

Brief Report

Changes in Accommodation Experienced by People with Down Syndrome and Dementia in the First Five Years After Diagnosis

Karen Watchman

Centre for Research on Families and Relationships, University of Edinburgh, Edinburgh, Scotland, UK

Abstract Research that has tracked living situation changes is lacking for people with Down syndrome post-diagnosis of dementia. Extant studies have not considered reasons for a move, the stage at which it happened, and how involved in the decision the person with Down syndrome was. To study this, a postal questionnaire was used with 35 carers of persons with Down syndrome who had been diagnosed with dementia during the previous five years. Results showed that there are fewer accommodation changes in the early stages of dementia among people with Down syndrome than have previously been suspected and that confusion exists over the interpretation of existing care models. Findings also revealed that adults with Down syndrome were often denied the opportunity to take part in discussions about their future accommodations and there was a lack of forward planning on the part of carers.

Keywords: accommodation, carer, dementia, Down syndrome, intellectual disabilities

BACKGROUND

Most adults in Scotland with Down syndrome live with older parents, while others move to either single tenancy or group homes within an intellectual disability specific supported accommodation complex (Scottish Executive, 2000). With the onset of dementia, families and social care organizations are encouraged to consider appropriate levels of care that take into account levels of support for the future (Seltzer et al., 2002). In many cases the decision to change accommodation has been recorded as having been taken in a crisis situation often leading to an inappropriate move (Haley & Perkins, 2004).

Janicki, McCallion, and Dalton (2000) referred to three models of care when researching the accommodation of people with Down syndrome and dementia. "Aging in place" refers to the situation where support is provided for a person with Down syndrome and dementia in his or her home environment. This includes the incorporation of specific aspects of health and social care that are directly related to dementia, training in dementia related issues for skilled staff and carers, and environmental adaptations to minimize the effects of dementia on the person and others in their environment. "In place progression" is a dementia specific program where people with broadly similar levels of need

are provided with a range of accommodation options and support in a specialized setting. It allows for progression through stages of dementia in a consistent environment. "Referral out" is the third model and involves a move to a generic social care facility or when health needs are prominent, to a nursing led facility such as a nursing home.

As part of a broader study determining the views of carers (paid and family) of people with Down syndrome and dementia on a number of issues, a postal questionnaire sought information about living arrangement changes within a five-year period after dementia diagnosis. This report focuses on issues related to accommodation in order to find out how relevant the concepts of aging in place, in-place progression, and referral out were in this sample. The extent of involvement of people with Down syndrome in discussions about their accommodations was also sought.

METHOD

A postal questionnaire, designed to capture data on any accommodation changes post diagnosis and the reason for this, was sent to 45 members of Down's Syndrome Scotland. A postal questionnaire was used as it was low cost, would minimize bias error (as the researcher was not present), and offered the informants time to think about their answers and remember details and reasons. A limitation was that participants may not have fully understood the questions; questions were specific, and

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Correspondence: Karen Watchman, Head of Centre International Study Centre, University of Stirling, Stirling, Scotland, FK9 4LA Tel: +44 1786 4467812; E-mail: karen.watchman1@stir.ac.uk

all except one closed with easy-to-understand language. One routing question (Oppenheim, 2004) was used giving a choice of options that varied depending on the answer given. This was only relevant if the person with Down syndrome had changed accommodation, in which case there was a query about the reason.

Analyses were carried out by identifying, coding, and categorizing the moves, the reasons given, and who was involved in the decision to move. Results are presented on the basis of accommodation and care types and subsequent moves, if any.

RESULTS

Despite the limitation of a small sample size, there was a high response rate (77.8%) to the questionnaire, with 35 questionnaires returned out of 45 sent to a combination of family and paid staff carers. The average age of the adults with Down syndrome was 52.8 years at the time of the diagnosis of dementia (men : 51.4 years; women : 53.9 years). The average age of family carers taking part in the research was 79.5 years for parents and 51.3 years for siblings; the average age of paid carers was 42.5 years.

No Change in Accommodation

Twenty of 35 (57.1%) people with Down syndrome had not changed accommodation since their diagnosis. Five had between one and five periods of respite for up to one week. Some 25 carers did not know if a change in accommodation would take place in the future.

