The impact of sleep disturbances on care home residents with dementia: the SIESTA qualitative study

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Abstract

Objectives: Nearly 40% of care home residents who are living with dementia also have symptoms of disturbed sleep. However, the impact of these disturbances is relatively unknown, and is needed to indicate whether interventions are warranted, therefore we aimed to investigate the impact.

Design: one-to-one semi-structured interviews.

Settings: Four UK care homes.

Participants: We interviewed 18 nurses and care assistants about 54 residents with sleep disturbances.

Measurements: We used a topic guide to explore staff experience of sleep disturbance in residents with dementia. The interviews were audio-recorded and transcribed, and then analysed thematically by two researchers independently.

Results: Staff described that sleep disturbances in most, but not all, residents impacted negatively on the resident, other residents, staff, and relatives. Residents became more irritable or agitated if they had slept badly. They slept in the daytime after a bad night, which then increased their chances of being awake the following night. For some being sleepy in the day led to falls, missing medication, drinks and meals. Staff perceived hypnotics as having low efficacy, but increasing the risk of falls and drowsiness. Other residents were disturbed by noise and staff described stress when several residents had sleep disturbance. Some of the strategies reported by staff to deal with sleep disturbances such as feeding or providing caffeinated tea at night might be counter-productive.

Conclusions: Sleep disturbances in care home residents living with dementia negatively affects their physical and psychological wellbeing. These disturbances also disturb other residents and increases stress in staff.

Keywords: dementia, care homes, sleep disturbance, qualitative research

Introduction

Sleep disturbances are a common neuropsychiatric symptom in people living with dementia, and include difficulty falling asleep, waking or getting up during the night-time, and excessive daytime sleepiness (McCleery et al., 2016). For those living in their own homes this often leads to interruption of family carer's sleep, as they need to be awake to provide comfort and ensure safety (Peng et al., 2019, Gao et al., 2019). Sleep disturbance, therefore, may precipitate a person with dementia moving to a care home (Rokstad et al., 2018, Hope et al., 1998, Risco et al., 2015), as the family may struggle to cope with their sleep being persistently disturbed, and may be unable to afford expensive night-time carers (Kinnunen et al., 2017).

In the UK, a third of people with dementia live in care homes, making up 80% of the 400,000 care home residents in the UK (National Institute of Health Dissemination Centre, 2017, Livingston et al., 2017). Our recent meta-analysis found that of care home residents with dementia, 38% have symptoms of disturbed sleep, with 20% having clinically significant sleep disturbances (Webster et al., 2019). Therefore, sleep disturbance is a common issue in care homes, and has potential to affect not only the resident themselves, in terms of their behaviour or the prescription of sleep medications known to harm (Webster et al., 2019, Westerlind et al., 2019), but also other residents and those caring for them.

Many people with dementia may not remember that their sleep is disturbed and it is not clear if it is always perceived as a problem to the individual (Gaugler et al., 2010). In a qualitative study of 12 people with dementia and sleep problems living in their own homes and their family carers, six participants with dementia did not think they had sleep problems; and their carers described how their relatives lack of awareness made it more difficult to cope with their own sleep being subsequently disturbed (Gibson et al., 2014). Family carers judge their relative's quality of life as lower when the person with dementia has sleep disturbances (Hodgson et al., 2014), however, in another study, carers discussed how sleep problems did not seem to matter too much to their relatives, but affected carers greatly (Kinnunen K. et al., 2018). However, there is a lack of qualitative research into the impact of sleep disturbances on care home residents with dementia, and no previous studies on the opinions of care home staff on this topic.

Within care homes, most residents with dementia will have moderate to severe dementia (Beerens et al., 2014), and therefore may not be able to remember whether they have sleep disturbances and what the consequences of these disturbances are, hence using proxy measurements from staff are common practice. Although there have been studies of night-time care practices and the causes of sleep problems in people living in care homes (Kerr,

2008, Ellmers et al., 2013, Nunez et al., 2018), there has been no reports on the impact of these sleep disturbances. Understanding the impact of sleep disturbances is important in identifying the value of interventions to manage sleep disturbances in this population, as well as people with dementia living in their own homes.

