ABSTRACT

Aim This research aims to provide a better understanding of the experience of support workers, as paid carers, caring for adults with learning disabilities (LDs) nearing the end of life in residential settings.

Background In the past 100 years, people with LDs (also referred to as ‘learning difficulty’, ‘mental retardation’ and ‘intellectual disability’ internationally) are living longer with life expectancy approaching the population norm and more likely to die from diseases such as cancer, respiratory and vascular diseases. Community-based supported accommodation has become the foremost provider for people with LDs in their late 30 s or over in the UK. In the midst of the transition from living to dying for people with LDs, and even postdeath, the needs of support workers are often neglected against a background where most are unqualified, often with little experience of death and dying event, and with limited access to clinical supervision and education.

Methods 3 focus groups involving 13 support workers were conducted at 3 independent service provider settings for people with LDs in London.

Findings In recounting the experiences of these groups of support workers, 6 themes are described: strong emotional bond and identification; collaboration with other services; training issues around the extended role; support within the organisation; relationship with family/other residents; and grieving the ‘loss’.

Conclusions Although support workers play a key role in meeting the end-of-life care needs of people with LDs in residential settings, their own needs are often neglected. There are still significant gaps in understanding these needs and practice development in this area.

BACKGROUND

Learning disability (LD) is ‘a state of arrested or incomplete development of the mind, which includes significant impairment of intelligence and social functioning’.1 It is also described as ‘a reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which began before adulthood and which has a lasting effect on development’.2 It is estimated that in England there are 1 198 000 people with LDs and that by 2021, the number of people with LDs over the age of 50 years is expected to rise by 53% as life expectancy is now approximating the population norm.3 While younger people may die from congenital abnormalities or infections, cancer, respiratory and vascular diseases are the most common causes of death for older disabled adults and these are conditions of typical concern to palliative care services. As people with LDs live longer, they will enter the dying phase of their lives in some form of LD service setting, requiring these services to be better prepared for the transition to end-of-life care.4–5

Evidence has continued to suggest that some groups in society are still excluded from the best of palliative and end-of-life care services, and continue to experience ‘disadvantaged’ dying.6 7 People with LDs have been identified as one of the most vulnerable and socially excluded groups in society, with their healthcare needs often unmet, particularly in relation to cancer care.8–10 The Disability Rights Commission and the Healthcare Commission have called for sweeping and sustained changes to services for people with LDs.11–12 In 2008, the Independent Inquiry into Access to
Healthcare for people with LDs reported that the healthcare system contributed to their vulnerability, resulting in undue suffering and a higher likelihood of avoidable deaths. Recently, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (COPOLD) highlighted the continuing need to identify people with LDs in healthcare settings and to ensure the provision of ‘reasonable adjustments’ to avoid serious disadvantages faced by them. On a more positive note, the document praises the inclusion of the specific needs of people with LDs in an equality impact assessment within the English National End of Life Strategy and the progress made by organisations such as the Palliative Care for People with Learning Disabilities (PCPLD) Network; http://www.pcpld.org

A 2008 UK survey revealed that one-third of specialist palliative care professionals had never supported a person with LDs in palliative care, even though it could be expected that 1 in 40 of palliative care patients should have a LD. The survey also identified delayed diagnosis, difficulties in assessment and control of symptoms, consent processes, communication and family dynamics as challenges in meeting the palliative care needs of people with LDs and cancer. Despite a steady increase in published materials since 2000, research data around the palliative care needs of people with LDs remains scarce. Subsequent position papers in other countries highlight this paucity of information, as well as the gaps in service provision and research evidence. In England, one of the key barriers to people with LDs accessing palliative care services is the lack of understanding and training of the staff working with them. LD staff are often young, lacking in training and experience, while staffing levels are low and turnover is high. In 2004, a study by Todd explored the way in which services organised care for 17 individuals with LDs who had died in supported living settings. Staff reported that they did not feel they were prepared for such endings, felt more and more drawn into a process of ‘contested dying’ where as the care became more complex, they were pulled in several directions, for example, between the continued emphasis on a life optimising service even when a person is nearing death. Kirkendall et al highlighted the challenges of different philosophies of care, where a person-centred approach within the LD services focuses on building autonomy and independence, compared with an approach in palliative care that promotes independence while recognising the progression of a person’s illness and the subsequent level of dependence and increased care needs. In another study by the Mental Health Foundation while interviewing the carers of 21 deceased people with LDs, a key variable around place of death was whether staff could ‘stay the course’, had access to other services as well as help with dealing with their personal and professional feelings. Where the care had worked well, it led to very positive feelings and seemed to have enhanced the status of the workers and the unity of the team. Where the death proved more difficult, for example, in the event of a sudden death, it led to the implosion of one team and possibly long-term distress. Another study by Ryan et al in Ireland interviewed 64 individuals from intellectual disability services about their experiences of end-of-life care for people with intellectual disabilities and many felt underprepared to meet the need and this led to staff stress.

