Caring for people with Dementia with Lewy bodies and Parkinson’s Dementia in UK Care Homes – A Mixed Methods Study.

**Introduction**

Although Lewy Bodies were first identified in the brain in the early 1900s [1], the clinical significance in dementia did not emerge till the 1980s [2]. Diagnostic criteria (though subsequently amended) for the condition now known as Dementia with Lewy bodies were first established by a consensus conference in 1996 [3]. A more recent review of dementia with Lewy bodies further defined it further [4]. This form of dementia is characterised by marked fluctuations in cognitive functioning and behaviour, by sleep disturbances and by the presence of often very vivid visual hallucinations [4]. It is particularly important to recognise, as people with dementia with Lewy bodies can be particularly sensitive to the side effects of antipsychotic drugs [5], which are often used to treat hallucinations associated with other conditions. Indeed the use of antipsychotics for people with dementia with Lewy bodies increases mortality [5]. Recognising the fluctuating nature and the associated physical symptoms such as rigidity and reduced mobility is also important in providing care and support [4].

The dementia which is associated with Parkinson’s (Parkinson’s disease dementia), which affects about 30% of people with Parkinson’s [6], also lies within the spectrum of dementia with Lewy bodies; dementia with Lewy bodies and Parkinson’s disease dementia are often considered to be two aspects of the same condition [7]. It has been demonstrated that the non-motor symptoms of Parkinson’s such as cognitive impairment, neuropsychiatric symptoms and sleep disturbance are associated with significantly poorer quality of life [8]; such symptoms are an integral part of the syndrome of dementia with Lewy bodies. Conventionally, a diagnosis of dementia with Lewy bodies is given when cognitive features appear first, Parkinson’s disease dementia when physical symptoms appear first [7]. Lewy Body dementia is a term which is used to include both conditions [8], and is the term used in this paper, other than when discussing the conditions individually.

People with a diagnosis of dementia with Lewy bodies are underrepresented in the care home population which seems surprising given that they tend to be admitted to such care on average 2 years sooner after diagnosis than those with a diagnosis of Alzheimer’s disease [9, 10].

Guidance is clear about the importance of subtyping different forms of dementia, particularly for people with dementia with Lewy bodies and Parkinson’s disease dementia [11, 12]. This is particularly important in understanding symptoms, in access to treatments and in avoiding often catastrophic reactions to medication, first described by McKeith in 1992 [3]. It is also important in understanding prognosis – people with dementia with Lewy bodies tend to have more rapid cognitive decline than those with Alzheimer’s disease [13]. A 2014 literature review concluded that both public and private knowledge about these conditions is lacking [9].

It is particularly difficult to establish an accurate estimate of the prevalence of dementia with Lewy bodies and Parkinson’s disease dementia, and indeed many people with dementia of any kind in care homes are undiagnosed [14]. A systematic
A review of the prevalence and incidence of dementia with Lewy bodies concluded that 4.2% of the dementia population has a diagnosis of dementia with Lewy bodies [15]. Similarly, the Dementia UK Report [16] estimated the prevalence of dementia with Lewy bodies to be 4% and Parkinson’s disease dementia 2% within the dementia population. However, evidence about the prevalence of Parkinson’s disease dementia and dementia with Lewy bodies in care homes is very limited. An American study [17] carried out in nursing homes estimated that 7.7% of residents had Parkinson’s and 48.6% of these met the criteria for Parkinson’s disease dementia but had not been given a formal diagnosis. A study in Swedish nursing homes found that 20% of residents had 2 or more symptoms of Lewy Body dementia, although only 19% of these had a formal diagnosis of either Lewy Body dementia or Parkinson’s disease dementia [18].

There is little research evidence available on levels of care home staff awareness of Parkinson’s disease dementia or dementia with Lewy bodies. One qualitative Dutch study [19] focused on perceived quality of care of Parkinson’s amongst residents and family carers; this study highlighted three main concerns, insufficient staff knowledge of Parkinson’s and its related problems, poor empathy and emotional support, and suboptimal access to specialists and their services. A UK based study [20] also highlighted carer concerns regarding staff’s level of understanding of Parkinson’s and its management, including a lack of knowledge of issues around medication.