In this qualitative study (SIESTA: Sleep problems In dEmentia: interviews with care home STAff), we interviewed care home staff about the effect of such sleep disturbance on residents and others in the care home. We aimed to investigate staff's opinions on how sleep disturbances manifest in residents with dementia and what the impact of the disturbances are on the resident with dementia, as well as other residents and care home staff.

Methods

Ethics

UCL Research Ethics Committee approved the study (October 2018; project number 14289/001).

Setting

We purposively recruited four care homes in Greater London, ensuring a mix of both charity and privately owned homes providing nursing and residential care. In the UK residential homes are "care homes which only provide accommodation and personal care" whereas nursing homes are "care homes which provide personal care and nursing" (Competition and Markets Authority, 2017). The homes were in both urban and suburban areas, owned by different providers, and of various sizes, with the number of beds ranging from 48 to 215.

Participants

We purposively recruited a maximum variation sample (Palinkas et al., 2015) of staff providing direct care; nurses and care assistants from a diverse range of socio-demographic characteristics (role, age, sex and ethnicity) who currently or had previously worked a mix of day and night shifts at the care home. We recruited participants until we reached theoretical saturation, which is when additional interviews do not add new information to the data already collected in the previous interviews (Fusch and Ness, 2015).

Procedure

We contacted care home managers to ask permission to approach their staff for participation, and then visited the home to recruit eligible staff. LW conducted and audiotaped all interviews within a private room at each of the care homes and gained written informed consent before each one-to-one interview. We also asked participants to complete a demographic questionnaire detailing their role, how long they have worked in the present care home and care homes in general, shift pattern, sex, age, and ethnicity.

We developed a topic guide (Appendix 1) from the literature with prompts to facilitate the interview, and altered this iteratively when new themes were generated. We asked participants to focus on three residents with dementia and sleep problems who they knew well enough to speak about in-depth. We asked for each of these residents how did they sleep, what did staff think caused them to sleep badly, how if affected the resident and staff, if the disturbances persisted and how sleep disturbances were managed. We audio recorded all interviews, which were then externally transcribed verbatim and anonymised. Each participant was given a £20 voucher as a token to cover their time.

Analysis

We used NVivo11 to manage the coding and analysis of the data. We used thematic analysis to analyse the data following Braun and Clarke's (2006) six phases of conducting thematic analysis: familiarising yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun and Clarke, 2006).

We developed a preliminary thematic coding framework from the first five interviews. LW and KP independently open coded the interviews to identify the main themes that occurred in line with the study objectives, and the coding framework was then discussed with GL and SC and a final framework agreed. LW and KP then coded each of the interviews independently using this framework, adding to it iteratively as new themes were generated, and reaching consensus over any disagreements until all data was coded.

Results

Participants

We interviewed 18 participants from four care homes between November 2018 and May 2019 about 54 residents with sleep disturbances and dementia. Nine staff worked in

privately funded care homes, and nine worked in charity funded care homes. The sociodemographic details of participants are in Table 1. We interviewed fourteen staff members whilst working day shifts, two were interviewed whilst working night shifts, and two were interviewed before or after working a night shift. Three care homes were rated good and one outstanding on statutory inspection by the Care Quality Commission.

Qualitative findings

We identified five overarching themes of the impact of sleep disturbances: (1) descriptions and interpretations of sleep disturbances, (2) impact on resident with sleep disturbances, (3) impact on other residents, (4) impact on staff, and (5) impact on relatives.

Descriptions and interpretations of sleep disturbances

Staff identified and described sleep disturbances in the residents they cared for with dementia. Some of the residents who were awake during the night did not get up, often due to restricted mobility, but staff saw they were awake during hourly observations or knew because they made noise.

"In the night, she'll be awake the whole night. She will just lie there and just be asking for the nurse all the time." (1; female care assistant)

Residents making noises during the night was a common occurrence described by staff, with residents talking, shouting out, singing, screaming, calling for help, and repetitively pressing their buzzers. However, not all of those who were awake in the night and making noise seemed distressed.

"She never sleeps as well, at night-time. Shouting, screaming with her language." (2; female care assistant)

"Or sometimes she'll sing. If she wants to sing, she'll sing. Because if you open the door, she'll disturb others." (3; female senior care assistant)

Some staff members described what they thought were residents' nocturnal hallucinations.