This study was motivated by GOS first experience as a clinical nurse specialist supporting a person with an LD, who had Down’s syndrome, advanced dementia and was dying in a residential setting. Along with my need to learn more about the end-of-life care needs of my patient, who had a prognosis of short days when she was referred to our service, I was able to observe the importance of her close relationship with her carers and their struggles to keep her at home. Subsequently, my project aimed to solely research support staffs’ experience of caring for people with a LD at the end of life, identify their own needs as well as factors that influence their ability to provide end-of-life care and impact on the quality of end-of-life care for people with LDs.

METHODS
Study design
A focus group data collection procedure was selected to enable support workers to jointly reflect on their shared experiences of caring for residents, and to facilitate differing viewpoints on shared themes.

Consultation and ethics
GOS consulted widely with key stakeholders including the PCPLD Network, a group of practitioners from disability or palliative care services that also has people with LDs and their carers as members, as well as with the local LD team where the study was conducted. Ethical approval for the study was obtained from the Kings College London Ethics Committee (CREC/07/07-49).

Recruitment
The support workers worked with residents of varying levels of disability and where the range of services included 24 h staffing, personal care, monitoring of medical needs, training in life skills, for example, hygiene and cooking. Three focus groups were conducted consisting of residential support workers who had direct experience of caring for a person with a LD towards the end of life. Participants were required to have cared for a service user who had died at least 3 months previously. Interviews were conducted at three different service provider settings in central
London. The managers of local care provision organisations were initially approached by a member of the local LD care team who passed on a letter of inquiry with an information pack. On approval, each manager was asked to discuss the contents of the letter with their teams, informing them of the nature and importance of the study. This was followed-up by a phone call from the researcher to confirm participation or not.

Data collection
Each participant was asked to provide demographic information: age, sex, ethnicity, educational background, personal experience of disability, LD work experience, opportunities for in-service training, access to support, understanding and experience of palliative care. The interview guide addressed their previous experience of death and dying event among service users, practices of disclosure in death and dying event, for example, talking about diagnosis and prognosis, relationship with others involved in client care, place of care and postdeath needs and support. Interviews were recorded and transcribed verbatim. In order to encourage participants to generate recommendations for better end-of-life care, a final single scenario was presented: “Sheila is a person with LDs you care for. She is very ill. She is not going to get better. What kind of support do you think you will need to be able to look after her as she nears the end of her life?”

Analysis
Demographic data were tabulated using descriptive analysis. The focus group data were recorded and transcribed verbatim. All identifiers were removed. The following steps were employed for all the data analysis. In order to ensure rigour and reliability, each focus group transcript was reviewed independently by the researcher and a colleague who was experienced in palliative care research. This was meant to address a common concern that in the reporting of qualitative data, anecdotes supporting the researcher’s argument have been selected, or that undue attention has been given to rare events emerging from the data. First, all the transcripts were read through to obtain a sense of the whole data and to develop themes. All transcripts were then subjected to line-by-line coding and the coding frame constructed to answer the study objectives. Each theme was given an identifying title, and codes were selected that best exemplified each code.

SUMMARY OF MAIN RESULTS
The sample characteristics are characterised in online supplementary table S1.

Six core themes were identified. These were (1) strong emotional bond and identification, (2) collaboration with other services, (3) training around the extended role, (4) support within own organisation (including resources), (5) relationship with family/other residents and (6) ‘grieving the loss’. Exemplary quotes are given for each theme in online supplementary table S2, with the anonymous participant ID shown for each quote to demonstrate reporting from the breadth of the sample.

