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## **Carers' perspectives on choosing a care home for a relative with dementia**

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***Abstract***

This paper describes findings from a project which explored what happens to people with dementia (pwd) following discharge from a general hospital to a residential care home. In 15 out of 109 cases referred to a hospital psychiatric liaison team, admission to a residential care home was indicated during the hospital stay. This 'last resort' for families, following repeated hospital admissions and a deteriorating condition, was accepted when all involved agreed it was in the best interests of the pwd. Four months after the move, carers reflected on their criteria for choosing the home, their expectations, and whether these were met. Carers' own wellbeing improved and their mental distress reduced as the pwd appeared settled and safer. However the findings suggest a continuing key role for in family carers of pwd in care homes and emphasises the need for advocacy for pwd without such support.

## ***Introduction***

The prevalence of dementia is increasing worldwide, anticipated on current projections to escalate from around 35.6m people in 2012 to 65.7m by 2030 and 115.4 m by 2050 (ADI, 2010). In the UK, around 800,000 people are living with dementia, about one third of whom live in residential care homes (Alzheimer's Society, 2012). However, relatively little is known about the outcomes of different kinds of living arrangements for people with dementia (pwd), and for their family carers. Moving into a residential care home, often seen as a last resort (Penrod et al, 1998) implies not only major life changes and a different environment for the person with dementia, but also different expectations and experiences of the involvement of family carers in the daily life of the person with dementia.

Half of new care home admissions in the UK come straight from general hospitals (OFT 2005). For some years official policies and statements in the UK have emphasised the importance of ensuring the active participation of carers and patients with hospital staff in deciding where to discharge older people. (Borthwick et al, 2009). Yet research has found that many carers feel stressed by this process (Duff et al 2006), and insufficiently involved and supported (Borthwick et al, 2009). Admission to care placements for people with dementia is acknowledged to be a complex transaction between many players, but often with the person with dementia playing a relatively passive role (e.g. Ryan and Scullion, 2000a). The care pathway of the person with dementia prior to care home admission may well have included a lengthy period during which decision-making was avoided or delayed whilst the person was being cared for at home: often with serious impacts on the well-being of family carers (e.g. Cooper et al, 2008). However this status quo then becomes interrupted during or following a medical or practical crisis when an urgent decision had to be made (e.g. Ryan and Scullion 2000b). In Nolan et al's typology of care home admissions (1996) the scenario of admission to care homes following a crisis admission to hospital is the least desirable outcome, yet for the older person it is often a *fait accompli* insofar as they have been doubly excluded - from making the decision, and being involved in choosing the specific home.

In addition, the outcome for the person with dementia of moving to a care home can be uncertain therefore complicating relatives decision making. For example in a study of over 11,000 residents of BUPA care homes (UK) conducted in 2008-10 (Forder and Fernandez, 2011) data showed that 20% of people (with and without dementia) died very soon after admission, although life expectancy rates in survivors then rose before falling back again.

This article reports findings from the second stage of a two stage study that explored what happened to people with dementia following discharge from general hospital: specifically from the qualitative second stage which looked at what happened where a decision had been taken during the hospital stay to discharge the patient to a residential care home.

## **Methods**

The study, funded by the UK Alzheimer's Society and approved by the local National Health Service Research Ethics Committee, took place in two general hospitals in central England, UK. It comprised two stages. The first stage involved a sample of inpatients drawn from referrals to a long-established hospital liaison psychiatry service. Patients aged 65 years or older with a diagnosis of DSM-IV probable dementia (APA, 2000) were recruited along with a 'carer', self identified as the key family carer at that time. Participant carers and patients were first interviewed during the hospital stay and a series of measures of physical and mental capacity, including the GHQ 12- Shortform questionnaire to assess general wellbeing and distress, were completed for both patients and carers (Sheehan et al, 2012). Surviving patients were followed for a year, with repeated measures at 6 and 12 months. In total 109 sets of data were collected in this phase of the research.

