

A qualitative study of the views of residents with dementia, their relatives and staff about work practice in long term care settings.

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Abstract

Background

Most people living in 24-hour care settings have dementia but little is known about what makes long term care a positive experience.

Method

This carer led qualitative study examined working practices in 24 hour long term care settings, including hospitals, nursing and residential homes with the aim of finding out and making recommendations about such settings. Using semi-structured interviews managers, nurses and care assistants were asked about work practices such as how they coped with difficult behaviour, and about their own shifts, staffing levels, retention and training. Relatives were asked about their perceptions of care and their role, and residents with dementia about their care.

Results

Staff reported that residents presented with increasingly challenging behaviour compared to the past, and sometimes staffing levels and skills were inadequate. Hospital settings had most problems with staffing levels, retention, staff-relative relationships and staff support systems. Relatives saw their own role as positive. People with dementia of varying severity could usefully evaluate some of the service they received.

Discussion

Dementia specific training and education of staff in all long term care settings including induction should address managing problem behaviour in dementia and improve staff fulfilment and relatives' satisfaction. We recommend that long stay hospitals may not be appropriate as a home for life, and that homes should be able to cater flexibly for a range of needs.

Keywords

Dementia, practice, long term care, carers, service users, care homes

Background/literature review.

There is extensive literature about the requirements of people with dementia but an ideal setting has not been established (Bowman et al. 2003). Within the United Kingdom, comparisons of care settings have found community homes better than hospitals, in terms of privacy, amenities, safety for residents and encouraging greater independence for residents. (Wills et al 1998). Hospital staff report being dissatisfied with pay, working conditions, and social status, while in other care settings, staff report dissatisfaction with staff co-operation (Wills et al 1998). All settings have a high staff turnover and staff shortages (Newcomer et al 2001) but retention and recruitment may be improved by training caregivers about dementia (Grant et al, 1996).

Most older people living in 24-hour care settings in Britain and the United States have dementia, although it may not have been formally diagnosed and the setting may not purport to care for dementia sufferers. (Schneider et al 1997, Stevens et al 2002, Macdonald et al 2002, Quinn et al 2003, Matthews and Dening in press).

Family caregivers find relinquishing caring for someone with dementia at home hard but only a minority continue to feel distressed, possibly because of unsatisfactory standards and processes or lack of involvement in care (Ballard et al 2001, Walker et al, 2001). They perceive deficits in care in all settings, particularly if they continue to provide some personal care (Rosenthal & Dawson 1992).

This study examined sources of satisfaction and dissatisfaction within 24-hour care

settings for people with dementia. We aimed to look at organisation within these care settings, to enable us to make recommendations for future management of 24-hour care settings.

This was a carer led project, initiated, designed, carried out and analysed with past and current family carers. We listened to the views of people with dementia, family carers and staff. The carer most closely involved, SN, who was caring for her husband with Alzheimer's disease, approached GL with her idea that little was known about what works well in long term care from the perspective of families of those with dementia. She suggested they prepare a proposal and approach the Alzheimer's Society (AS) for funding, which was modified by caregivers in the AS, and further developed through a steering committee including family caregivers and professionals from different disciplines. The steering committee met throughout the project to discuss the methods, progress and results.

Users of mental health services can be successfully involved in research (Simpson et al, 2002). Carers of people with dementia have participated as research subjects but people with dementia have rarely been asked their views (Cheston et al 2000). Surprisingly high numbers are able to talk about life in the home and express preferences about their care (Moriarty and Webb 2000; Mozley et al, 1999). One small study suggests that semi-structured interviews with people with dementia are reliable and the same issues are raised several weeks later (Smallwood 1997).

Methods

Local ethical committees approved this study in inner London and West Essex .

Settings

The 10 homes covered the full range of 24-hour care, from a small church-run home with 24 beds, to a large purpose built 130 bed home and included mixed sex hospital wards. The settings were residential, nursing and hospital and the provision and provider varied (specialist dementia or generic; NHS, local authority, voluntary and private sector), and location (inner city/suburban - North London, and suburban/semi-rural - Essex). Residential homes provide social care as opposed to nursing homes that are for those with nursing needs.