Strong emotional bond and identification
The strong emotional bond and identification that exists between support workers and their residents was demonstrated across all groups. Respondents struggled at times to maintain the boundaries between their personal and professional relationship with the resident, which often reflected the length of time they had worked with the resident, in some cases more than 10 years (quote 1a). Although staff referred to residents using professional terminology such as ‘service user’, in some cases it was clear that they were very deeply attached to the person they cared for (quote 1b).

Level of collaboration from other services
The experiences of the carers was largely positive regarding collaboration with other services, and where the person died at home, this was acknowledged as a key factor in supporting staff (quote 2a). However, there appeared to be evidence of denial and a lack of preparedness for seeing residents entering the dying phase of their lives, which meant that one of the homes with a resident in the advanced stages of dementia was slow to engage with palliative care services despite a clear picture of gradual deterioration over months (quote 2b).

Training issues around extended role
The data corroborated the broad feeling among support workers that they needed access to extra training and support when caring for a resident near the end of life. This was heightened in a workplace setting where it was standard practice for support workers to be on their own with residents, even when they were dying (quotes 3a and 3b).

Support within own organisation (including resources)
Another critical factor for staff was the level of support that the teams had from their own organisations. For one of the teams this was an ongoing battle (quote 4a), whereas both of the other teams felt highly supported by their management when provided with extra staff at night, thus giving increased individual support and affirmation (quote 4b). Ironically, the appreciation from senior management created a paradoxical fear among staff that the home would develop a reputation for end-of-life care in LD circles, prompting increased referrals of that nature (quote 4c). Again, the lack of a specific organisational policy or guideline or formulated plan on caring for residents...
who have a terminal illness was seen as a way of denying death (quote 4d).

Relationships with family/other residents
Support workers evaluated relationships with individual families in both a positive and a negative light, but were convinced of the importance of collaboration. However, they did highlight incidents where their relationships with family/other residents led to a shift in responsibility to caring for the resident’s parent (quote 5a), and to the resident’s friendships within the residential setting (quote 5b).

Grieving the loss: coming to terms with the loss of a resident
Staff in all three focus groups raised the difficulty of coming to terms with the loss of a resident, the necessity of filling the resident’s space after they had died (quote 6a), and the importance of the organisation taking a sensitive approach. Even where a long time had elapsed since a resident had died, staff still expressed strong feelings of attachment (quote 6b).

Recommendations for better support: scenario responses
The three focus groups made recommendations for better end-of-life care that centred on organisational support (quotes R1–3) and service development, including earlier involvement from the specialist palliative care team (quotes R4 and R5). Exemplary quotes are given in online supplementary table S3.

DISCUSSION
This study builds on previous studies acknowledging the important role that LD staff have in providing quality end-of-life care. The findings confirmed the strong emotional bond and identification that the support workers felt towards the residents they cared for. It also raised the potential for staff to use their own human responses over any formal training to respond to people in distress and highlighted a concern for their emotional well-being when providing end-of-life care in the absence of more formal support systems. There was an absence of a supervisory relationship or a reflective space where support workers could process emotional difficulties, especially as it was standard practice for staff to be managed and supervised by the same line manager. Ryan et al’s study corroborated this study’s findings in a number of areas, for example, that health and social care professionals experienced disenfranchised grief following the deaths of service users when their loss and grief was not acknowledged and due to their reluctance to avail of formal support offered by their colleagues. Collaboration between family members and staff was also evaluated in both a positive and a negative light, where a difficulty in the relationship appeared to consistently heighten the emotional distress of staff caring for service users at the end of life.

Participants in this study were also broadly positive about the importance of collaboration between services. At the same time, with long periods lapsing between cases, there were challenges to sustaining these relationships, including the potential for significant clashes of professional interests and organisational culture.