The second stage involved a sub-sample of those patients for whom at baseline (interviewed on the hospital ward) it had been decided (or seemed most likely) that on discharge from hospital they would be entering a care home. As part of the Study One protocol, researchers (principally KM or CS) interviewed potential Study Two participants (patients and carers) about their expectations of the transition to a care home. Consent was requested for more detailed interviews once the pwd had been resident in the care home for around 4 months. These second (Study Two) interviews took place in a mutually agreed quiet room, (care home; carer's own home; or university premises) and were conducted by CH or NT. Twenty-three pairings of pwd and carers were initially selected for Study 2: in 7 of these pairs the pwd died before the second interview and one family withdrew from the study, hence 15 cases were eventually included in Study Two.

The first interview of carers for the 15 pwd took place during the hospital admission, Patients were also interviewed but the extent of the interview depended on whether their ability to respond to questions. For example if the pwd was not aware or able to remember of the planned move to a care home, they were not asked questions about their expectations of the move. By the second interview around 4 months post-move, the condition of most of the participants with dementia had deteriorated to the extent that only eight could be interviewed in person, resulting in very limited direct responses. Therefore as the questions about the transition to the care home required a high degree of retrospection, most of the data discussed here was provided by the key family carer, sometimes with contributions from another carer (spouse or sibling of the main carer) who was present and also had significant caring responsibilities for the pwd.

All interviews were audio recorded with participants' permission, and the researchers used pre- and post- discharge interview guides for the pwd and separately for the carer. For the pwd, the interview was terminated whenever the person appeared to become bored or agitated or unable to respond to the general thrust of the questions. These discussions focussed on:

1. issues that pertained to the care of the pwd prior to hospitalisation,
2. experiences whilst the pwd was a hospital inpatient,

3. the decision making process in relation to admission to the care home,
4. expectations and experiences of the transfer and initial period of care home living.

This article focuses on points 3 and 4, regarding the transition to a care home.

### ***Data analysis***

Table 1 summarises the status of the participants with dementia at the point of inclusion in Study Two. Of the fifteen pwd, thirteen were identified as having moderate or severe dementia. The mean age of the pwd was 88, and 87% were female. The mean length of the stay in hospital was 44 days. These characteristics were in line with those of the larger cohort of 109 patients in Study One from which they were recruited. However the percentage of the carers who were children/children-in-law in Study Two (87%) was greater than in Study One (67%), where there were more spouses and others. Of the key carers taking part in in Study Two, eight were male and seven female, but few of the participants had sole responsibility for the pwd, acting instead with the active co-operation of their own spouse or a sibling. In only one case in Study Two did the pwd co-reside with the carer prior to the hospital admission: one person was already living in another care home, one with someone other than the carer, and the remaining twelve lived alone with the support of family and in many cases other carers. The amount and nature of formal (paid) care provided varied both between pwd and over time depending on changing circumstances, but in these cases the family carers were making a significant contribution in terms of time, with visits to undertake practical caring at least once a week and more often several times a week or daily. In addition there were frequent phone calls and in some cases the carer contributed to the cost of paid support. Carer stress was measured at baseline and again at 6 months, shortly after the Study Two second interview – the carers' own perceptions of changes in their feelings of stress are discussed in this article.

[table 1 about here]

The interviewers and other members of the wider research team, working in pairs, undertook an initial coding of the first five second interview transcriptions, working with the responses to questions in the broad subject areas: Home (pre-move); Moving to a care home; Carers (including self-care); Health; Social Life; Activities. The initial codings included 26 categories within direct response to questions (e.g. experiences with care services in response to 'Carers'; current activities in response to 'Activities'; visitors in response to 'Social Life'). Additionally 12 categories related to emerging expressions of emotion: fear; guilt; confusion; frustration; unhappiness; anger/annoyance; acceptance; relief; looking forward; happiness; trust 3 further categories explored their management of the situation – these included: accounting for dementia; euphemisms; information.