Aims

The aims of the study were to estimate the prevalence of dementia with Lewy bodies and Parkinson’s disease dementia in care home settings, and staff’s level of knowledge about dementia with Lewy bodies and Parkinson’s disease dementia. This was assessed in two ways, by a survey of care home managers, and by interviews with a number of key staff in a small number of homes.

Method

This work was carried out in two localities in Scotland and two in England, selected by their geographical accessibility to the research team. Both localities are covered by two local authorities and one main mental health provider, and each has a mix of rural and urban areas. A survey was developed to meet the project aims [21]. The survey was designed to explore four key areas:

- The possible prevalence of Lewy body dementia (or symptoms suggestive of Lewy body dementia) amongst care home residents.
- The nature of the challenges that caring for a person with Lewy body dementia presents for different groups of staff and for care homes with different characteristics (e.g. size, ownership, registration type)
- The extent to which the care homes and their staff (at all levels and in different roles) have the appropriate knowledge and skills to care for residents with Lewy body dementia
- Sources of advice/training they can access if they needed specialist support in caring for a resident with Lewy body dementia,
The content of the survey was informed by a project Steering Group set up by Parkinson’s UK, and by telephone discussions with six key informant carers (i.e. carers with an association with Parkinson’s UK who have had a family member with Lewy body dementia in a care home). The survey collected data on the characteristics of the care homes (including details such as size and ownership type (part of a group or individual, private or not for profit) and the number of residents with a diagnosis of Parkinson’s disease dementia or dementia with Lewy bodies. There were also questions covering symptoms associated with dementia with Lewy bodies, developed from a recognised and validated symptom checklist [22]. The survey was piloted with two care homes not involved in the study.

As part of the survey, managers were asked whether they wished their home to participate in the interview phase of the study.

**Ethics**

Ethical approval for the study was granted by the University of the West of Scotland School of Health Nursing and Midwifery Research Ethics Committee.

**Distribution of the survey, response and analysis**

The survey was sent to all 144 care homes for older people in the two areas, 80 in England and 64 in Scotland, identified from social care listings, in January 2015. Homes were initially contacted by both email and letter, and following this non-responders were contacted by telephone to ask if they wished to participate. The overall response rate was 48%. All participants were assured that their own anonymity and that of their care home would be preserved.

Responses were entered into an Excel spreadsheet. The quantitative data was analysed in Excel using descriptive statistics and a thematic analysis was undertaken of the responses to the open questions. The data from the survey was also used to estimate the prevalence of Lewy body dementia.

The proportion of ownership status in the group of homes that responded to the survey was almost exactly the same as the total contact database. Of those that completed the survey, 38 were in England and 30 in Scotland, with one unspecified. Twelve of the homes in England were nursing homes and 26 were residential homes. In Scotland almost 75% (n=22) were registered for nursing care. Perhaps linked to this, a much higher proportion of Scottish homes had one or more Registered Mental Nurses (RMNs) on their staff team – 70% (n=21) in Scotland and 26% (n=10) in England.

In response to the question - *Does your home specialise in the care of people with any specific condition?* 40 homes said they did. Of these, 37 said they specialised in dementia or the care of elderly mentally infirm people, with one highlighting challenging behaviours and another Alzheimer’s and Parkinson’s.

**Interviews with Care Home Staff**

As part of the survey, homes were asked if they would take part in the interview stage. From this self-selected group, a pragmatic sample of six homes in each locality were approached, based on five characteristics: the size of the home (i.e. under or over 50 beds), registration (i.e. residential home or a nursing home in England or registered for personal care or
personal and nursing care in Scotland), part of a local/national group or standalone home, employment of RMNs, and any specialism. Nine homes took part in the interview stage, four in England and five in Scotland. The mix of participants varied between the homes, but in each the home manager, a deputy manager and/or registered nurse (RMN or Registered General Nurse (RGN)), senior care workers and care assistants were involved. In total the interviews involved eleven managers and deputy managers, four RGNs, nine senior care workers, twenty five care assistants and two activity coordinators.

A combination of face-to-face individual interviews, paired interviews and small group discussions were used to gather participants’ perspectives, the approaches being tailored to the homes’ individual circumstances and associated availability of staff.