Sample

Interviewees had lived in, worked in, or had a relative in a care home for at least three months, ensuring we did not interview during the adjustment period. Managers listed all eligible staff, residents with dementia and relatives. Computer generated random numbers determined whom to approach (two care assistants or nurses, one manager, two family carers and two residents from each setting).

Procedure

Participants were given written and verbal information. Written informed consent was obtained from staff and carers. Residents were only interviewed after a mini mental state examination, showed they were cognitively impaired (Folstein et al 1975).

Those with dementia without capacity to consent were asked for verbal assent, witnessed by a statutory carer and the interviewer. The interview team consisted of doctors (GT, MM), a nurse (GK) and a family carer (SN). Demographics were noted and the interview audio-recorded. Interviewing ceased when saturation had been reached with no new themes emerging.

Interview

Initial interview topics were derived from the literature. The interview was semi-structured, with a set of initial topics, but with flexibility and respondents determining the content. A pilot study in one home ensured that the interview was acceptable. Researchers observed each other and discussed results to ensure mutual understanding and avoidance of leading questions. Interviewers met to read each other's transcripts ensuring reliability and to add emerging themes.

The interview began with "Tell me a bit about yourself/home/hospital" prompted by "we want to know about things that work well and those that do not, if any".

Staff were asked about coping with difficult behaviour, support, shifts and staffing levels, and whether colleagues tended to stay or leave. They were asked about training and whether they ever did tasks without training.

Relatives were asked about their perceived role and whom they approached with concerns or suggestions.

Residents were asked about their care, staffing levels, any special member of staff, and views on good care.

The interviewees views about the building, environment, food and activities is covered in a separate paper (Train et al, in press).

Throughout the interview there were a series of prompts if participants did not elaborate. Finally we asked if there was anything further they wanted to say.

The residents' interview was simplified, questioning their likes and dislikes using the interview setting (e.g. garden) avoiding complex issues. They were questioned both in a positive and negative direction to avoid suggestibility. The interviewer noted how much the resident understood of the interview.

The family carers and staff were given the General Health Questionnaire (GHQ-28: Goldberg 1978) to measure psychological caseness (defined as a score of >4) to see if negative comments came from GHQ cases. Half of the negative comments came from people having significant psychological morbidity on GHQ.

Analysis

Transcripts were read and recurrent themes identified and coded. The coding frame classified themes as positive, negative, neutral and suggestions. We used the Non-numerical Unstructured Data Index themes Searching and Theorising programme (NUD*ist) to index and retrieve data. The verbatim accounts preserved the richness of data.

Results

Participants

We interviewed 68 people.

18 people in residential homes (13 in London, 5 in Essex) - 2 local authority, 1 voluntary sector. 21 in nursing homes (14 in London, 7 in Essex) - 2 voluntary and 1 private. 29 in hospitals (14 in London, 15 in Essex).

21 residents were interviewed, 6 were single, 6 married, 8 widowed and 1 divorced; 12 were men and 9 women. 16 were white British, 3 white Irish, 1 mixed race, and 1 black Caribbean. Ages ranged between 64 and 99 (mean 81). The median MMSE of residents interviewed in social care homes was 14.0 (range 7-23), nursing homes 7.5 (range 1-9) and hospitals 8.0 (range 1-21).

9 residents were judged to have some understanding including some with very low cognitive scores (median MMSE=12, range 8-23). Table 2 and 3 show the

demographics of staff interviewed, length of employment, and score on GHQ. Staff interviewed had been in their jobs for between four months and 24 years (median value 6 years) with little difference between settings. In London most (11/12) hands-on staff worked both days and nights, with little choice of working pattern. In Essex 4/9 worked both days and nights and had more choice of working patterns. Most staff classified themselves as white British but there was a mixture of ethnic groups.

Six of the relatives interviewed were from nursing homes, 3 from residential homes and 8 from hospitals. Seven were husbands, 3 wives, 6 daughters, 1 sister and 1 male friend. All identified themselves as White British, except one Black Caribbean. GHQ range was 0-11 (6/17; including four spouses were cases).

Non-participants

Two homes (one nursing and one social care, both in Essex) and 12 individuals refused to participate. These comprised 5 residents (2 male), 6 relatives (3 male) and one care assistant (female), all from London.