These codings were discussed and refined, and the emerging themes were agreed. In relation to transition to care homes, JK and CH further analysed the data using the following themes, which incorporate elements of all the categories of coding:

- Factors leading to the acceptance of the need for a care home admission
- Care home selection
- Care home expectations
- Care home residents experiences
- Post-admission carer experience

## ***Findings***

### **1. Accepting the need for a care home admission**

Respite services, in the form of short-term care home admissions had not often been used by most of these families, notwithstanding their evident beneficial effects on carer burden, as described elsewhere (McConaughy and Caltabiano, 2005), and the high levels of carer stress that were recorded pre-admission (see also Gaugler et al, 2000). Participants (all the carers and some of the pwd) talked about the discussions and negotiations that had been involved in making and adjusting the support arrangements in place, and as part of this the consideration from time to time of whether and when the pwd would be better off in a residential care home. In most cases up until this most recent hospital admission families had felt that on balance the pwd should still be in their own home, which in most of these cases had been independent homes in the community without live-in companions. Sometimes this was based on the carers' respect for opinions or preferences that had been expressed by the pwd at earlier times, before they had become significantly cognitively impaired. This was often associated with the carers' reluctance to cede what they considered to be a filial duty of care that included both practical support and taking moral responsibility for the care provided by others. However some families had begun to feel that the welfare of the pwd might be better served if they were to go into a care home, particularly if there had been a recent series of hospital admissions. The length of these admissions was also a factor, in some cases associated with reduced capacity for the pwd to self-care. This was particularly striking in one case where a hospital ward had been closed because of contagion, delaying discharges for weeks and preventing visiting, so a blind pwd became immobile and as a consequence incontinent. In other cases the carer's own health was poor, and in many cases the carers themselves were approaching or post retirement, sometimes with significant long-term health problems.

By the time of this first interview, the point had been reached where the balance tipped so that a care home admission was, even if reluctantly, accepted as the best option. This was usually described as a collaborative decision involving the family, medical staff, and in some cases the pwd. Within this collaborative process, some carers described themselves as taking the lead in this decision, having taken on board the opinions of medical staff. However, more carers positioned themselves as agreeing to a professional opinion against the status quo.

*...then we were told well, we didn't have any choice, he needed, the psychiatrist said to us, he really needed the 24 hour care and as much as you can do for him, there's no way you're going to be able to give him the care he needs because at that stage he needed err...to be dressed....erm...washed..every single thing done for him, so it broke my heart but I had to say yes. Well, it was a choice...we both had to say yes, and um...so um...and then it was a question of where do we let him go...and again...two or three of the places I went to I was (hushed tone) so, so distressed I couldn't believe it. (daughter)*

The following quote is typical of how carers were 'informed' that the pwd would 'not be discharged home':

*I had discussions with the social worker and the psychiatric care nurse. Well she's the care assessing, care assessment nurse, erm, on Monday and they explained that they would not allow her to return directly home. .... Because of the level of care that she needs, as she's become incontinent... in hospital. She wasn't before she went in. (son)*

It has been argued that health and social care practitioners can potentially greatly influence the perceptions of relatives regarding a move to a home (Davies and Nolan (2003). But this is not to suggest that in this study professionals were reported as disregarding or over-ruling families' positions on wanting to maintain the pwd in their own home. At earlier points in the journey, practitioners' suggestions about care home admission had been rejected by some of these same families (as it was, presumably, by many of the other families in Stage One where a care home admission did happen further down the line but was not agreed at this stage). In a study which consulted ninety-nine health and social care professionals, Taylor and Donnelly (2006) described decisions on the discharge of older patients to an institution as often being prompted by a crisis, and strongly influenced by the context of social, family, and care service availability into which the patient would be discharged. Livingston et al (2010) have described how the support of others can help responsible relatives to re-contextualise the care home as a place of safety for their relative rather than seeing it as reflecting a betrayal of trust. Although we acknowledge that in some situations relatives may feel pressurised to agree to the discharge from the hospital of the pwd (Duff et al 2006) in this particular study the experience for most of the carers was more a case of direction by the authoritative medical staff involved rather than pressure from them. We suggest that 'not allowing' a patient to be discharged to their own home may, in some cases, be a way of 'allowing' family carers to accept a difficult change in their conception of the best interests of the pwd as well as of their own well-being.