Two semi-structured topic guides were used in the interviews and discussion – one for managers/deputy managers and nurses, and one for other care staff. Both had three main sections:

- Experience of caring for people with Lewy body dementia
- Information and advice available about the care of residents with Lewy body dementia
- Staff training in relation to dementia and Lewy body dementia

The interviews and focus groups were audio-recorded, transcribed as detailed notes and quotes, and then analysed thematically using Framework Analysis [23]. The main areas of inquiry covered in the interview and focus group topic guides were used as the framework for analysing the data across all homes contributing to the study. The framework was created in Excel and populated with data from the transcripts by the three researchers who had conducted the interviews and focus groups. Within each main area an ‘inductive’ process was used to identify themes and issues, and to explore shared experiences and perceptions or points of difference between the homes and/or groups of staff.

A small number of local health care professionals involved in the care of residents with Lewy body dementia were also approached to augment the staff interviews. These interviews provided some useful insights into aspects of caring for people with Lewy body dementia that staff find most difficult, and areas where training might be most productive. Interviews were conducted with: the lead Parkinson’s Nurses for the two localities, two Consultant Old Age Psychiatrists, one Care Home Mental Health Liaison Nurse, and one Senior Nurse Consultant in older peoples’ mental health.

**Survey results - Prevalence**

Six questions in the survey looked at prevalence. A number of respondents found it difficult to differentiate between the specific symptoms listed in the question e.g. significantly fluctuating cognitive impairment or unusual sleep disturbance and the symptoms that many residents with dementia might exhibit. Close examination of the responses to this question found that nine homes had indicated that all or the majority of their residents with dementia had the symptoms of dementia with
Lewy bodies, in particular unusual sleep disturbance. These responses have been excluded from the analysis of this question, as it indicates a particular interpretation of unusual sleep disturbance.

While the data gathered from these six questions needs to be treated with some caution, it does provide a picture of the prevalence of Lewy body dementia in care homes. The results suggest that:

There were 40 (62%) homes which had residents with a diagnosis of Parkinson’s, with the proportion of residents ranging from 2% to 30%. In total 3.4% of residents had a diagnosis of Parkinson’s (3.2% in residential homes and 3.5% in nursing homes).

Fifty seven per cent of residents had a diagnosis of dementia (49% in residential homes and 63% in nursing homes).

Almost a quarter (23%, n=16) of homes had residents with a diagnosis of dementia with Lewy bodies with the proportion ranging from 1.8% to 26.7%. Of the residents with dementia, 2.8% had a diagnosis of dementia with Lewy bodies (almost the same in residential and nursing homes) and a further 4.6% had symptoms suggestive of dementia with Lewy bodies without a diagnosis, a total of 7.4% with possible dementia with Lewy bodies.

In total 4.3% of residents with dementia had either a diagnosis of Parkinson’s and dementia or Parkinson’s and the symptoms of Parkinson’s disease dementia (3.4% had a diagnosis of both Parkinson’s and dementia and a further 0.9% had Parkinson’s and the symptoms of Parkinson’s disease dementia without a formal dementia diagnosis).

Residents with a diagnosis of both Parkinson’s and dementia were present in 42% (n=29) of homes with the proportion ranging from 2% to 16.7%, and 10% (n=7) of homes reported having residents with Parkinson’s who also had the symptoms of Parkinson’s disease dementia, with the proportion varying from 2.5% to 12.5%.

Factors affecting diagnosis

The care home clinicians, managers and staff interviewed highlighted a range of barriers to people receiving a specific dementia subtype diagnosis - particularly dementia with Lewy bodies - including a lack of staff awareness about indicative symptoms, care home staff not realising the value of obtaining a diagnosis, variable practice amongst General Practitioners (GPs), where there was an impression that some did not see the point of obtaining a specific diagnosis “because there was nothing that could be done” (Home Care Manager) and a lack of awareness amongst family members, who may therefore not ‘push’ for a specific diagnosis.

A number of those interviewed thought there should be more emphasis on obtaining a specific diagnosis, however some expressed concern that this should not always be a priority. In some cases this linked to people at particular stages of the disease and/or where they are very frail, and it was not considered appropriate or ethical to put them through extensive testing. There were also concerns that a diagnostic-led approach could result in an erosion of person-centred approaches.
The recognition and management of specific symptoms associated with Lewy body dementia in care homes, and the factors that influence symptom management and associated quality of care were explored. Some of the issues described may apply to care home residents regardless of their condition, but this exploration serves to highlight where they may have a particular impact on supporting people with Lewy body dementia and recognising associated symptoms. The baseline knowledge of Lewy body dementia amongst care home staff is relevant to these issues.

