse than what my husband is. I would not want him to think, well am I going to end up like this, [...] that can be very distressing in itself, I mean going down to [hospital] you see people in a worse state than yourself, which is distressing. No, I am satisfied with people coming. (*Maude, a carer*)

Feelings of anxiety and distress were also linked to the experience of traveling to the clinic, either as a result of the actions and behavior of others, or from feelings of stigma from exposure to the public gaze. Carers' own fears regarding the actions of people with dementia in public settings were an important element in their general unwillingness to use public transport. In contrast, home was viewed as a safe, secure and comfortable place, which removed the burden of attendance on the part of the service user and carer.

**The memory clinic**

Participants were generally positive about the performance of the memory clinic. However, themes in which people with dementia and their carers discussed their satisfaction or lack of satisfaction were commonly based upon the characterization of the clinic as an institutional space involved in formal treatment provision. This was in stark contrast to the more personal connections highlighted by users of the community service. Two themes were identified: personal reactions to service design, and preference for treatment location.

PERSONAL REACTIONS TO SERVICE DESIGN

Issues relating to service design had a significant role in determining an individual's satisfaction with the service. In the majority of cases treatment was seen as beneficial. However, some questioned whether the level of benefit achieved was worthwhile, given the perceived difficulty and effort in accessing treatment:

> I mean the treatment is limited, as you know, so it makes you wonder sometimes if you are going through a lot of hoops for no reason at all, if you understand my logic. (*Stephen, a carer*)

Most service users felt that the staff put them at ease during appointments, and were happy with their relationships with clinic staff. However, such views were framed by the clinic setting. Individuals generally understood the clinic as a formalized setting of timetables, appointments, waiting, consultation rooms and testing. They expected such activities within a clinic setting.

> To be quite honest, I was quite surprised because you're always hearing about these people who have to wait so long. Mind you, you have to wait a little bit, but that's inevitable isn't it really. (*Dorothy, a service user*)

Participants commonly felt that they were had to work according to the requirements of the clinic system, rather than it operating to meet their own needs. This was influenced by the experience of having to wait in the clinic, and of difficulties relating to traveling to and from the clinic. Although appointments with different staff in the clinic were designed to run concurrently, they often failed to operate in this way, occasionally resulting in lengthy waits between appointments. Traveling to the clinic was also described as problematic, particularly where people had to rely on public transport, or on ambulances, which took a long time. Such delays heightened the perception that service users had to operate within the confines of a system that was not designed to meet their specific physical and psychological needs.

PREFERENCE FOR TREATMENT LOCATION

All participants using the memory clinic who were interviewed as part of this study were questioned regarding their preferences for a clinic or community-based model. Four of the five dyads gave a preference for a community-based service, with such opinions being based on previous experience of such services.

Carers felt that any anxiety resulting from attending "a clinic" influenced their partner's cognitive and functional abilities during consultations, which might adversely affect any assessment on the progression of the disease. Several carers noted that prior to consultations their partner became nervous, often because of their expectations of being tested and of the need to perform well during tests.

One carer, Paul, stated that his wife May felt anxious when visiting the memory clinic and described how her lack of familiarity with the clinic environment and staff increased her feelings of anxiety and discomfort. This unfamiliarity was reinforced during each visit due to her being unable to recall previous appointments. As such, each visit was thought of as the first visit, a particularly daunting experience for her to relive:

> It may all be completely new once again so they go through the initial anxiety each time again. I have found with [May] that if she is anxious . . . she will almost become like a headless chicken you know, things are going round in the mind, which are completely unrelated to what is going on around her . . . (*Paul, a carer*)

## Discussion

In the current study, participants were generally satisfied with both services, with many being happy to be in receipt of any kind of effective intervention, particularly drug treatments. However, when discussing the services, the cognitive benefits of the treatments were often secondary to the psychosocial support they often gained from the service. Receiving treatment at home gave a person a greater perception of control and empowerment over their own treatment, transcending their common experiences of health-care services.

Carers commonly noted the benefits of being seen at home through a community-based memory service. Among individuals using the community service, the most significant conceptualization involved a removal of the service from traditional interpretations of hospital, clinic and other institutional settings (Kearns and Gesler, 2002). The personal qualities of the nursing staff placed descriptions of the service within social discourses rather than as an institutional service providing health interventions. Many participants saw the community service as an exemplar of patient-centered care, allowing users to retain a higher level of self determination and choice (Percival, 2002).

In contrast, the setting of the memory clinic resulted in its interpretation as an institutional environment among service users. Satisfaction with memory clinic personnel was high, but was based on experiences of the clinic as an institutional system. Therefore, issues such as waiting times and areas within the clinic, and stress caused to service users during appointments and when traveling to and from the clinic were of key concern. Such issues were expected to occur within the context of an institutionally based system. These are particularly important given the negative impact that anxiety and stress can have on the cognitive, emotional and behavioral state of people with dementia (Heine and Browning, 2004).

The initial results reported in this study were derived from a small-scale, qualitative case study evaluation of two specific memory services, which limits the empirical depth of the findings, and their generalizability to populations in other services or geographical areas. The cross-sectional nature of the study also limited the findings, as the effects of changes in attitude or service delivery over time could not be detected.

## Conclusion

This study provides an indication of the contribution that spatial issues can play in mental health service delivery and in their acceptability to service users and carers (Kearns and Gesler, 2002). This is particularly true in the context of dementia, in which experiences of anxiety and confusion can be integral parts of the disease process, which are profoundly influenced by social and environmental processes. In designing present and future services, a consideration of spatial and location-based factors may assist in the development of services that are more user-friendly and less distressing to people with dementia, thereby reflecting patient-centered care practices and acknowledging the psychosocial support needs of service user and carers.

## Conflict of interest declaration

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## Description of authors' roles

G. Gibson collected data and wrote the paper. A. Timlin collected data and assisted with writing the paper. S. Curran and J. Wattis designed the study, supervised data collection and assisted with writing the paper.

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