Theme analysis

We identified the following themes:

1. Clientele and how staff cope with increasing problem behaviour;
2. Training and staff support ;
3. Staffing levels and retention;
4. Relationships (staff/staff and staff /family and the role of relatives)

1. Clientele and how staff cope with problem behaviour.

Staff often commented that current residents had more challenging behaviour than previously, without there being an increase in staffing, coupled with delays in moving residents if their needs changed.

Managers

"The system is taking too long to move somebody on...she needs nursing care now ...been waiting for a nursing home since last year" (female, residential home).

Nurses

"More and more now, I mean every new patient that comes here now has got some type of challenging behaviour...."(male, hospital).

Care Assistants

"We have residents here that really need more care than what we can actually give.." (female, residential home).

Managers felt challenging behaviour was managed well. Many staff members had skills and patience, being "gentle" and "giving time", in contrast to others who were coercive.

Managers

".... we don't believe in forcing, we give them time out..."(female, hospital).

Nursing staff

"We people who are trained, it's easy...but for those who are not trained...it is very stressful because they don't understand that it is sometimes part of the illness" (male, nursing).

"However on some occasions we do have to be quite firm, that's not to say that we're abusive but we are firm..."(male, hospital).

Care Assistants

"Very difficult because obviously they're nervous and confusedsometimes it's

very hard especially when you've got residents lashing out and kicking , biting, punching you... but the best thing you can do is just explain everything you are doing and be as gentle as you can..."(female, residential).

Relatives

"It's almost as if they're looking after a doll... functional, distant" (Re: agency staff, male, hospital).

Resident

"It could be a lot better, but there you are, when you get old you have to just put up with things." (male, residential).

2. Training and staff support systems.

Staff training available in all settings was considered positively. Staff, however sometimes found availability or geographical access was limited. Most staff, particularly care assistants, felt supported at work.

i) Training

Manager

"... was dumped in the deep end.. no induction. I had many a night of self doubt in those first few months" (female, nursing).

"... training is very high priority now" (female, hospital).

Nurse

"No training here. You have to educate yourself" (male, nursing)

"Excellent, there is every type of training ...numerous opportunities" (male, hospital).

Care Assistants *There is.... plenty of outlets if you're willing ..."(female, nursing).*

"There is training offered like 3 day courses.... You have to get your name down quick" (female, residential).

ii) Staff support systems.

Managers

"I have an open door ... everybody is my friend."(male, residential)

"I do have a senior manager that I can talk to... It would be nice to have a support group" (female, hospital).

Nursing staff

"Managers they don't have much insight.. they speaking it, but I'm doing it" (female, residential).

"Manager.... she's very good. She would always lend an ear" (female, nursing).

Care assistants

"If there is a problem our first port of call should be one of the care co-ordinators ...if you still have a problem I believe you go to her boss" (female, residential).

Relatives

"Manager is a great help because her personality her relationship with themis very significant" (daughter, residential).

"Manager he's very good, nothing is left unsaid..."(male, hospital).

3. Staffing - levels, systems, recruitment and retention.

While all other interviewees felt the staffing level was too low, most managers thought them satisfactory.

Care assistants and half the nurses were part of a rotating shift, nearly all managers only worked during the day. These shifts were usually compulsory in London while those in Essex could choose. Care assistants generally liked this shifts system, but nurses were negative about it.

i) Staffing levels and systems:

Managers

"Staffing levels are very good" (female, nursing).

"If they rotate it's good for their development" (female, hospital).

“Our staffing levels are as registration has told us we should have. We need more staff on the floor” (female, nursing).

Nurses

“We have got two or three very demanding patientsthey have increased our staffing levels by one in each shift which is good” (male, hospital).

Care Assistant

“....we need more male carersThe men are embarrassed and refuse personal care” (female, residential).

“We are dealing with society’s most vulnerable people...making do shouldn’t enter the vocabulary” (female, residential)

“Oh it’s dreadful (working shifts) maybe if you’re younger it will be OK...” (female, residential).

Relatives

“I feel we’ve lost a little something. It would be nice if we could see her (key nurse) regularly” (daughter, residential home talking about shifts)

“...It’s going downhill.These girls are run off their feet” (wife, nursing).