## **2. Choosing a care home**

General and specific information about care homes came from a variety of sources, but primarily from hospital staff, local knowledge, and information from friends and acquaintances who had been in a similar position. In a few cases there had been short periods of respite care. The carers generally expressed satisfaction with the

guidance provided by the professionals about the specific needs of their relative and the types of homes that could meet them, for example:

*Yes, yeah. Primary Care Trust... gave me the name of three [homes]. I think there was three, but because dad needed nursing care as well ...um...it couldn't just be a straightforward err...home....old people's home. (daughter)*

However most carers, having taken on board the professionals' opinions about the need for a care home and the care criteria they specified, still retained responsibility for making the final choice of home:

*Erm, we were given by Social Services, erm, a few homes. We had looked independently before that, but we hadn't come to any conclusion. But, erm, it was quite hard because there were two homes and each of them had, err, their own, erm, good points and bad points. (daughter)*

*We were provided with a list from social services/from the hospital with ...not recommendations, but at least they gave us the star ratings for the places and... and we then did some research and identified a short list but we didn't follow that short list up... because we found the other place [in another county close to another relative] (son)*

While some of the participants referred to 'EMI' facilities (elderly mentally infirm) as distinct from more general care homes with and without nursing, the key issue for them was finding a home where their relative would be safe and happy. Some but not all of the participants knew about the then available star ratings and official care home inspection reports, but these tended to have little influence on their decision-making about which home would best suit everyone involved. Instead (or sometimes in addition, where they did know about officially available assessment information) carers described using their own criteria which included geographical locality; the general reputation of the home; the 'atmosphere' of the home; the physical appearance of the building; and, most importantly, expectations of the level of care on offer.

### ***The geographical location of the home***

For all carers easy access to the home to visit was vital, and a criterion about which they weren't willing to compromise. Frequent visiting was central to being able to retain person-to-person involvement with the pwd as well as being able to maintain some sense of control over their care even as the family handed over much of the day-to-day practical caring to the care home staff:

*I put it to them specifically that I wanted one this side of the town. I didn't want somewhere that was the other side of the town.... And I'd got a long journey to make [now] after going on two buses to the hospital twice a day.... (wife)*

However what is local to one family member may well be more distant to another, with consequences about who can most easily visit. One participant described how this had been resolved by finding a care home close to his sibling which was also on

his route home from work. Given the importance of visiting to the well-being of both the pwd and involved family carers, in practical terms the pool of acceptable care homes was even smaller than those homes which happened to have vacancies at the right time, and it is in this context that decisions were being made about appropriate placements.

### ***The reputation of the home***

Information about particular homes was gleaned from hospital and social service staff, personal experiences and experiences of others in their social circle. In two cases families relied almost totally on this information without inspecting any homes themselves. However most families did visit one or more care homes that they thought might be suitable. Most of the homes relevant to these participants (i.e. in a reasonable location, and with vacancies) had been awarded one or two stars in the previous Care Quality Commission quality rating system (0-3 stars) based on inspections that had taken place at different times. With often little to choose between homes in terms of this rating, the evidence of their own 'inspection' was therefore most important in enabling carers to make a decision.

### ***The atmosphere of the home***

In making exploratory visits, carers were primarily influenced by the atmosphere of homes. A combination of the way in which residents appeared to interact, the friendliness of the staff and the accessibility of management, within an evidently clean and cared for physical environment, gave the right signals. For some people, this was more important than evidence of past shortcomings:

*The lady that's in charge now, she's been brought in because it had got a bad report..... and this is her words, they had poached her from .....(another home). From a care home which they knew she was doing a really good job on and we choose that home because of the [way] she welcomed us and talked to us and made us feel, made US FEEL at home there, let's put it that way.....*

*She was the only one, well we only had four to go to, but she offered us tea .....but the other three homes we didn't feel quite so welcome, and we thought it would be like home from home, ....and even as we were being shown around the carers and the helpers there, they were smiling at us and saying hello to us.... (wife)*

The first impressions of a warm caring environment, often decorated with flowers and odour-free, intimated to carers that not only would their relative receive good care, but that they would be welcomed as visitors and have ready access to management if they needed to discuss any concerns.

