

The impact of early dementia on outdoor life: a 'shrinking world'?

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Abstract

This paper reports the voices of twenty-two people with early to moderate dementia and their carers about the use of the outdoor environment. Analysis of semi-structured interviews demonstrates that people with early dementia value the outdoor environment for reasons such as exercise, fresh air, emotional well-being, the opportunity for informal encounters with neighbours and friends and the appreciation of the countryside. Conversely, not being able to go out was associated with depressive feelings. Carers reported that the impact of dementia was to decrease the frequency of outdoor activity and to limit the areas visited to those that were the most familiar. Maintaining outdoor activity is likely to be an effective preventative measure in extending the period of good quality living and might decrease the period when intensive services are required. It should therefore be considered in planning for both residential care and community living in the future.

Key words: outdoor environment; dementia; quality of life.

Background

With more people living into old age and increasing longevity in many parts of the world, the global prevalence of dementia, primarily a disease of old age, is set to increase significantly. In 2005, Ferri *et al.* estimated that 24.3 million people in the world had dementia with a predicted increase to 81.1 million by 2040. In addition, the numbers of those as yet undiagnosed but in the early stages of cognitive decline will also increase. While there is as yet no cure for dementia, after diagnosis life extends for an average of seven to eight years. Although the trajectory is uncertain and comorbidity is common in old age, many older people with dementia continue to enjoy good physical health.

The Joseph Rowntree Foundation's Older People's Inquiry (2005) found that older people considered the ability to get out and about and keep active an important aspect of their lives. They valued support in enabling them to live in their own homes and have 'a life worth living'. Most older people with dementia have the same priorities, preferring to remain in their own homes for as long as possible rather than move to residential care homes or other types of assisted housing (Goldsmith, 1996). Evidence obtained from people with dementia suggests that they 'hope to maintain an ordinary way of life' (Fukushima Nagahata, Ishibashi, Takahashi and Moriyama, 2005). The symptoms of dementia, however, can present significant problems for maintaining independent living.

It follows that ways of supporting people with early to moderate dementia so that they can continue to live at home but not be confined indoors need to be found. This is recognised in a recent policy document for older adults with mental health problems in the UK, which states that 'While people are choosing to remain living at home they should be offered support to enable them to live as full lives as possible' (Department of Health, 2005a, p. 27). In addition, in the UK there has been a marked shift in provision away from residential care towards domiciliary care. In 2001, 827 private and voluntary care homes closed with the loss of 16,600 places while only 117 new homes opened providing 3,800 places (Laing and Buisson, 2002). This has resulted in a requirement for services which will enable older people, with or without dementia, to remain at home. The advent of assistive technology, the possibility of respite at home and specialist supported housing schemes are examples of proactive

approaches towards this end. Early interventions of this kind are targetted at extending and maintaining independent living and the prevention of crisis situations.

At the same time, the stigma and negative stereotype attached to dementia and to old age itself pervades the attitudes of the public and of health professionals, leading to a risk of social exclusion. Clarke, Heyam, Pearson and Watson (1993) found that many health professionals regarded people with dementia as 'effectively dead'. Iliffe (1994) found that many GPs in the UK expressed despondent attitudes towards dementia, believing that 'nothing can be done'. Katsuno (2005) reports the emotional and social experience of negative public attitudes towards those with early stage dementia. Bond (1992) argues that the medical model of dementia leads to professionals ignoring the perspective of people with dementia and reinforces social exclusion. Blackman *et al.* (2003) argue that dementia is a condition conventionally regarded as needing confinement indoors, with little consideration of how people with dementia might be assisted with activities of everyday living in the outdoor world.