"So, I went to the room to see and he said to me, where is the person I was talking to? I said, there was no one here... But I think maybe he was hallucinating." (4; female senior care assistant)

For some residents getting up during the night, walking and moving around the common areas and into other people's rooms was commonly described. Though getting up during the

night was dependent on mobility, even those who struggled to get up might still try, for example crawling around instead of walking.

"During the night-time, you think like he's somewhere. You think, like, you left him asleep... When you come back, the gentleman is not there. Maybe he's in someone's room by the corner." (5; female care assistant)

"And then she'll crawl around into the corridor because she can't walk, but she can shuffle herself around... That goes on for the whole night." (6; female care assistant)

It was also common for some residents to get up in the night and then fall asleep in chairs or sofas in the common areas of the homes or their bedroom instead of their own bed.

"She also like, stays in the lounge to sleep, in the chair... and then when she goes to her room she will sleep on the chair." (7; female team leader)

Whilst up during the night some residents would remove objects from the common areas.

"They are both hoarders. We were looking for the phones in the night. The handsets. And we can't find them. And [resident's name] has one in the bag and then [another resident's name] has one in his." (7; female team leader)

Some residents also wanted to go home during the night, and for example, they packed their belongings, were distressed about not being at home, or physically tried to leave the care home.

"During the night, that's when she packs. She'll pack her stuff, she'll get all her things from the wardrobe, pack, maybe she says she's going home."
(3; female senior care assistant)

Impact on the resident with sleep problems

All staff members interviewed described negative impacts on the residents whose sleep was disturbed, particularly during the next day.

"So that's how I know when they don't sleep well at night, it really affects them during the day." (4; female senior care assistant)

Behaviour and mood

According to staff, one of the main impacts on residents from having disturbed night-time sleep was the effect on their behaviour or mood the next day. Staff described how residents might be more agitated and aggressive the next day if they have not slept well, often comparing their behaviour to when they slept well or to other residents with dementia who slept well.

"When she have enough sleep, she's always calm. But when she doesn't have enough sleep, she's always very, like, angry, very annoyed with every single small thing." (5; female care assistant)

"But I have observed, the one that doesn't sleep has got challenging behaviours." (8; female senior care assistant)

Some staff observed that lack of sleep was linked to residents becoming more physically aggressive the next day. Staff also observed that residents who did not sleep well may be more verbally aggressive or may refuse personal care.

"And sometimes in the morning, I think because she had a bad night, she can even bite you. Yesterday she gave me a scratch." (9; female care assistant)

"During the day, when he doesn't sleep in the night, sometimes we will say to him [resident's name], you need personal care, can we help you? He will say no." (3; female senior care assistant)

Sleeping during the daytime

People with sleep disturbances often used the daytime to catch up on sleep, and some said they felt tired the next day and requested to go back to bed.

"But he's catching up the sleep, during the day. Of course, he will complain that he's tired. I think that's the effect of not sleeping completely, the rest."

(2; female care assistant)

"During the day she will say, okay, could you put me to bed? I want to go to bed." (11; female nurse)

Staff observed that residents sleeping during the daytime could then lead to their night-time sleep being further disturbed.

"Generally, when a resident sleeps too much in the day, it will affect the night... So during the night, they don't want to sleep because they already slept during the day." (4; female senior care assistant)

For some residents being sleepy affected their ability to communicate and interact with others as they normally would, or their motivation to join in activities in the daytime.

"She communicates a lot. When she's not feeling sleepy you can talk to her. But if she's sleepy, no." (9; female care assistant)

"If you're not sleeping, like she wasn't sleeping, you don't want to be participating in an activity for long." (8; female senior care assistant)

Being asleep during the daytime was often discussed as increasing a resident's risk of becoming dehydrated and missing meals. Some residents would fall asleep whilst eating, and this increased their risk of choking.

"So, during the day, she'll be sleeping instead of eating... Because if she doesn't eat, she's going to be dehydrated and she'll just go down." (3; female senior care assistant)

"She's at risk of choking when they're too drowsy." (12; female nurse)

Missing meals also had implications on residents losing weight and the management of health conditions such as diabetes. Sleeping during the day could also have a knock on effect getting residents to take their medication, including covert medications.