### ***The physical appearance of the home***

Most carers were also swayed by the physical appearance and lay-out of the home, taking particular account of material aspects of the building, such as toilet and washing facilities and stairs, that would affect the comfort of the pwd. For

this reason a purpose-built home seemed to many carers preferable to an older building. This was often a matter of room size and 'lightness':

*...we felt she'd got to have a downstairs room. Especially after living in a bungalow. That she was used to. She didn't like lifts. Stairs weren't an option. Erm, and lifts, she didn't like. Never has liked going in a lift. ... for, course there was a room in another house. What put us off was the fact that she had to go up in a lift. Whereas now, the room that they showed us was actually on the ground floor. Erm, it hadn't got en suite, but the bathroom's opposite. And just, err, it's not very far to the lounge from her. So it's quite, sort of, local to the amenities for the home. So that that was, you know, that was quite good really. (daughter)*

Some homes were rejected immediately as entirely unfit. As carers explained:

*When I visited the others, I mean, some of them just shouldn't have been open to be honest ...One was unbelievable, but run by a doctor. I come back a second time (to this place) and thought, no, this is the one. Just the minute you walked in the door it was better.....first thing is visually: clean, tidy, smelt reasonable. 'Cos, these places, you know, older people. (son)*

*. ...it reminded me of an old work house...and it wasn't an old building. It wasn't an old building...I went in, we walked in and it smelt from the moment.....OKAY...I understand that...you...some...sometimes it's inevitable but I looked around and it was filthy. I looked at the skirting boards, paintwork and everything and I thought: Gosh! This is dirty, and then we were taken onto the floor...cos on...on the occasions I went, I didn't let them know I was going ...so they then took us along the corridor to one of the rooms my father would have; went by the bathrooms – disgusting! (daughter)*

### **Carers' impressions of the home's care standards**

To some extent the physical appearance, reputation and atmosphere of homes contributed to expectations about the standard of care that would be offered in that environment.

As previous described, a key factor in making the decision to move to residential care from domiciliary care in the first place was the idea that for this stage of the pwd's needs, care available in a residential facility would be more constant, attentive, and expert than that available either from a fragmented domiciliary provision or on stretched hospital wards. Carers acknowledged that maintaining high care standards with pwd could be challenging. However some were appalled by what they saw when visiting prospective homes. The following example was described by a carer who subsequently found a very satisfactory home for her parent:

*.....I could hear this person, turned out to be a lady, screaming and crying and totally distraught. The door was open as we walked by; she was laying on the floor. Two young girls, young carers, I would have said 19 or 20, chatting away to each other, walking up, the person we were with was*

*obviously erm...like erm.. some sort of qualification of a nurse; very pleasant person but...totally out of control of disciplining these people and I said: 'That lady's laying on the floor'. And I said it to these two girls, and they said 'Oh yes, we've been and picked her up twice. Put her in bed but she keeps falling out so she might as well stay there'. And I just could not believe it, and I just said: I'm sorry, I've got to go'.*

*Because I just thought ..how could you...she was just ...how can you do this and how can you ...and how can a home be ALLOWED to do this? And (my sister) and I came out and we just sat and cried. (daughter)*

Carers needed to feel that the care home would show compassion and professionalism before they could agree to an admission for their relative.

During these interviews, expectations were also explored of how the move to a care home might benefit both the pwd and the carer, and also any worries or hesitations about the impending move. In most cases the specific receiving care home was identified, but in a few cases where this was still to be finalised participants discussed these issues in relation to the 'possible' care homes they had visited. Key issues in both positive and negative terms included: safety and security with benign practical care; a social and therapeutic environment; sustainability; and also the family carer's own continuing involvement.

### **3. Expectations of what the Care Home could (and couldn't) offer**

#### ***Safety, security and care***

Throughout the interviews, carers talked about the difficulties they had faced in helping their relative to stay at home, and in many cases their anxieties about safety when the pwd was alone. In addition some experiences with formal (professional) domiciliary care services had raised issues about the ability of services to produce good enough quality care given time constraints and, sometimes, evidently undertrained staff.