Living in Single Tenancy Supported Accommodation

Eight persons (22.9%) with Down syndrome lived in a supported accommodation in a single tenancy at the time of diagnosis. Four of the eight had not since moved and did not have any additional supports in place. Three had moved within the same complex either to another single tenancy physically nearer to staff support or to a single person ground floor flat to facilitate mobility. The reasons given were related to higher support needs being identified. One of the three had a further short-term (three weeks) move to a general hospital ward to be treated for pneumonia. One of the eight moved to a generic nursing home because care staff had identified a greater nursing care need than they felt able to provide. Two carers noted voluntarily on the bottom of the form that it was their intention for the person to remain in the same accommodation for the duration of their illness. Six were unsure if the person would move in the future.

Lived-in Shared Tenancy Supported Accommodation

Thirteen of the 35 (37.1%) lived in supported accommodation in a shared tenancy with between two and four other tenants;

10 of them had not moved from the supported accommodation since the time of their original diagnosis of dementia. Three had made permanent moves, one to a generic nursing home, one to a general hospital for short-term treatment and then onto a generic nursing home, and one to a generic residential care home. One of the ten remained in the same complex but moved to a ground floor single tenancy accommodation. The reason for the moves was the disruption that was experienced by other tenants living in the same accommodation rather than the needs of the individual person. Eight carers were unsure if a move would take place in the future.

Living with a Sibling

Three of the 35 (8.6%) lived with a sibling (two with a sister and one with a brother). None had moved since their diagnosis of dementia. All of the siblings were unsure if a move would take place in the future.

Living with Parents

Eleven of the 35 (31.4%) lived with their parents at the time of their diagnosis. Eight continued to do so, although five of them had short-term moves for either respite (four people) or illness (one to a general hospital) and then moved back to the parental home. Three had moved permanently away from their parents home, one to a sister's home and two to generic care homes. The reason given for the move to their siblings was the ill health of their parents. Short-term moves for respite were used to give parents a break and in one case a hospital stay was for treatment of pneumonia. Nine of the 11 carers in this group were unsure if the person they cared for would move in the future. Of the sample, no one had experienced more than one permanent move since diagnosis.

WHO WAS INVOLVED IN DISCUSSIONS TO CHANGE ACCOMMODATION?

Of those 16 moves, only three adults with Down syndrome were included in discussions prior to the move. Reasons given included the person's inability to communicate in three cases, and an inability to take part in meetings in two cases. Eleven carers either did not answer the question or indicated that they did not know why the person with Down syndrome was not included. This can be compared with professional involvement in all moves with a minimum of three professionals involved in each change in accommodation and family members who were involved in nine moves. Not all of the people with Down syndrome had contact with family members and only one had an advocate.

DISCUSSION

Although some 57% of the survey participants with Down syndrome had not changed accommodation, it should not be

assumed that this means they are “aging in place” as support, environmental adaptations, specific skills, and training for carers were not always present. This “stay at home” option is only likely to be effective if the principles of “aging in place” are followed at the same time. An additional element was the number who used respite facilities. While it appears that the “stay at home” option is working, despite not following the principles of “aging in place,” it may be due to carers getting some breathing room every now and again rather than the required ongoing support and long term systems that the “aging in place” scenario requires. Hatzidimitriadou and Milne (2005) found that parents wanted to continue as the main carers for as long as possible but needed support and information from services to enable them to do so.

We observed that the average age of people with Down syndrome at 52.8 years when diagnosed with dementia. This is consistent with the findings of others who have noted onset between ages 50–55 (e.g., Tyrrell et al., 2001—noted 54.7 years). The average age of parents who cared for a person with Down syndrome and dementia at 79.5 years is older than family carers of people with dementia in the wider population whose average age was recorded as 72.1 years (Ballard, Eastwood, Gahir, & Wilcock, 1996). This may relate to carers in Ballard’s study caring for a spouse or older parent whereas participants in the present study were caring for an adult child with Down syndrome, a situation that Janicki et al. (2000) referred to as “dual aging.” Where the main carer was a sibling, then their average age at 51.3 years is likely to coincide with additional responsibilities for them arising from also caring for older children, grandchildren, or aging parents, or dealing with their own health issues (Fray, 2000).

