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Care Home Residents' and Relatives' Expectations and Experiences

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Care home residents' and relatives' expectations and experiences

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Introduction

Although residential care has long been viewed in negative terms, notably in Townsend's *The Last Refuge* (1962), relatively little information has been obtained about residents' experiences of living in a care home. From Townsend's study onwards, obtaining an accurate picture of residents' views has proved difficult, with residents tending to express satisfaction with their home, either because of a reluctance to complain, or because they find it difficult to think of alternatives (Sinclair, 1988). A central principle underlying the policy of recent governments has been to help people maintain their independence in their own homes for as long as possible, with a move to residential care sometimes being seen as a negative decision (Department of Health (DH), 1998). However, in relation to self-funders, Laing and Buisson (2012) suggest that their decision to enter a care home could be viewed as an expression of their preferences. Furthermore, anecdotal evidence suggests that, although people may dread moving into a care home, their experiences once there can be very different. Work by Towers (2006) has indicated that the experience of living in a high-quality care home environment can afford residents the same level of wellbeing and sense of control that is experienced by residents of extra care housing. Despite the development of such new forms of provision, care homes still provide the great majority of places, and are likely to continue to support people with intensive care needs (Laing and Buisson, 2011). One of the aims of the recent White Paper (HM Government, 2012) is to improve the quality of life of residents by building links between care homes and their local community.

In 2006, the Registered Nursing Home Association (RNHA) approached the Personal Social Services Research Unit (PSSRU) to examine the neglected area of residents' own views of living in care homes. The DH also agreed to support the study, in particular to examine concerns about the possibility of abuse of residents in care homes, following the national study of the prevalence of abuse and neglect of older people living in their own homes (O'Keeffe et al, 2007). A full report of the study is available (Darton, 2011), and this paper summarises the results of the study.

Design

A sample of 1200 care homes run by private or voluntary organisations was drawn from local authorities selected to represent a cross-section of authorities throughout England, using the list maintained by the Commission for Social Care Inspection (CSCI) as described in the technical report (Charlton et al, 2010). From the sample of 1200 homes, plus four additional homes in Suffolk recruited via the RNHA, 605 homes were recruited. Data were obtained for

residents in 46 homes, 19 of which provided nursing care and 27 of which provided personal care. CSCI star ratings were used to compare the participating homes with the whole sample. Although the participant homes included a slightly higher proportion of homes with the highest star rating, 19.6% compared with 15.9% in the sample as a whole, each star rating category was reasonably well-represented, with 4.3% of the participant homes having a zero rating, compared with 3.3% of the sample as a whole.

The recruited homes were asked to ask each new resident whether they would be willing to participate. Once consent was obtained, arrangements were made for an interviewer to visit the home. Where the home decided that the resident was not capable of providing informed consent, it was asked to approach a relative to invite them to participate in the study. Once consent was obtained, a telephone interview was arranged with the relative. Two interviews were conducted with residents and relatives, the second a minimum of 3 months after the first. The initial interviews were conducted between March 2008 and January 2009, and the follow-up interviews were conducted between August 2008 and April 2009. Information was collected from 69 residents, 50 of whom were followed-up, and from 33 relatives, 24 of whom were followed-up.

Ethical approval was obtained from the appropriate Research Ethics Committee at the University of Kent.

The decision to move to a care home

The most important reason reported for moving into a care home, for those who had been living in their own homes, concerned their physical health, reported by 79% of residents and 88% of relatives. A majority of relatives reported that the resident was a danger to themselves or others (81%), or had mental health problems (69%). Other important reasons for moving into a care home were difficulties with coping with household tasks, mobility in the home and general upkeep. An inability to return home from hospital or to provide continuing support in their home were important reasons reported in the survey of relatives, and for one-third of those in the survey of residents. Relatives identified social issues, such as social isolation, living alone and a fear or experience of crime as more important factors than residents.