While the development of training and information for LD services has received increasing attention and has resulted in the development of some resources, it is not clear how much the support staff are enabled to use them. Despite commitment to keep terminally ill clients in their own environment for as long as possible, even where there was overwhelming support from two of the organisations, this failed to translate into policies and procedures. Organisational responses that could address common issues include a shared philosophy towards end-of-life care, training needs, disclosure of diagnosis, advanced planning, dealing with family/relatives, access to different services, extra resources availability, support for staff, as well as a meaningful person-centred plan. Good practice examples are rare and key factors identified were attentiveness to the person’s needs; a commitment by all staff to provide person-centred care; and collaboration between healthcare staff, LD staff and family.

It is important to note that for the person with LDs, the family of choice can also include community support workers. Where support workers take on a family role, there is a strong argument for bereavement support, particularly for those who have known a resident for a long period of time. This study also supports the proposal that some form of ritual of remembrance is important for staff and residents when a resident dies; this has significance for the organisation taking a sensitive approach to workers’ needs. Reporting from their experience of implementing a project aimed at increasing access to palliative care for people with LDs through strengthening relationships between LD and palliative care services, Cross et al concluded that any effective change in care has to be embedded, that is, tackling culture (how people think) and structure (how things are organised).

STRENGTHS AND LIMITATIONS
The voices of support workers are currently under-reported in palliative care literature. This study, as well as adding knowledge in this area, focuses solely on their experiences of providing end-of-life care for people with LDs. It also seeks to identify factors that affect support workers ability to ‘stay the course’ of providing end-of-life care, which has implications for clinical practice in this area.

The study also has a number of limitations. The principle researcher was involved clinically with one group of support workers so there was a clear potential for bias. This highlights again the difficult
challenge of recruitment into palliative care research, even when the use of staff and lay carers is thought to reduce this. Recruitment was via access through the local LD team. This is likely to have introduced an element of bias in the study as stable services which were thought to have delivered a good quality of care may have been more likely to be referred to the study. Although the transcripts were posted to participants for comments, the research data analysis stopped short of any further informant feedback to help improve the accuracy, validity and transferability of the study. As a novice researcher, it was challenging to both facilitate equal participation within the focus groups and avoid the domination of the discussion by established peer leaders.

IMPLICATIONS FOR CLINICAL PRACTICE
Although support workers play a key role in providing end-of-life care for people with LDs in residential settings, their own needs are often neglected. The evidence suggests that there are still significant gaps in supporting LD staff in this area. There is an urgent need to develop strategies that will guide LD organisations to start formulating policies and procedures that address some of the issues already identified in this study, such as: extra resources for training; staffing; corroborating with other services; bereavement leave; more time for regular meetings; sensitive approaches to difficult issues such as disclosure, marking the loss of a resident and filling the space left behind. These policies and procedures are critical for preparing and equipping LD staff to provide good-quality palliative care.

Palliative care organisations need to look at more robust ways of improving their partnership with LD services in order to improve the quality of death and dying event for people with LDs. Several UK hospices have developed education programmes for care staff. For example, Dorothy House Hospice Care in Bradford-on-Avon (UK) has a series of rolling programmes for nursing and residential home care workers which are cofacilitated by hospice educators, LD professionals and service users. Another possibility is the development of ‘link workers’ who can improve care outcomes and maintain the partnership between both services.

CONCLUSION
Adults with LDs are now enjoying a lifespan similar to the norm for the general population that has heralded a new transition from living to dying for people with LDs. Although people with LDs can access mainstream palliative care services, the reality is that access to such a service does not necessarily imply benefit. One of the key barriers to people with LDs accessing palliative care is the lack of understanding and training of the staff working with them. A key variable around preferred place of death is whether support staff can ‘stay the course’ of providing end-of-life care. Despite a desire to provide PCPLD, support workers often lack experience and confidence to do so. This has a direct effect on the quality of end-of-life care that their residents receive. Just as importantly, for any kind of change in care to be embedded, both cultural and structural issues have to be addressed by LD service providers. Greater effort is also needed by palliative care services to build on the highly valued partnerships with outside agencies that need to have greater expertise in supporting both people with LDs and their support workers. As services that are often proactive in developing new responses, hospices and palliative care services are well placed to lead this process.

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Contributors
GO conceived the study, was engaged in all aspects of design, execution, analysis and reporting. RH was engaged in design, analysis and reporting.

Competing interests
None declared.

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