Various ways of promoting an alternative model focusing on social inclusion are explored by Cantley and Bowes (2004). These include 'hearing the voices' of people with dementia and their views and feelings about how they want to live. This approach is supported by Wilkinson (2002) who argues the case for including people with dementia in research to increase understanding of their quality of life so that we can reduce barriers to participation and bring them more inclusively into society. There is a need to hear more from people with dementia themselves about the ways in which dementia affects their 'ordinary' lives. What do people in the early stages of dementia value most about their everyday lives? What aspects contribute to their quality of life? In what ways can their quality of life and independence be maximised for as long as possible?

This paper reports the voices of people with dementia concerning their use of the outdoor environment and how dementia impacts on it. The interviews were part of a larger project exploring how the outdoor environment can be adapted to be 'dementia friendly'¹.

¹ See <http://www.tees.ac.uk/depts/socialfutures/research11.cfm>

Method

Approval was obtained from the Local National Health Service Research Ethics Committee for the project. Participants were recruited with their carers through National Health Service consultant psychiatrists of old age on the basis that they had a diagnosed dementia of the Alzheimer's or vascular type at the mild to moderate stage, were aged 65 or older, were living in their own home, and were mobile outdoors. Following initial agreement to participate during a visit to their consultant, the researcher working on the project made a home visit to the patient and invited him or her to sign a consent form together with their main carer. A total of 22 people with dementia agreed to an interview, out of about 100 who were approached. Reasons for refusal ranged from carers wanting to protect the privacy of their relative to a deterioration in their health; no specific characteristics that only applied to refusers could be identified.

Participants were aged between 71 and 84 years. Half were males and half females. All had a diagnosis of mild to moderate dementia with MMSE (Mini-Mental State Examination) scores between 15 and 29 (the lower the score, the greater the impairment). Eighteen were receiving medication for dementia. Most (19) were interviewed in their own homes, the remaining three being interviewed in a private room in a day hospital. Wherever possible, simultaneous but separate interviews were also carried out with carers to provide an additional perspective, and also to clarify accounts when the person with dementia was unclear or uncertain. Fourteen carers were interviewed. Of these, 11 were spouses or partners, two were daughters and one was a carer/housekeeper. The interviews used a semi-structured questionnaire and focused on experiences of the outside environment. Questions included asking about level of activity, reasons for going outdoors, any difficulties encountered in using the outdoor environment and any changes since the onset of memory problems. Some examples are shown below:

How often do you go outdoors? Do you find it easy or difficult to cross roads when you're out? Do you avoid going to places you haven't been to before? How has outdoors changed for you since you've had memory problems? What would you do if you got a bit lost when you're out?

The carers were asked to answer the same questions for the person they cared for. The interviews were recorded and transcribed, and the transcripts were analysed using NVivo.

After an initial reading through of the individual answers, a grounded theory approach was used to explore emergent themes. For example, there were no specific questions about confidence or anxiety, but loss of confidence and anxiety were important factors raised frequently in relation to going outdoors. Three main themes emerged and are reported below: the significance of the outdoor world to people with early dementia; the impact of dementia on outdoor life; and the importance of the familiarity of the outdoor environment. The responses of the carers and the people they cared for were mostly in agreement, with exceptions noted below. To ensure anonymity, participants with dementia (PWD) are identified by number only.

Results

The first theme apparent from our analysis was that the outdoor world had a notable significance in the lives of our participants. All except two interviewees with dementia went outdoors on their own but, of those who did, half went outside for short distances only, being out for less than an hour. The most common reason for going out was for shopping, with about half of participants shopping every day, if only for a newspaper. When asked what they liked about walking outdoors, the interviewees gave responses which indicated their enjoyment of the outdoor environment. Reasons were primarily social and aesthetic rather than functional.

Going out of the house was seen by some as an opportunity for enjoyable informal encounters with friends and neighbours:

I usually find someone to talk to en route (PWD 13).

It's a change, I love seeing people. I'm well known, you know, in the town. There's usually lots of people who stops and talks (PWD 20).

You can always hear him talking to somebody when he goes out (CARER for PWD 20)

This interaction with familiar people outdoors was a source of identity and social inclusion for participants. An appreciation of the countryside was also often mentioned:

Fresh air, the sunshine and just the view, nature, the nice views ... (PWD 2).