A minority (23%) of residents were less dependent. These residents were more likely to have been single or divorced and to have been living in their own home as owner-occupiers. They were also more likely to have been living in homes providing personal care, and to have been privately funded.

In the survey of residents, 81% reported that the decision to move into a care home was entirely or partially theirs, supported by family and friends, and 33% reported that their family or carer could no longer look after them. Family and friends provided the main source of help according to the relatives, and 62% reported that the family or carer could no longer look after the resident. In addition, a higher proportion of relatives than residents reported that a doctor or other professional was involved in the decision.

Expectations and experiences of life in the home

Residents' views

Residents expected to have a moderate say in the day-to-day life of the home, but their expectations of the comfort and care provided and in aspects of their control over their life were more positive. Residents' experiences of day-to-day life in the home tended to be higher than their initial expectations, with the majority (over 80%) indicating that they had a say in most aspects of their daily life (table 1). Fewer had control over whether they could lock their bedroom on leaving it (60%) or over the heating in their bedroom (54%), although the proportions were higher than initially expected. Although residents had relatively high expectations about the comfort and care provided in the home, the proportions of positive responses were higher in the follow-up survey (table 2).

A majority of residents expected either no change or an improvement in the level of social contact, and the proportions reporting no change or an improvement were slightly higher in the follow-up. For the majority of residents (68%) the home was the focus of their social life, but 28% indicated that at least half their social life was outside the home. The majority were happy with the amount of contact with their family and friends (68%), but 20% indicated that they would like to see them more. Within the home, 70% of residents reported that they had made two or more friends, but 18% were not interested in making friends.

Two-thirds of the residents reported that they took part in activities in the home. However, 40% indicated that health and mobility problems prevented them from taking part. The main benefits of participation were in the enjoyment of friendship and company.

Relatives' views

In general, relatives expected that residents would have a greater say in the day-to-day life of the home than the residents did themselves. Relatives also had higher expectations of the comfort and care provided and of aspects of the resident's control over their life, and their responses to these questions were similar for both surveys. However, fewer relatives in the follow-up indicated that residents had the choice of who would help them, or when.

All relatives expected the home to be comfortable and warm, that staff would look after the resident's health and needs, that the staff would be caring and sensitive, that the resident would feel safe in the home, and that the home would be secure. Almost all expected the resident to be clean and appropriately dressed, to have company in the home, and that the residents would be friendly. In terms of the resident's control over their life, almost all expected the resident to keep their own possessions, and all expected them to keep their own clothes.

Excluding cases where the resident's state of health, such as dementia, was expected to be a factor, the majority of relatives (72%) expected either no change or an improvement in the level of social contact, and 94% of all respondents expected that the resident would see their family and friends as much or more than before.

In the follow-up survey, 75% of relatives indicated that the resident socialised more or that there was no difference in their social life, and 88% indicated that they saw their family and friends as much or more than before. However, in five cases (21%) the resident's social life was affected by the presence of a condition such as dementia, and almost all of the other residents had the same or more social contact than before moving in, a higher proportion than expected in the initial survey.

Three-quarters of the relatives reported that the resident took part in activities in the home. However, 71% indicated that health and mobility problems prevented the resident from taking part in social activities and one-third indicated that hearing problems prevented the resident from participating.

Design of the home

Similar proportions of residents (74%) and relatives (67%) reported that the resident's room was well-designed to meet their needs, and that the home was well-designed (78% and 75%, respectively).

Under half (44%) of residents were able to get around the home without problems, and 46% were able to get to all the places in the home that they needed to with help. Relatives reported that one-third of residents were able to get around the home without problems, and 63% were able to get to all the places that they needed to with help. In two-thirds of cases, the resident's mobility in the home was much or somewhat easier than in their previous accommodation.