*I will feel perhaps not so afraid of something happening to him which I always dreaded the phone going EVERY single day ..I mean the last time...the last time but one...umm...I had a phone call on a Sunday.....no a Saturday evening. The carer had gone in and said he'd fallen and he'd fallen in the lounge and by the settee and she said "I have to go to my next call ..I can't stay". And she left, and it took me 35 minutes to get across [town] driving as fast as I could, knowing that he would have been left on his own all that time and when I walked in the room and saw him lying ..so fragile on the floor and he was crying out because his neck was hurting him because of the way he had been left...he hadn't been covered up... (son)*

These carers accepted that their relative now needed more care than they could actually offer themselves, even with the support of formal services, certainly in terms of hours and sometimes in terms of the kinds of care needed. But they also felt that care in the Care Home needed to be better than what was being provided in the community. This meant 'total care': 24/7, and above all, safety.

*Well the care home does have people, is staffed, er, twenty four hours a day seven days a week. So the problems I've just, you know, outlined with potentially... no care at night.....are covered. Er, so we would certainly have, sort of, more peace of mind, if you like, er, with a care home.*

*That's one thing. Obviously, erm, you know, you want to look more closely at the care home and at the type of carers, but, erm in a general sense .. that would give us more confidence with a with a staffing arrangement that she was being looked after more consistently round the clock. (daughter)*

Hence in looking for a suitable care home, family carers took into account evident levels of care and ethos: however they also acknowledged that they would still need to remain vigilant themselves and they anticipated having close involvement with the daily life of their relative within the care home. They expected the chosen care home to welcome their involvement, accommodate visiting arrangements and facilitate communications with management.

### ***Opportunities for interaction and stimulation***

Carers often felt that while living at home, the pwd had lacked opportunities for social interaction with people other than their carers and certainly had lacked engagement in sociable activities. Carers often compared their relative's earlier social and active lives with their diminishing ability to engage with various activities as the dementia progressed, and regretted their own inability to do much about this. Information from care homes had suggested that there were activities for residents, and seeing residents sitting together in lounge and dining areas indicated the possibility of companionship. Consequently carers often hoped that moving into a care home would restore something of their relative's previous sociable self.

*Erm, obviously my feeling if she's going to go into care means that I know she's going to be safe. Which is my main concern, myself, in her returning home in her current state. Err, I think that, hopefully, her quality of life will improve... when she goes into a care home because they will make her get up and do things. And I think that, err, I think actually she'll improve from... the fact that there'll be less boredom. (son)*

*... but more importantly she'll have the interaction with other people which she was only getting at home with the carers during the normal day and then between myself, my brother and my sister, we would each visit about once a week but that would only be for a limited time, so the interaction, we feel, will help to keep stimulating her mind which should slow down,..... my view is, it should slow down the dementia take hold... (son)*

An aspiration for an improved social life could even extend to previously less sociable relatives:

*It's hard to say really. Er... from years ago I would say no he won't get on very well. But in the state he's in now I'm just hoping that, erm, that he will because he's a changed personality. He's erm...he's just different to what he used to be so I'm hoping that he will be able to... perhaps make friends with somebody or, erm... well I just don't know. (daughter)*

#### **4. The experience of care home life for the pwd**

The participants with dementia who took part in Study Two were, by the time of the second interview, considered by their family carers to be reconciled with their move or, in some cases, oblivious to the change in their circumstances. In several cases this was difficult to determine from the responses of the pwd. For example one carer said of his mother: 'You get a lot of mmms and ahhs from her rather than yeses and noes'. She responded to most of the interviewer's questions with mmm, ahh, yeah, and pardon. Asked about the move to the care home, she responded:

Interviewer: *What was good about moving here?*

Participant: *Well nothing bad*

Interviewer: *What made you decide to move to a care home?*

Participant: *I don't know. I think it's just we fell to it, that's all*

Interviewer: *are you quite happy here?*

Participant: *Ahh*

Interviewer: *You are?*

Participant: *Mmmm*

This exchange is typical of many with people where dementia has advanced to a stage where verbal communication becomes difficult, though close attention to non-verbal communication can provide insights to the comfort or discomfort experienced by the person living with dementia.