In the survey respondents were asked, ‘How easy or difficult does your home find it to deal with the following symptoms of Dementia with Lewy Bodies/Parkinson’s Dementia?’ As can be seen from Figure 1, homes found hallucinations, delusions, unusual sleep disturbance and distress or behaviour that staff find challenging the most difficult symptoms to deal with.

These findings are supported by data from the interviews although more concern was expressed there about the difficulties of caring for residents with limited communication and physical symptoms such as stiffness and balance problems than was the case in the survey.

Some of the professionals working with care homes interviewed said that homes routinely ask for support with the kind of symptoms associated with Lewy body dementia (particularly hallucinations/distress, behaviour that staff find challenging and reactions to medications). Requests for support did differ markedly between homes with or without Elderly Mentally Infirm (EMI) specialty.

Many of the staff interviewed indicated that they found hallucinations and delusions difficult to manage. Where they did not appear to be distressing to the person experiencing them it was less of an issue, though some described care staff who still challenge or try to “put right” residents who are experiencing them. They indicated that this was linked to a lack of training and experience. Several staff said they were unsure of how to manage hallucinations and delusions where these are upsetting or damaging to the individual:

When delusions were paranoid (e.g. accusing staff of things), some staff said that they found this alarming: 'It was quite scary because I just didn’t know what to do - we’re just not trained for that.’ (Care Worker)

In one home, a member of staff described how they first learned that a resident with Parkinson’s disease dementia had hallucinations when this was reported back by clinicians at the Parkinson’s Clinic which the resident attended every 6 months. She told clinic staff about her hallucination but had not discussed it with staff in her care home. The staff were very surprised as they had not observed anything. This demonstrates that hallucinations can be discreetly experienced and suggests that effective prompting, observational skills, and the building of trusting relationships are important factors.

Caring for residents with limited speech and facial expressions was thought to be challenging because it can be difficult to ascertain what residents want and whether they are happy or in pain. “You’re just guessing all the time.” (Senior Carer)
Several staff explained how important it is to observe body language in order to obtain cues about the residents’ mood and needs. It was also stressed how vital it is to be able to spend time with residents who have communication difficulties in order to get to know them properly and provide quality care. This is increasingly challenging with limited staff/resident ratios and the demands of supporting more residents with complex needs.

Some staff found the fluctuating cognitive impairment that accompanies dementia with Lewy bodies and Parkinson’s disease difficult to understand and to manage:

"The mental capacity thing - it seems to come and go again more than other residents." (Senior Care Assistant)

The majority of staff, however, said they did not really struggle with fluctuations in cognitive ability. A consultant psychiatrist who was interviewed said that he did not see this as a major presenting problem for staff unless it was very extreme, which he considered rare.

Some staff talked about residents who had unusual sleep disturbance but generally they did not say they found this difficult to manage. Most managers said that staff were used to dealing with residents with severe night-time disturbance.

Whilst supporting residents with mobility problems was routine for care staff, there were some physical motor symptoms that they found difficult to manage. Rigidity was felt to be particularly hard to deal with, making it difficult to help residents to dress and to assist with personal care. The often rapidly fluctuating nature of the physical symptoms of Lewy body dementia and Parkinson’s brought additional challenges.

**Distress or behaviour that staff find challenging**

Distress or behaviour that staff find challenging often relates to the difficulties in understanding certain symptoms and behaviours (perhaps triggered by care or environmental factors) and includes situations where staff may create distress for the individual because they do not communicate effectively. Some found aggressive behaviour on the part of the resident difficult to manage, though there were some positive examples where staff had thought creatively about how to respond. For example, where a man was resistant to using the toilet a care assistant said she and a colleague used to walk him there whilst singing a song, which worked very effectively. Several staff said they felt they needed more training to be able to respond to behaviours they found aggressive or hard to understand.

**Medication**

Many care staff did not seem to be aware of the risk of severe side effects with antipsychotic medication in people with Lewy body dementia, and the majority said that they would like to know more about the risks and what to look out for. Nursing staff (in particular registered mental nurses) were more familiar with the risks but would like to have routine updates.

**Factors Influencing Management of Symptoms and Quality of Care**
It is clear from the exploration of symptoms above that a wide range of factors influence how they are managed. The priority that needs to be given to personalised care and building staff knowledge and experience is clearly fundamental to the quality of the support provided.