“Aging in place” actually occurred in just four cases, with carers noting that this was only possible if a bedroom was available on the ground floor to allow adaptation and if staffing levels could be resourced or increased to enable a move within the same intellectual disability specific environment. “In-place progression” did not take place for any of the people being cared for. This might be due in part to the current situation in Scotland with a lack of specialist resources for people with Down syndrome and dementia. Seven persons were “referred out,” which involved a permanent move to a generic nursing or care home despite research considering it unnecessary or unsatisfactory (Moss, 1992). Findings support Thompson and Wright’s (2001) research that people with intellectual disabilities are often moved to care homes for older people inappropriately and at a younger age than specified in the homes’ admission criteria. The postal questionnaire suggests that this, at least in part, may arise from support systems breaking down with carers also noting a lack of available information and advice.

Data derived from the general population in the United Kingdom (Alzheimer’s Society, 2007) indicated that 63.5% of people with dementia live at home, albeit alone or with a spouse rather than aging parents. A lesser number, 36.5%, live in care homes although the number rose with age from 26.6% of those aged between 65–74 to 60.8% for those aged 90 or over. Staff in generic care homes are not trained to work with this younger population who have an intellectual disability (Hatzidimitriadou & Milne, 2005).

The involvement of professionals and family rather than the person with Down syndrome themselves in any decisions is not

a new finding in the field of intellectual disability (Goodley, 2000). More recently, research has promoted a person-centered approach with the wishes of the person with an intellectual disability central to any discussions. McConkey, Sowney, Milligan, and Barr (2004) recommended that greater consideration be given to preferences over choice of home. Person-centered work has an impact on the general population who have dementia with an increasing number of people having more of an input to their future care and provision (Kitwood, 1998). The same impact and choice is not obvious when people with Down syndrome have dementia.

Some 55.6% of the carers chose “don’t know” as the option for future accommodation suggesting that although moves are not common in the early stages—the stages when people with Down syndrome are most likely to be able to take part in planning and decision making—there is a high level of uncertainty over longer term planning. It is often in the later stages that crisis moves take place. The Edinburgh Principles (Wilkinson & Janicki, 2002) relating to the importance of planning to maximize the person with Down syndrome staying in his or her own home are not being met. Uncertainty over future accommodation supports findings from research funded by the Joseph Rowntree Foundation (Wilkinson, Kerr, Cunningham, & Rae, 2004) highlighted the lack of firm plans over accommodation. The willingness of some carers in supported accommodation to keep adults with Down syndrome in the same accommodation is commendable but may not be practical in terms of the environment or available future support and care. By not addressing the possibility of a future move at an early stage, all options are not being considered and the person with Down syndrome is often not having his views taken into account.

CONCLUSIONS

Persons with Down syndrome who are “staying at home” seem to be confused with “aging in place,” which involves more than just the accommodation remaining the same. This must be addressed when deciding the most suitable housing options with a person who has Down syndrome and dementia. If a person is staying at home, then consideration should be given to respite and advocacy alongside the principles of “aging in place.” Changes in accommodation have been seen to occur less often in the earlier stages of dementia. There is agreement in the literature (Wilkinson & Janicki, 2005; Watchman, 2003) that due to the known progression and implications of dementia among people with Down syndrome, advance preparation is both possible and practical. This is not happening at the most opportune time when, should a move be made, the consequences in terms of health and confusion may not be as drastic as middle or end stage crisis moves. Longer-term research is needed to fill the gap of knowledge in this area. Over a longer period of time the researcher will track people with Down syndrome through different stages of dementia as part of an ethnographic study. This includes people in different accommodation settings, as McCallion (1999) noted an earlier death for people with Down syndrome and dementia following a move to care or nursing facilities. The current research highlights a lack of involvement of

people with Down syndrome in discussions about their future accommodation. The experience of people with Down syndrome should be sought firsthand, thus preventing further marginalization of an already isolated group. To rectify this research is needed that directly explores the experience and identity of people with Down syndrome and dementia.

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