Now and again he takes his camera and takes some photos because he does painting you see (CARER for PWD 2)

I like the countryside, I love the countryside and I love to be outdoors especially where there's a river (PWD 14).

Functional reasons for enjoying a walk outdoors included exercise and the benefits of breathing fresh air:

It's good, it's good to have fresh air. I mean I clog my lungs up with pipe tobacco so I can get them cleaned out when I go outside (PWD 11).

But er, yes I like to do that. I don't think I can just sit all the time ... it's a change to get out you know. Well fresh air, makes you think better. If I've been walking around the garden, then I come back and I feel great (PWD 16).

The last quote above (PWD 16) also refers to the emotional well-being (feeling 'great') that walking outdoors can bring. In the same vein, a sense of relief, escape and freedom were mentioned by other interviewees:

Fresh air, exercise, meeting people - I usually find someone to talk to en route and escaping yes yes ... it's just nice for a change of scenery yeah (PWD 13).

Well the outdoors is a relief to me now ... she [wife] goes to the hospital and she leaves here at 9 o'clock and she doesn't get back here 'til 3 so I'm on me own. I've got a great opportunity for my freedom, I can go wherever I like (PWD 21).

He said it makes him feel free. (CARER for PWD 7)

Conversely carers identified the 'need' to go out and that staying in the house all day could have a depressing effect on mood:

Up the village and back - he needs to do that - if he didn't, he would really get depressed

(CARERfor PWD 12)

Most days he goes out even if it's just to the library or summit – he needs to go out (CARERfor PWD 9).

These reasons for enjoying the outdoor environment are also likely to be reasons why the majority of people with or without dementia enjoy being outdoors. What these responses demonstrate is that the enjoyment of being out of doors was maintained in the early and moderate stages of dementia and that going outdoors appeared to be an important contributory factor in maintaining quality of life.

The second main theme was the impact of dementia on outdoor life. When asked 'how has outdoors changed for you since you've had memory problems?', most people with dementia in our study thought there had not been any change. But their carers did describe effects that the illness was having in this respect. The lack of awareness of change by people with dementia may be a reluctance to admit to these effects, a form of denial or simply the result of cognitive impairment in that they were unable to compare the present with the recent past. The following carers cited a direct effect of dementia on activity and independence, which in turn affected the mood and quality of life of the people they cared for:

He's had to stay in the house more and it gets him down (CARER for PWD 7).

It's actually erm his quality of life, I would say, has gone down cos he has always been extremely independent. He's stopped being as active (CARERfor PWD 11).

Specific symptoms or factors associated with dementia were also referred to by interviewees. The problem of a deteriorating memory was identified by these carers, and also one of the participants with dementia:

I think he knows he has a bad memory and so doesn't want to ask people, so he would rather not go out than constantly asking someone (CARERfor PWD 4).

But I can get there and forget what I have come for and that's the biggest thing I have got at the moment, forgetting why I am doing it and where (PWD 18).

He's probably forgotten what he's doing or where he's going half the time, that's why we're mostly together when we're doing anything (CARER for PWD 9).

Confusion was referred to as being a factor placing limitations on outings:

And when that confusion comes on he doesn't know where he's going, or how to deal with it, or how to handle it (CARER for PWD 11).

'Cos he gets confused easily oh yes, oh yes even if he stopped to ask somebody he'll go 'oh yes! Oh right' and we close the door and walk away and he'll say 'what did he say'? (CARER for PWD 9).

He'll tell me he's going such and such a place and then he ends up somewhere else (CARER for PWD 23).

The disorientation that can be a symptom of dementia and the associated fear of getting lost was a further feature:

It is more difficult when we go out now And I worry about it a little bit 'cos he'll always say well I'll just go here while you go there and I don't like us to be split up 'cos he'll forget where I've said, 'cos I'll say in the beginning we had some horrendous rows, I'd sit and I'd wait and I'd think where is he? He was in the wrong place, see (CARER for PWD 9).