The physical move from hospital to the care home was usually arranged between the hospital and the care home with little or no family involvement. This had generally been a trouble-free process, although some carers would have preferred advance warning about timing so that they could be there. We asked whether they felt that their relative had settled into the care home, and whether there had been an evident improvement in their well-being. Generally, views were positive, in line with a median satisfaction rating for homes in Study One of 9/10: only 3 carers scoring the home at less than 7/10. This was in spite of an acknowledgement, often, that the dementia was progressing or their relative was becoming less resilient.

*But yes, we've got no worries with her at all, touch wood. She's been great hasn't she. She's lovely and ...you know she's always looked after people and cared. You know it's her turn now isn't it? You know, you've got to make sure. If I wasn't happy she wouldn't be there. If I wasn't happy with everything I just couldn't leave her there'. (daughter)*

*She seems okay at the moment. She's had her ups and downs, you know she goes a bit one way or the other but at the moment she's as sound as anything, she really is. She was sick a couple of weeks ago ... but they've got her over that now ... she's okay she's really happy in herself. She keeps explaining to us 'I like it here, I don't want to leave here, I like the food, the food's great, and they're great' and that. You know there's no problem (son)*

Negative comments related primarily to what they saw as minor issues, as with the following quote:

*I'm very happy with the standard of care. There's only one thing...there's only one thing and it's not a complaint really ..clothes go.... I mean he went in with 8 shirts, we bought...we had all new clothes and they told us to get this tag, it's like a button with his name and things on. Just before Christmas he was down to two shirts and so we bought another, so he's got 8 shirts again, and I had name tabs made to put in the back of his neck now, because they were maintaining that the people who were doing the washing weren't looking for the tags so I don't know what happened to them, they got on different floors and things but other than that..yeah, I'm.. I'm happy (daughter)*

However this does not mean that carers were unaware of other shortcomings in the reality of care home life compared to what they had hoped for: rather that they accepted the inevitability of shortcomings given the resources available relative to the needs of residents:

*I think they've fallen down in some areas. I think there is an element because there are obviously a number of people there, some probably in a slightly worse situation than my mother, some in a far better situation and, and the carers can only spare so much time with each individual person, so er, it's... it's adequate. (daughter)*

This acknowledgment particularly applied to the reality of engagement in activities in the home, and socialisation with other residents, which had generally not reached the expectations generated during the selection process.

*I know when I've been there, she's been sitting next to the same woman, she's quite talkative the other woman, but I think my mum even forgets about that because when I saw her on Sunday she was saying, 'well I don't know anybody here'. I said 'well you do, because you've been here for ... months and ... you're always talking to [her]'. I think she does know people to talk to but she forgets very quickly. (son)*

Carers felt that they were welcomed into the care homes and could visit as they wanted to, and thus remain able to keep a watchful eye on the well-being of their relative. Most carers at this stage were continuing to visit very regularly: some daily, some several times a week, some on a rota with other family members. While some carers wanted to visit as often as they could, others were gradually

visiting a little less. In one case sons '(1) and (2)' who visited daily had been advised to step back a bit:

- (1) *My Mum's fortunate really, [brother] visits every night, I visit most nights. Lots of them don't have visitors for weeks and weeks on end.*
- (2) *We probably come too much*
- (1) *Yeah*
- (2) *We are going to cut down.*
- (1) *No, the staff have advised us. ...they've said it is perhaps the wrong thing to do. Just cut it down a little bit.*
- (1) *'No need for you to sit here': she [Mum] said that to me recently.*
- (2) *... she said you don't have to sit here all the time you know, which I thought, um, I've been sitting here too much.*
- (1) *She does have lucid moments every now and then. (sons)*

This quote from two brothers, still involved with their mother's care underpins the very engaged nature of most carers in this study. However many pwd in care homes do not have an advocate from outside the care home itself to regularly check on their well-being, and this is a major omission.