Care services and staff support

Prior to admission, over one-third of residents received chiropody services, but few received other therapy services. After moving in, the proportion that received chiropody services more than doubled, to 72%, and 20% reported that they received physiotherapy. Similarly, relatives reported that a higher proportion of residents received chiropody services after moving in, but that residents were no more likely to receive other therapy services after moving in.

Residents were generally satisfied with the help that they received from staff, 80% were very satisfied and 92% reported that staff were welcoming to visitors. The majority of residents (86%) reported that they were always treated with respect by staff, 82% reported that staff always knocked on their door and waited before entering their room, 78% reported that all staff treated them as an individual, and 74% reported that staff were never in a rush when helping them. However, a smaller proportion (61%) reported that they were always informed about changes in their care.

All relatives were generally satisfied with the help that the resident received from staff, 71% being very satisfied. All relatives reported that the staff were helpful, and 92% reported that staff were welcoming when they were visiting the home. In most cases (88%), the relative had regular contact with the home, and 74% of those who needed to make contact with a member of staff found it easy to do so. Smaller proportions of relatives (75%) reported that the staff

always treated the resident with respect, that all the staff treated the resident as an individual (71%), or that staff were never in a rush when helping them (63%). However, the same proportion (61%) reported that they were always informed about changes in the resident's care.

In response to a general question about complaints, five residents and six of the relatives reported that they had been dissatisfied with the home or the staff, and four had made a complaint in each case.

Satisfaction with life in the home

Residents' views

Overall, 86% of residents indicated that their experience of living in the home was good and the remainder indicated that it was both good and bad. Three-quarters indicated that the home was at least as good as expected, while four stated that it had not been as good. One-third of the residents had previously lived in a care home, and three-quarters of these residents indicated that the home was the same or better than the previous home.

Around three-quarters of the residents responded to a few open-ended questions about their satisfaction with life in the home. The majority (58%) had no complaints or made general positive comments about the home. Around one-third made comments about the staff, the majority of which were positive, but there were a few instances of insensitive or rushed treatment. The other issue that generated a number of comments was the quality of the food. Five residents made comments on the food, four of these being negative, relating to the choice and temperature of the food. Small numbers of residents commented on issues of independence and freedom (positive), the cleanliness of the home (both positive and negative), the security of the home at night (negative) and the laundry arrangements (negative). The negative comments on cleanliness concerned a lack of dusting and a failure to change bed linen, and the negative comments on the laundry arrangements concerned the loss of items and damage to clothing. Although residents made some negative comments, overall their comments indicated a substantial level of satisfaction.

The views of residents about care homes were more favourable in the follow-up, but the proportion that believed that residents may be abused did not decrease between the two surveys. In response to specific questions in the two surveys about whether they believed that residents may be abused, the proportions that believed that residents may be neglected (28% and 24%), or have money (18% and 20%) or possessions (16% and 20%) stolen, remained fairly constant, but the proportion that believed that residents may be physically or psychologically mistreated doubled, from 12% to 24%.

Relatives' views

Relatives reported that their previous impression of care homes was generally bad (42%) or both good and bad (30%). Around 60% believed that some people in care homes were

neglected or psychologically or physically mistreated, and around 30% believed that some residents in care homes had money or other possessions stolen.

Among the relatives who were included in the follow-up, 92% reported having a favourable general impression of care homes. All but one indicated that they would be quite or very likely to recommend the home. However, around two-thirds still believed that some people in care homes generally were neglected or mistreated, and substantially higher proportions believed that some residents in homes generally had money (38%, compared with 21% in the initial survey) or other possessions stolen (54%, compared with 21%).

All relatives responded to a few open-ended questions about their satisfaction with the home. The great majority (83%) made general positive comments, with most expressing a high level of satisfaction with the home. The main issue raised by the relatives, mentioned by four respondents, concerned the level of staffing, which could limit the number of activities provided for residents. Individual comments by relatives concerned various unsatisfactory aspects of the design or maintenance of the home, and the cleanliness of the home (both positive and negative).