He used to walk a lot more than he does now ... and he still goes to the same places he used to but he might have gone into town for shopping. But now I wouldn't dare let him (CARER for PWD 12).

Places that I haven't been to I'm a bit worried about these days (PWD 11).

In addition, interviewees recognised that reduced confidence and consequent anxiety can cause people in the early stages of dementia to themselves restrict the outdoor environment in which they move:

I've got to be very sure about what I'm doing, and I must admit, I don't go out very often without [partner] (PWD 8).

She wouldn't go very far afield now whereas she would before, and she would go on trains and planes on her own, and there is no way she would do it now and I would be too

frightened to let her anyway, you know, I would be nervous for her. But she wouldn't like to do it and she would be scared which platforms and times and she gets nervous and she is always asking what time is it you know (CARER for PWD 15).

Well I would say that she has suffered a considerable loss of independence and would not be very happy to go places on her own (CARER for PWD 17).

At present he avoids making journeys at all. He just seems to avoid people he knew. He just seems like he doesn't want to get in company. But he was the chatty one ... it's totally not him (CARER for PWD 23).

Our findings suggest that declining memory, confusion, disorientation, reduced confidence and anxiety are all interlinked. These factors can impact significantly on the use of the outdoor environment by people with dementia by restricting and limiting the areas which they access and reducing outdoor activity.

The third main theme was the familiarity of the environment and this emerged strongly during the interviews. The following quotes suggest that being in an unfamiliar place can be stressful and increase the feeling of confusion:

He wouldn't want to go somewhere that he didn't know... if he was just local he'd be alright but he wouldn't want to be on his own somewhere he's not familiar with, he'd get worked up (CARER for PWD 1).

If he was in a strange place he would become very confused - it's just his memory, his illness (CARER for PWD 4).

Another interviewee reported that a change in the environment (the bus service), caused her to stop her outdoor journeys altogether:

But that has all stopped now I just can't seem to do it, it's the buses you see they altered the buses (PWD 5).

Feelings of safety and comfort were associated with familiar areas:

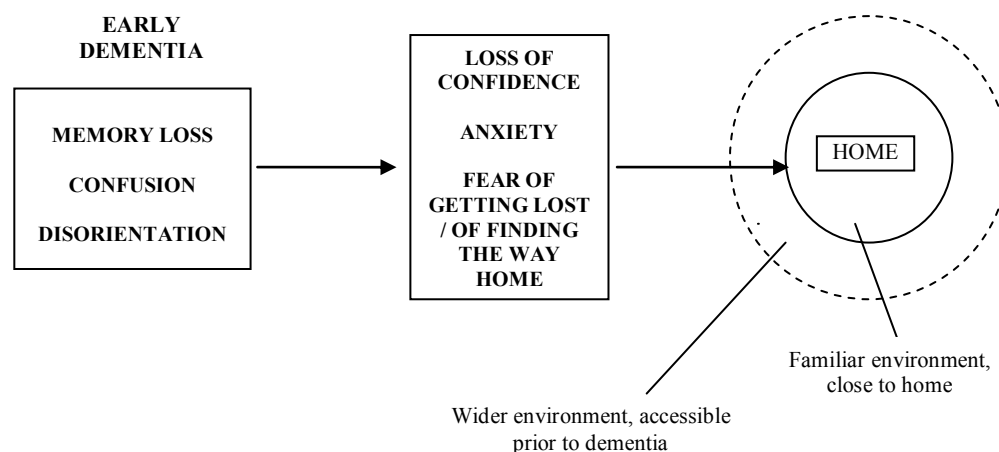
She likes to go where she knows and where she feels safe and comfortable I think (CARER for PWD 15)

Again, the effect of the fear of unfamiliarity was to reduce the outside area in which the person with dementia was active:

I think he's often unsure, if you took him to a new place I think he's fearful of not finding his way back. So he can only go to the places that he knows (CARER for PWD 11).