"Especially if the person is diabetic, you have to get them up to have something to eat and things like that." (4; female senior care assistant)

"Because you know in the morning he's going to be sleepy and he's not going to eat. And he's on covert medication and that we're trying to make sure he has taken the medication covertly, (that) he has the food." (11; female nurse)

Staff would then also give residents food or cups of tea in the night to compensate for the lack of food and fluid intake during the day.

"He doesn't eat well during the day, either. That's why at night, what we try to do is, we always have a lot of sandwich. Every time he pass, just go, and then he'll grab one." (6; female care assistant)

"During the night, because we have to push fluids for her because of her condition, it's a struggle to give her fluids but the tea, she really loves." (13; female senior care assistant)

Being sleepy during the day for some residents also led to an increased risk of falls, or residents being unable to bear their own weight.

"But daytime, the last time she had a fall, she was sleeping while she was walking and she fell." (9; female care assistant)

"But when she's on sleepy days, she needs to be hoisted." (13; female senior care assistant)

Other potential impacts of sleep disturbances

Staff described how medication is sometimes considered to help manage those who have more severe sleep disturbances. They talked about the limited efficacy they had experienced with these medications in terms of reducing sleep disturbances, as well as the impact of the medications themselves in terms of the side effects they often had, mainly increasing risk of falls.

"In the beginning it was helping because it calmed him down, calmed the brain... But like I said, in the long term, it doesn't work that much... Zopiclone have a side-effect as well." (14; male senior care assistant)

"And it's really hard for them to decide or the doctor to decide if we can put it back because we don't want the same thing to happen again when she fell... But yes, since then when they tried to give back the sleeping medication, it's not really effective. She's feeling drowsy and all but that's it, she's still not sleeping." (13; female senior care assistant)

Sleep disturbances also had other physical effects. For example, pacing during the night was described as causing weight loss for one resident, and preferring to sleep on chairs in the common areas of the home instead of their own bed could also result in swollen legs.

"Especially with that kind of pacing, day and night, since he is not sleeping well. So he's like using much energy and that contributed to the weight loss." (12; female nurse)

"Also the fact that she doesn't sleep in her bed and her legs swell sometimes, so you find that her ankles are quite swollen." (7; female team leader)

No impact or positive impact

In a small number of residents, staff members described how they did not think the resident having sleep disturbances had affected them in anyway.

"If you look at her face she looks like she's been sleeping all night. And, in fact, she probably got two or three hours sleep the whole night." (15; female care assistant)

"She's actually very alert the whole time and she's eating and drinking. It hasn't really affected her." (1; female care assistant)

Though increased aggression was often thought to result from poor sleep in many residents, this did not happen unanimously.

"Do you know what she's not even aggressive or anything like that so, no, her behaviour is fine." (15; female care assistant)

"Even though he is not having a complete sleep sometimes, he'll never be aggressive. Never." (2; female care assistant)

Impact on other residents

All staff reported impacts on other residents from being disturbed by those with sleep disturbances, often by shouting or screaming.

"Screams... there's a resident nearer to her room, she get scared." (10; female care assistant)

In addition, noises from sensor mats and call bells going off awakened other residents.

"Just like what I was talking about with [resident's name], she sleeps opposite a lady whose door is open and because the call bell is opposite the lady's door if there's a lot of buzzing it does disturb her a bit." (16; female team leader)

Sometimes the residents with sleep disturbances would also enter, or attempt to enter, the rooms of others whilst they were sleeping.

"He did manage to get into one of the resident's rooms at night-time, which frightened the person." (17; male senior care assistant)

"But he used to walk around in the unit, and opening other people's doors.

And also, shouting a lot, you know, disturbing the rest of the service users."

(14; male senior care assistant)

Impact on care home staff

All staff reported difficulties in caring for residents with sleep disturbances, particularly when the resident in question disturbed and woke up other residents.

"When she wakes them up... And when all of them wake up, you've got to attend to them. Maybe one person will visit, shut up, and the other will be calling Nurse, Nurse. And then some of them that can walk, they'll just open the door, who is that?... During the night, it's really stressful." (3; female senior care assistant)

"Yes, for staff it can be challenging. But then, again, it can be tiring for them, honestly. Let's say with [resident's name], every five, ten minutes when she comes out, you have to make sure that she doesn't go to other rooms." (17; male senior care assistant)

Staff described how dealing with those who had sleep disturbances made them feel stressed and guilty, as it often conflicted with their ability and desire to provide care to other residents. Often more than one member of staff would be needed to deal with residents with sleep problems during the night, which can be intensive to manage, meaning limited resources to assist others who require attention.