Key factors which influenced the ability to provide suitable care for residents with the symptoms of dementia with Lewy bodies or Parkinson’s disease dementia included resources, leadership and culture, the environment, internal systems and communications, relationship with family carers, and external support. These factors all affect residents’ treatment and quality of life regardless of their condition, but may have a particularly profound impact on people with complex conditions (such as Lewy body dementia) and/or specific symptoms (such as limited speech).

**Resources**

In the interviews, the availability of staff time and resourcing issues came up repeatedly. Many staff highlighted the difficulty of providing person-centred care when time is more pressured due to looking after an increasing number of people with complex needs and higher dependency levels. High staff turnover also makes it challenging to ensure that staff are kept up to date with training and are able to build expertise. Tight budgets also affect staff ratios and limit the amount of quality time that staff can spend with residents.

Staff ratios are generally higher in nursing homes relative to residential homes, and the presence of RGNs and RMNs on the team was thought by care home staff to improve their ability to manage the symptoms associated with Lewy body dementia as they were able to share their expertise, and support less experienced members of staff.

**Leadership and culture**

Interviews with care home staff and external professionals highlighted the key role managers have in raising awareness of dementia with Lewy bodies and Parkinson’s disease dementia amongst their staff. They are central to ensure quality care and for activating referrals to professionals who can support individuals with these conditions. The manager of one care home described their role as “critical” to the culture and standards of care. Another manager said it was essential to provide necessary leadership and act as the “lynchpin”. This was emphasised both in homes that were part of larger chains and in the small independent homes.

Many of the NHS clinicians interviewed also stressed how important it is that care home managers create the right ethos and provide leadership in their homes.

All care home managers and nurses interviewed expressed unhappiness about the quality of information they received from other professionals/agencies about new residents, including diagnosis and care needs. Information varied depending on the type of professional input and the route through which someone had come to the home, but information from hospitals was thought to be particularly poor. A dementia diagnosis was often not provided or made clear – often termed ‘confusion’ or
'memory difficulties' or just 'dementia' with no subtype. If any diagnostic information (such as Lewy body dementia) was provided it was "starkly clinical", with little personalised information about supporting the person or the impact of the condition. This resulted in care homes starting initial assessments "from scratch", which risks certain clinical or other care issues related to specific conditions being missed.

In terms of external support following admission, this was addressed in the survey and explored in the fieldwork. When asked where they look for advice or support in caring for someone with dementia with Lewy bodies or Parkinson’s disease dementia, the response from the homes in Scotland and England varied, probably reflecting local provision and policies. In one area care home staff had to go via the resident’s GP to access more specialist services. However, the findings broadly reflect those obtained from the survey, in that Community Mental Health Teams (CMHTs) and GPs were seen as the main sources of support and advice to care homes overall, though other useful sources of support included Parkinson’s Nurse Specialists and pharmacists.

The availability of Parkinson’s Nurses varies and some operate only in hospital settings. Some also provide wider neurology support, or work alongside neurology nurses. The Parkinson’s Nurses said they provided advice concerning care of individual residents, and there were also examples of them providing short training sessions for groups of staff; however they were clear that they focused on physical symptoms and would refer to mental health colleagues for anything dementia related.

**Staff Training and Awareness**

**Baseline knowledge**

There is a large body of research literature on the quality of dementia care in care homes, including care home staff training and awareness, but to cover this is outside the scope of this study. However, as part of this study, the person completing the survey was asked to rate how knowledgeable their staff team is in caring for people with dementia in general, and caring for people with a diagnosis or the symptoms of Lewy body dementia. Figure 2 below show the results for both questions.

In terms of knowledge of dementia generally, the combined ratings from England and Scotland suggest that about two thirds of care home respondents thought that this was at a reasonably high level (4 or 5). This contrasts with lower ratings for knowledge of Lewy body dementia, where the combined scores of 4 and 5 drop to around one third. Also, a larger number of respondents rated knowledge of Lewy body dementia at a low level, with combined scores of 1 and 2 making up over 25% compared with 4% of scores 1 and 2 for dementia generally. There were, however, some differences between England and Scotland, with higher reported levels of knowledge of dementia in general and of Lewy body dementia in England. It is difficult to know what the reasons for this reported difference might be.