Discussion

Our results suggest that the outdoor environment is important to people with dementia. Participants derived considerable pleasure from being outdoors but their symptoms caused a reduction in the area around the home in which they felt comfortable. Figure 1 presents a model derived from these findings. A 'shrinking world' tends to lead to an overall decline in independence as places such as town centres become 'no go' areas, and even shopping locally often becomes dependent on being accompanied by a carer.



Our findings relate to 22 people with mild to moderate dementia but the extent to which there were common themes suggests a wider relevance to people at these stages of dementia. The results are also based on self-reports rather than observations. We found, however, that most participants with dementia gave similar reports about their current lives to those of their carers, suggesting that the reports are reliable given that the interviews were undertaken separately by two interviewers. Other studies have found that people with mild to moderate dementia are capable of giving accurate and reliable information about preferences (Whitlach, Feinberg and Tucke, 2005; Mozley et al., 1999). There were, however, two aspects where reports diverged. Participants with dementia in our study did not think that any changes to their outdoor lives had occurred as a result of their dementia, whereas their carers were able

to identify significant changes. Additionally, when asked to describe going outdoors and outdoor behaviour, participants with dementia tended to reminisce about activities they used to do before their dementia rather than their current behaviour.

Our results suggest that, in the early stages of dementia, people continue to value the benefits of the outdoor environment. 'Going out' is a significant factor in contributing to well-being and hence quality of life. The familiarity of the environment is also important; changes cause confusion and, as a result, sometimes people with dementia may stop going out altogether. People with dementia tend to avoid unfamiliar environments. They also tend to move within gradually smaller areas as their cognitive ability decreases.

The fact that our participants with dementia did not recognise any change in their use of the outside world since diagnosis is interesting in itself. This could be interpreted as indicating that the changes did not matter to them, perhaps since most were still able to get out independently. But the obvious and likely trajectory, as the dementia inevitably worsens, is that the accessible environment continues to decrease until the person with dementia is unable to leave the home unaccompanied. There may not be an awareness of this trajectory in their memory but the effects on their quality of life in the present are evident.

A shrinkage in the geographical area in which a person with dementia is active is likely to be experienced as a loss of independence and control. This was hinted at by one of the carer's comments ('he *needs* to go out') and another who thought that if her spouse did not go out 'he would get really depressed'. It seems likely that a reduction in a person's normal use of the outdoor environment can heighten the risk of depression that dementia already poses (Paterniti, Verdier-Taillefer, Dufouil and Alperovitch, 2002).

Kitwood's work (1997) on the subjective world of dementia defines the main focus of dementia care as being to maintain personhood in the face of cognitive decline. Some of the needs identified by Kitwood which are necessary to maintain personhood, such as identity, inclusion and occupation, can be regarded as being at least partially met by the experience of going outdoors regularly. Kitwood suggests that the need for occupation persists in dementia despite the fact that many of the possibilities for occupation are removed because of cognitive

impairment. Walking outdoors seems a relatively simple occupation to maintain but one through which significant needs can be met.