"And sometimes it's very hard to give every single person the same caring, because sometimes you have to spend a lot of hours with one of the residents... sometimes you still feel guilty." (5 female care assistant)

"Yes, especially those that are at very high risk of falling because you have to be monitoring them every minute... You have to have one staff watching that resident specially. So, you have to have another staff going around checking residents and in case the bell goes off, the third person will have to go. So, it's like every sometimes, all of us are occupied the same time." (4; female senior care assistant)

Having residents up during the night-time meant staff had less time to do other tasks often assigned to staff working in the night, such as updating care plans.

"But with that kind of situation, I have to stop whatever I'm doing and attend to her... So if I do night, I always get time to update my care plans. But because of that situation, I don't get that time." (9; female care assistant)

Staff also described how residents being up in the night was tiring, both from what they had felt personally but also from what they observed in their colleagues when arriving in the morning.

"And you can imagine, she's wandering throughout the night. It gets very tiring as well." (8; female senior care assistant)

"You would really know because first thing in the morning as soon as I arrive I'll ask: Is it a quiet night? And then you can see in their face, oh no... So you can really see in their face that they are really tired." (12; female nurse)

Impact on relatives

The impact on the relatives of those with disturbed sleep was also mentioned in a small minority of the interviews. Relatives were concerned by the subsequent effect on their behaviour. In one case their relative used to call home during the night-time.

"Even the family as well are concerned with the reverse pattern he's had, it's something unusual to them as well." (16; female team leader)

"He used to call to his wife every night, all... During the night... So that's what she said, just take the phone away from him. In the morning he wakes up, we give phone back and that's it. Because wife can't sleep as well at night." (18; female care assistant)

Discussion

In this, the first qualitative study of care home staff's opinions of the impact of residents with dementia's sleep disturbances, we found a wide-ranging number of consequences. We found sleep disturbances to have both a behavioural and physical impact on residents with dementia. Despite not necessarily remembering their sleep was disturbed, and being able to sleep during the day, care home staff reported sleep disturbances to negatively impact not only the resident themselves, but also other residents, staff and occasionally their relatives. Residents were often more irritable the next day, more likely to refuse personal care and less likely to want to take part in activities. They were often described as being more agitated or physically aggressive if they had not slept well, compared to their behaviour after a good night's sleep, or to residents who always slept well. Staff assumed that the agitation was caused by sleep disturbances, but the direction of causation is unknown, and both agitation and sleep disturbances probably reinforce one another (Webster et al., 2019).

The adverse physical impacts of sleep disturbances often came from residents sleeping during the day, which had an effect on their ability to eat and drink, leading to risk of dehydration and risk of choking while eating or falling due to drowsiness. Previous research in older adults living in care homes has found that behaviours other than sleep disturbances, including agitation and aggression, are associated with dehydration (Masot et al., 2018). Staff also described adverse effects on residents' enjoyment making them communicate less than usual, and stopping them enjoying activities during the daytime. Though it may be assumed that care home staff would be less affected than relatives who would be caring for someone at home, they often discussed how it made their job more stressful. Sleep disturbances in care home residents have been associated with staff distress in a number of quantitative studies (Aasmul et al., 2016, Zwijsen et al., 2014, Song and Oh, 2015), and may cause particular distress for staff caring for residents with early onset (van Duinen-van den IJssel et al., 2018).

The results of the interviews revealed that some of the strategies used by staff to cope with sleep disturbances might be counterproductive. For example, feeding people at night might

reinforce their sleep disturbance as they learn it is a time to eat, and their body may expect food, potentially maintaining the cycle of sleep disturbances (Kinnunen K. et al., 2018). In addition, residents were often given caffeinated tea in the night, which contains about half the caffeine of a cup of coffee (Oddy and O'Sullivan, 2009), more than enough to aggravate sleep disturbances. Older adults are often more sensitive to caffeine (Clark and Landolt, 2017), and drinking it at night increases the frequency of people with dementia getting up during the night (Kromhout et al., 2014). Reducing caffeine improved sleep in a small study of care home residents with dementia (de Pooter-Stijnman et al., 2018).