Residents

“Sheer volume of work....they (the staff) say they are unavailable”...(male, residential).

ii) Staff retention.

Managers and nurses reported difficulties with turnover; care assistants had a more positive perception of this. Comments about retention came from staff scoring throughout the GHQ range.

Manager

“I don’t have turnover....nobody resigns because people are happy ...”(male, residential)

“This areacould be a dead endand the young students want something more

challenging. We are always low" (female, hospital).

Nurses

"The older ones stay, some of the carers here have been for years and years but the younger do go quite quickly" (female, nursing).

"Those who have left find the care too strenuous" (female, hospital).

Care assistants

"They (staff) come inthink it is going to be a really easy jobthey are shocked" (female, residential).

"We've got another lady who has been here 18 years, two 16 years" (female, residential, about staff).

4. Relationships - staff/staff, staff/family and the role of relatives.

Relatives saw their own role as positive across settings. They were viewed positively in residential homes but less so in hospital and nursing homes.

Residents generally enjoyed visits, but some staff reported residents were more distressed afterwards. Views were the same in London and Essex. Some relatives (throughout the GHQ range) felt staff did not inform them of progress.

Managers

"Families tend to criticise it keeps us on our toes" (female, residential)

"..... takes a huge portion of your time (caring for relatives)..." (female, hospital)

Care Assistants

"That can disturb them....., they want to go home, they think they have been abandoned" (female, residential)

"Some relatives are fantasticsome can be terrible "(female, residential)

"I think you take your guilt out on the carers and .. it's just nature really" (female, residential).

Relatives

"I get on very well with the staff considering, 'cos I'm not the easiest person" (male, hospital)

"But this particular one I did have an argument with her" (male, hospital)

"We just come and say good afternoon and I just go where he is" (female, nursing)

Residents

"Visitors.. every day... I love it when they come" (male, hospital)

"I don't encourage anyone to come and visit me... I like to be by myself" (female, nursing).

Relationships between staff

Manager

"Some qualified staff ... I shouldn't say this should I, they don't actually do any hands on... .. lot of them think their job is the office and drugs,.. not the heavy dirty bits.." (female, nursing)

Nurse

".. management would say we use too much equipment but then us hands on we know we don't" (female, nursing).

Relative

"These people here are wonderful.. it is an example for race relations.. we've got people from all over the world.... see them all working together.."(male, hospital).

Comparison of themes across hospital, nursing and residential care.

There were more problems in hospitals than in other settings. These were related to staffing levels, support and retention (particularly in Essex).

Staff in residential homes felt more supported than those in nursing and hospital, particularly in the private sector. Relatives were viewed more positively in residential homes than in the other two settings.

Discussion

There were several predominant themes arising from this study about what promotes or hinders long term care as a positive experience. Firstly, staff reported that residents had more challenging behaviour than in the past; as the population has aged the number of dementia-specific beds has dropped (Laing 2002), resulting in residents being admitted with more severe problems, particularly challenging behaviour. A recent UK study of care homes found that most residents had behavioural problems associated with cognitive impairment and that residents needs change (Rothera et al, May 2003). As this occurs staffing levels and the skills available may become inadequate. Conversely, other residents no longer have the challenging behaviour which had led to hospital placement (Fahy & Livingston 2000). In either case it is not easy to arrange a move and this is complicated by funding differences between settings.

Many homes are set up with dementia care as a specialist need rather than acknowledging that older residents have dementia. It would, therefore, make more sense to have dementia training in all homes that might improve retention and recruitment (Grant et al 1996). In a study looking at the effects of integrating mental health care into residential homes for the elderly the most promising model was when there was continuing mental health training and expertise available (Depla et al, 2003).

Secondly, hospitals consistently had more problems related to working practice particularly staffing levels and retention, relationships between staff and relatives, and staff support. This is in keeping with previous findings of a less satisfactory physical environment (Wills et al 1998). This may relate to hospitals admitting those who have the most difficult behaviour although challenging behaviour is found across all settings.