There is an increasing amount of research investigating 'good cognitive health' or 'successful ageing' and a general consensus that remaining active and productive contributes to successful ageing (see, for example, Fisher, 1995). In the UK, the Department of Health (2005a) recognises that physical health and mental health are 'inextricably linked' (p 12). Rappe, Kivela and Rita (2006) point to the restorative effects of outdoor green environments on self-rated health among older people in long-term care. The authors found that the more frequent the outdoor visits, the stronger the association with positive self-rated health. As well as the physical health benefits of even low-intensity exercise such as walking, there is evidence that the more that older people walk and take exercise the less their risk of dementia (Abbott et al, 2004; Scherder et al, 2005; Larson et al, 2006). There are several possible explanations for this, such as the effects of walking on cognitive activity and links with cardiovascular health. The former explanation is supported by a study by Weuve et al (2004), which found that older women who are more physically active, including walking, had better cognitive function across general cognition, memory, fluency and attention and, in effect, aged more slowly. Women with cognitive impairment who walked more also experienced less cognitive decline. Friedman and Tappen (1991) found that a planned walking program (30 minutes, three times a week) for people with Alzheimer's disease resulted in significant benefits in the ability to communicate. As well as having a preventative effect, walking may slow the progression of dementia. A study by Burgio, Burgio, Engel and Tice (1986) report that providing care home residents, half of whom had dementia, with the opportunity for walking led to significant improvements in well-being. Overall, these findings support the argument that going outdoors regularly is likely to contribute to the well-being of people with dementia.

If we accept that the benefits of going outdoors are worthwhile, then ways of promoting going out need to be explored, especially if they are cost effective in terms of extending independent living and preventing or decreasing periods of time in residential care. Although ways of maintaining skills and confidence are regarded as important in early-stage intervention, currently in the UK the services offered tend to be orientated to essential tasks

(e.g. meal preparation) rather than focused on social and emotional needs. Our study suggests that going out can meet social and emotional needs and that the importance of going out may be undervalued. Assistive technology might offer some solutions in terms of tracking devices or simplified mobile phones, which can give both the person with dementia and their carer more confidence in using the outdoor environment independently. Another approach is in adapting outdoor environments with better planning, design and signage to promote their 'dementia friendliness' (Blackman *et al.*, 2003).

There may of course be good reasons why older people with dementia prefer not to go out independently. They might rarely have gone out alone prior to the dementia, preferring to go out with their spouse or family. There may be reasons related to physical health why they cannot go out alone or they may have already lost the confidence to do so. In the latter case, carers could be encouraged to accompany the person within their familiar environment to maintain their interest in the outdoors and continue to enjoy its benefits. For those living alone without a spouse or close family, it may be that formal carers should be urged to add 'encouraging walking outdoors' to their list of tasks.

The significance of remaining at home where appropriate as opposed to residential care is mentioned in a recent report by Department of Health (2005a, p. 30) who recognise that people with dementia 'may find leaving their home surroundings and routine particularly distressing and confusing'. Support workers employed to help people with dementia in their own homes need to identify their specific needs and help them to maintain their use of the outdoor environment. In the same vein, the Department of Health's (2005b) vision for the future states that, over the next ten to fifteen years, people who use social care should be given the opportunity and support 'to do the things that other people take for granted' (p. 16). Going outdoors is of course something that is taken for granted, although perhaps easily neglected for a person with dementia.

Finally, we should not forget those in residential care, whose appreciation of the outdoor environment is equally important. Here again priority tends to be given to physical rather than emotional needs, although this is beginning to change with the development, for example, of outdoor gardens planned with safe but interesting walking routes. Walking paths with features of interest along the way have been found to decrease exit seeking from residential care

homes and improve the mood of residents (Zeisel et al, 2003). Gardens have also been found to reduce attempts at elopement and aggression, to improve sleep, and to engage family members with residents.

Conclusion

With an ageing society and the global increase in dementia, there is a need to understand the factors that contribute to quality of life for people in the early stages of dementia from their own perspectives. The data gathered in the interviews for this study suggest that people in the early stages of dementia value the experience of being outdoors. It is an aspect of their everyday lives that contributes significantly to their overall quality of life. The interviewees appreciated the outdoor environment itself, valued the opportunity of seeing and meeting people, and valued the exercise and the emotional benefits. Conversely, interviewees also referred to the negative effects on emotional well-being of not going out regularly. This aspect of quality of life should not be underestimated in planning services in the community and in residential care. Maintaining physical and emotional well-being is likely to be an effective preventative measure in extending the period of good quality living and may decrease the period when an intensive use of services is required.

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