In terms of pharmacological strategies, staff discussed how they thought sleep medications did not necessarily help, and their effect on increasing the risk of falls (Westerlind et al., 2019, Reynolds and Adams, 2019) was widely observed by staff. A previous qualitative study about the prescription of psychotropic medications in care homes found that staff were worried about sleep medications making residents too drowsy, but a pharmacist reported they had also felt reluctance among staff to reduce these medications as they made it easier for them to cope with sleep disturbed residents (Sawan et al., 2017). All interviewees described how sleep disturbed residents often impacted other residents as their sleep was disrupted. A previous qualitative study focusing on how care staff manage residents agitation also discussed how residents shouting in the night disturbed others sleep (Rapaport et al., 2018).

Strengths and limitations

This study included staff who worked a mix of day and night shifts to get information about the effects of sleep disturbances at both day and night-time. It is particularly important to include the views of staff working night shifts, as they see residents at a time when they would normally be sleeping. We also used a maximum variation sample to ensure we included staff with a wide range of demographic characteristics, reflecting staff who work in care homes, as the majority are females (Skills for Care, 2019) and from a mix of ethnicities, including many who speak English as an acquired language (Robertson et al., 2019). We recruited staff from a mix of residential and nursing homes to ensure we had a range of experiences and continued recruitment until theoretical saturation was reached. We developed a framework analysis of themes and by asking staff to choose three particular residents who had sleep disturbances, we focussed on real experiences rather than hypothetical.

However, we recruited care home staff from homes only in Greater London. Therefore, the results are only the opinions of the staff working in these homes and may not reflect the

range of experiences of care home staff, who have different experiences based on their roles, training and education (Law et al., 2019). Interviews were only with staff, and therefore we only present their subjective perceptions of how they deliver care for their residents with dementia (Rapaport et al., 2018), and not the views of people living with dementia. Staff were asked to think about residents with dementia, and we did not check diagnoses of the residents they spoke about, though it is likely that they had dementia, most people living in care homes do.

As they were staff who opted in to take part they may have more positive experiences within their roles than those who did not, which may bias the results (Law et al., 2019). We asked staff about their experiences and to pick the residents they wished to speak about, however, they may have been more likely to think of residents when sleep disturbances were more disruptive or had a greater impact. Sleep disorders may be the result of a variety of dementias, pain, anxiety, discomfort, fear or other sleep disorders or a combination of these and lead to differing symptoms. We have not focussed on this because our primary interest was in the impact, and it is difficult for care staff, or anyone else to judge the causes of the sleep disturbance but they can observe the impact.

Implications and conclusion

Overall, sleep disturbances were described as having a negative impact on care home residents with dementia in the opinions of care home staff, affecting individuals in terms of their behaviour, physical health and ability to enjoy their day-to-day lives. They also affect staff working night shifts who are trying to comfort distressed residents during the night, as well as affecting the sleep of other residents who may be disturbed in the night, which may then have negative consequences for these individuals. This, therefore, highlights the need for appropriate identification, management and treatment of sleep disturbances in care home residents living with dementia. The management strategies care home staff often used may be counterproductive and reinforce sleep problems, such as napping in the day and giving caffeinated drinks at night. Appropriate management strategies may also help reduce the distress these disturbances can cause for staff themselves, and other residents.

Conflict of interest

The study was part of a PhD funded by the UK Economic and Social Research Council. There are no conflicts of interest to report.

Description of authors' roles

L. Webster, G. Livingston and S. Costafreda formulated the research question and designed the study. L. Webster collected all data. G. Livingston and S. Costafreda supervised data collection. L. Webster and K. Powell analysed all interviews. L. Webster wrote the first draft of the paper and all authors revised the paper critically for important intellectual content

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 Table 1. Participant demographics

Characteristics		Participants
Sex	Male Female	2 16
Age (years)	Range Median	21-64 38
Ethnicity	Black British African Black British Caribbean	7 2

	Filipino Mauritian South American White British White Other	3 2 1 1 2
Time working in care homes	Range Median	1-25 years 6 years
Time working in current care home	Range Median	1-15 years 5 years
Role in care home	Care assistant Senior care assistant Team leader Nurses	8 6 2 2