A related theme was the insufficiency of current staffing, both because of recruitment

difficulties and unchanging recommendations about staffing levels despite residents' increased dependency. Like others we found better training and flexible working hours were linked to increased staff satisfaction and wish to stay (Newcomer et al 2001).

Finally, participants commented on the need for improved communication between staff, relatives and residents who often do not understand each other's viewpoints. Regular staff/relative/resident meetings should lead to improvements.

Strengths and limitations of the study

We were able to interview people in all roles, ages and groups in all settings with few refusals. The two settings which refused interview did not know the clinicians involved in the study and we have made an inherent but reasonable assumption that this affected their decision. We interviewed residents with dementia of varying severity but found that they were less able to answer questions about practice than about the physical environment (Train et al, in press). This may be because the physical environment is less abstract. The residents were, however, able to make comments about, for example, care, staffing levels and being visited. We can therefore conclude, as have others, that people with dementia can usefully evaluate the service they use but only in particular fields (Moriarty and Webb 2000, Mozley et al 1999). Those with the most severe dementia could not talk and we cannot comment on their views.

Staff interviewed had been working for three months or more. Therefore those who left after a very short period of employment were excluded and we do not know their views, although they may be less satisfied than those who stayed.

As caregivers completed GHQs we were able to ascertain that negative comments were not just a reflection of pervasive low mood, fewer staff than relatives had significant psychological distress. Staff who were stressed, however, felt less

supported by other staff members, and we do not know the direction of causation.

Managers were usually more optimistic about the care homes than family caregivers, residents and other staff. This may be because they are less involved in delivery of day-to-day care, or because they wanted to create a positive impression.

Users as researchers

This study was initiated by a current family carer (SN) and designed with the input of several past and current family carers. Carers took an active role in all stages including the design, interviews, analysis and writing of the paper. Two members of the Alzheimer's society consumer network were on the steering committee.

Input from carers with experience of long term care ensured that topics covered during interviews were relevant, and included issues seen as important by families that may not have been picked up by the research team.

Carers and other researchers can interpret comments made by participants differently, highlighting the importance of the use of the NUDIST qualitative database, and a degree of understanding between researchers from different backgrounds.

As a team we found that carer involvement broadened and enriched the perspective of the research. This is consistent with a major movement in the NHS for the involvement of users and carers in the delivery and evaluation of health services, and with previous research showing that users of mental health services can be involved as researchers successfully (Simpson et al, 2002, Faulkner et al 2002), including helping to define standards of good practice in mental health care (Rose 2001).

Conclusions and recommendations

Our findings from lead us to three key recommendations for changes in practice in homes.

The first is that it should be explicitly recognised that most long-term care is for people with dementia. The training and education of staff, including managers, should be targeted appropriately, widely available, evaluated, accessible (possibly in house) and include induction. This would address managing problem behaviour, should improve staff fulfilment and increase relatives' satisfaction.

The second concerns hospital continuing care. People with the most problems are placed in long- stay hospitals, but the drawbacks we found mean that it may not be appropriate as a home for life if there is any other possibility. There should be longer stay places for those with the most needs with regular re-assessment to see whether the resident may be able to move. This movement from long-stay placement in hospital has been associated with improved residents' quality of life (Knapp et al 1994). Thirdly, and linked to this, we would recommend that homes should cater for those with different levels of need, and be staffed appropriately, so that increasing needs does not necessarily mean residents moving.

Table 1: Demographics and role of staff interviewed

Role	Number	Age	White UK/Irish		Black Caribbean/ African		
	Other	GHQ Cases		Time working			
Care Assistant	13	23-60	9	3	1	3	
	4m-24yrs						
Nurse	8	42-58	3	2	3	1	17m-
	15yrs						
Manager	9	44-60	4	1	4	1	1 -15
	yrs						

Table 2. Demographics and GHQ scores of staff working in different settings.

Accommodation	Nursing Home	Residential Home	Hospital Ward
Number	9	9	12
Age (mean)	47.9 yrs	46.7 yrs	48.6 yrs
GHQ (mean)	2.9	2.1	2.4
Time spent working (mean) months		36 months	108 months 78
Sex	1 male, 8 female	1 male, 8 female	3 male , 9 female
No. care assistants	4	7	2
No. nurses	2	0	6
No. managers	3	2	4

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