The low level of awareness of both dementia with Lewy bodies and Parkinson’s disease dementia was largely associated with limited training and infrequent contact with people with a known diagnosis:
More experienced staff who had direct and ongoing contact with individual residents with Parkinson’s disease dementia or dementia with Lewy bodies generally appeared to have better awareness of the condition, and some had used their own resources (e.g. internet searches) to develop this. However, many of them said they still did not feel they had the baseline knowledge to help them care for people as well as they could. This emerged during the interviews, where questions and prompts about certain symptoms associated with dementia with Lewy bodies and Parkinson’s disease dementia made participants question what they knew.

**Limitations**

The survey information relies on information provided from care home managers, based on their knowledge of their homes, and not on clinical examination of the residents. The number of people with a diagnosis of dementia is below that of some other studies, so the prevalence data must be treated with caution. However it is the first study looking at the prevalence in UK care homes.

Only 9 homes were involved in interviews, though there was a wide cross-section of different staff groups. Homes which agreed to take part may not be representative of average the care home.

The number of health care professionals interviewed was small and therefore cannot be regarded as fully representative.

**Discussion**

There are clearly several contributory factors as to why the population of residents in care homes with Parkinson’s disease dementia and dementia with Lewy bodies may not have a formal diagnosis. This may be starting to change in the current policy environment, where there is a clear focus on diagnosis in dementia strategies, and more emphasis on care staff training and public awareness. However, a lack of an appropriate diagnosis is a barrier to more effective and person-centred care. This applies to dementia in general; particularly in this population, there is a lack of specific diagnoses [15]. Further to this, diagnosing dementia with Lewy bodies can be very difficult clinically [24].

The research also highlights factors which relate to quality of care and symptom management that are considered to be of paramount importance. Experienced managers and nurses reflected that they had not cared for many people with a formal diagnosis, even though they fairly routinely worked with people who had symptoms associated with the condition. This was illustrated by a comment from one of the Parkinson’s Nurses interviewed. They described how a colleague had been asked informally to see a number of other residents with motor symptoms when she was on a routine visit to a resident with Parkinson’s, and this had revealed “four or five people who had dementia with Lewy bodies”.

There was less concern amongst care home staff, about people with Parkinson’s disease dementia being under-diagnosed. This was based on the assumption that because people affected already have a diagnosis of a physical condition, they are more likely to have more contact with clinicians who will be alert to this. However, the two Parkinson’s Nurses involved in
the study observed that staff do not always spot the signs of deterioration in Parkinson’s disease dementia early enough and may misattribute deterioration to age-related decline when it may be associated with poor medication management. The importance of knowing and observing residents was emphasised.

Many of the issues raised are of a generic nature and not specific to Lewy body dementia (such as recording systems, staff communication, managing behaviours that may challenge, involvement of family carers); however, failure to get these things right where residents have more complex conditions brings a greater set of risks that need to be avoided through the reinforcement of best practice. In particular the fluctuating nature of both the physical and psychiatric symptoms of Lewy body dementia may lead to a resident with the condition being labelled as difficult, or awkward, with staff finding it difficult to understand how someone can behave so differently on different occasions. This can lead to what is termed malignant alienation [25] where residents can receive sub-optimal care because of how carers feel about them.

Similarly, care home relationships with external sources of support may impact on residents regardless of condition, but there are particular factors at work in relation to Lewy Body dementia where the nature of these relationships can influence staff understanding, opportunities for identification and diagnosis, and multi-disciplinary approaches and quality of support for residents with Lewy body dementia.

**Conclusion**

With changes in the NHS across the UK, as well as in other healthcare systems, increasingly complex conditions are being managed in non-hospital settings, particularly in nursing and residential homes. Lewy body dementia is a particularly difficult condition to deal with [9] and it is important that this condition is recognised and the specialist care required provided. It is underdiagnosed and the symptoms are under recognised [26]. Providing appropriate care involves proper recognition of the particular symptoms, the issues around care and treatment including appropriate use of medication, and access to coordinated specialist support including experts in mental health and Parkinson’s including nurses and allied health professionals.

There is a clear need for further staff training around this. Whether it is better to provide this as specific condition specific information or more information on dementia in general is difficult to say, but certainly people with Lewy Body dementia do have specific care needs. Good Quality of Life is increasingly recognised as being very important in care homes [27], and addressing the symptoms of this complex group of disorders is essential in order to do this.

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