Quality of life

Both residents and relatives reported improved quality of life following the move into a care home. Of the residents included in the follow-up, 68% rated their overall quality of life as good or very good prior to admission, rising to 82% since admission, and the proportion that rated their quality of life as very good increased from 26% to 48%. Prior to admission, 46% of the relatives included in the follow-up reported that the resident's quality of life was bad or very bad but, since admission, 75% reported that it was good or very good. All relatives in the follow-up believed that the resident was settling in as well as or better than they had hoped.

Implications

Overall, residents and relatives expressed favourable views of the homes, but a number of particular areas of concern were identified by some respondents. These included general housekeeping issues, such as cleanliness and laundry arrangements; the quality of the meals provided; problems of staff being too rushed to give sufficient attention to the residents or to organise activities; and perceptions of abuse or mistreatment. Laing and Buisson (2012) note that housekeeping issues are frequent areas of concern, and are more visible to relatives than issues of personal or medical care. However, it is surely reasonable to expect poorly-performing homes to improve, and create a more pleasant environment for staff, as well as for residents.

The importance of staff and residents having adequate time to spend with each other is recognised in *My Home Life* (Help the Aged, 2006). It is understandable that staff may feel rushed, and the management of the home needs to ensure that sufficient staff are available to provide the care and support that residents require. In particular, understanding the concerns of residents and relatives about abuse or mistreatment is likely to require that staff spend more

time listening to their anxieties, and for both staff and management to examine how to counter such perceptions. Some of the issues are due to resources. Care staff are often blamed for poor care, but they are often poorly-remunerated and accorded low status, and deserve greater support from the wider society (Help the Aged, 2006).

Conclusion

Despite generally favourable impressions of the homes, both residents and relatives retained a belief that residents may be abused in care homes. Public perceptions of the relative level of abuse in care homes and private households may be influenced by media and other reports. However, it is of concern that a higher proportion of residents in the follow-up survey stated that residents may be psychologically or physically abused, while substantially higher proportions of relatives in the follow-up stated that some residents may have money or other possessions stolen, since these views may have been affected by their experiences of living in or visiting a home.

This study did not achieve the intended sample size, and it is quite possible that the participating homes and respondents formed a self-selected sample, although the comparison of the star ratings does not suggest that the homes were particularly unusual. However, the study does suggest that the residents and relatives that responded generally valued the care and support provided by the homes. Their experiences of the homes tended to exceed their initial expectations and the quality of life of residents was often judged to have improved. The positive responses indicate that care homes can provide welcoming and comfortable places to live for residents who choose to live in them, and providers should be able to achieve the standards of the best.

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Table 1: Expectations and experiences of say in life in home

	Survey of residents		Survey of relatives	
	Expectations	Experiences	Expectations	Experiences
	%	%	%	%
When can be visited	74	94	88	83
When can come and go from home	64	74	64	67
When can be alone	62	100	79	83
Time to go to bed	58	96	70	75
Whether can remain living in home	57	86	73	83
When can have a hot drink	55	80	76	79
How arrange bedroom	51	86	70	67
When staff come to help	49	82	82	54
Time get up	43	84	70	67
Choice of meals	41	84	82	88
Which staff come to help	41	62	67	17
Adjust bedroom heating	35	54	33	25
Locking their room	29	60	27	21
Total number of cases	69	50	33	24

Table 2: Expectations and experiences of living in home

	Survey of residents		Survey of relatives	
	Expectations	Experiences	Expectations	Experiences
	%	%	%	%
Staff look after health and physical needs	93	96	100	100
Feeling comfortable and warm	90	98	100	100
Feeling clean and appropriately dressed	88	96	97	100
Home secure	88	98	100	100
Feeling safe	87	98	100	92
Staff caring and sensitive	83	88	100	100
Company	81	86	91	79
Friendly residents	65	92	88	96
Total number of cases	69	50	33	24