## **5. Effects on carer well-being of the care home admission**

All 15 of the key family carers taking part in Study Two showed decreased mental distress at the follow-up interview six months from baseline (measured using GHQ-12, as part of Study One). This relief of some of the burden of care is in contrast to reported findings from an Australian study (Bramble et al, 2008) which found that care burden persisted for family carers after the care home admission. The qualitative data from the Stage Two interviews a couple of months before the 6 month assessment suggests some of the reasons why for these carers distress levels decreased, even where they continued to feel a certain amount of guilt about 'putting' their relative 'into care'. First, as discussed, was the perception that in spite of some expectations not having been met entirely, the overall standard of care in the home was good and the safety and well-being of the pwd was probably as good as it could be. Second, carers felt relieved of the burden of constant worry and potential for being called upon at any time of day or night if their relative needed help: and indeed of much of the hands-on care which they had been providing, often around their other work and family responsibilities. While these family carers still felt responsibility for the well-being of the pwd, they had now delegated most of the practical caring. Third, for some carers there was a change in other practical burdens including distances travelled to visit (where a local care home had been chosen); the time and financial costs to themselves of maintaining the previous domiciliary arrangements; and the ability to resume other activities and take leisure breaks.

## **Discussion**

The findings described here relate to a very small study within one geographical area of the UK and should be read in that context. They do however sit alongside other qualitative studies elsewhere, some of which have been cited here, that show similar stresses, dilemmas and routes to care home admission. Most carers

taking part in this study were at best reticent and at worst very distressed by the idea of 'putting' into care the pwd who they loved. For many carers, this prospect was one that they had weighed carefully with all its associated financial and other considerations, but hitherto rejected as a possibility, over the often long period when the pwd was cared for in the community.

These considerations applied even where carers themselves were under a great deal of emotional, physical and/or mental stress, with the care home admission subsequently reducing their burden. The circumstances around the present hospital admission, including factors such as the declining condition of the pwd and sometimes a pattern of recurring hospital admissions; changes in the carer's own health or other family circumstances; all combined to bring about a tipping point. At this stage the strongly expressed opinion of health and social care professionals could be very influential but unlike Bauer et al. (2011b) Australian study, family carers in this study did not perceived the hospital staffs' attitudes as unsupportive.. Similar results have been described elsewhere – for example a small qualitative study of institutionalisation in Quebec (Caron et al, 2006) found that some caregivers 'gave themselves the permission to relinquish home care when the initiative came from HCPs[health care providers]. For these caregivers, negative emotions such as guilt and a sense of betraying their relative were diminished' (p9). Livingston et al (2010) in a UK study of decision-making by relatives of pwd also found that the authority of professionals could be used to advocate interventions.

But having then accepted the need for a care home admission, the family carers looked for a placement based on a number of criteria including proximity to their home or work, and good level of care and safety for the pwd, which they tended to assess for themselves. Based largely on conversations with care home staff and on visits to homes, the carers were hopeful that the pwd might also get more social contacts and stimulation in the care home compared to in their previous environment. Once the pwd had settled into the new environment, most carers described them as in a good place and well looked after, although not participating in the anticipated stimulating activities the carers had hoped for. Significantly, in most cases the carers had accepted this as an inevitable consequence of the progressing dementia and of less importance than good physical care by kindly staff. It seemed that there was little discussion about the kinds of activities, such as music, or one-to-one interactions, that might be more accessible with increasing dementia.

Where people living with dementia have a family carer or carers committed to continue caring through and beyond admission to a care home, these family carers might have a significant role in ensuring the well-being of the pwd, and they may expect this to be recognised by care home managers and staff. Our participants indicated a long-term and on-going commitment to this role, and a willingness to work with care home staff well past admission and settling in. The transfer to the care home appeared to be one of many landmarks along a journey, rather than a discreet or defining event in itself. The outcomes from the carers' perspectives were usually positive. We suggest that radical change in managing this process is not required, but there is a great opportunity to optimise

collaborations between care home staff and relatives, where they are involved and motivated to contribute. This could potentially influence future attitudes to care homes as positive choices and support care home staff in delivering warm and comfortable environments for people living with middle and late stage dementia.

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