

“What is my experience of what I am in relation to people who I have shared my life with for the last 34 years?”: exploring care relationships at the end of life in two life-sharing communities for people with a learning disability

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Abstract

Old age is still an under-researched stage in the lives of people with a learning disability. Providing support to people towards the end of their lives can be challenging for services and involves complex ethical decision-making processes. This study explored the experiences of social care staff in two life-sharing communities, where adults with a learning disability and staff live together. Four main themes were identified, highlighting different dimensions of care. This included an emphasis on relational care, responsive care, collaborative care, and lastly practices that allowed or hindered people with a learning disability to stay within the communities till the end of their life

Introduction

As life expectancy improves, more and more people with learning disabilities live into older age (Emerson and Hatton, 2008). Yet, the life stage of old age for people with a learning disability is still a relatively new research field with continuing questions on how to best support people as their needs change (Araten-Bergman and Bigby, 2021). People with a learning disability are not a homogenous group and live diverse lives. This also holds true for older people with a learning disability (Watchman, 2018). However, people's life paths in adulthood and old age often differ from the general population. Fewer people with a learning disability experience employment, and retirement often has a different meaning. This is particularly true for the current generation of older people with a learning disability, many who will have experienced institutional living or worked in sheltered workshop (Finkelstein et al, 2020; Welshman and Walmsley, 2006). Fewer people with a learning disability marry or have children and many receive social care support throughout their lives (Power, 2013; Watchman, 2018). Additionally, while people with learning disabilities now live longer, their life expectancy is still shorter than that of the general population (Truesdale and Brown, 2017). Research indicates that people with learning disabilities face inequality in relation to

health and social care and are less likely to receive adequate services or regular health check-ups (Emerson et al, 2011; Krahn and Fox, 2014). This is of particular concern in older age as people's health needs increase.

A relatively small body of studies has given insights into the experiences of people with a learning disability of the aging process. Past studies have described increased risk of social isolation and a narrowing of people's lives (Lloyd et al, 2007; Watchman, 2016). People show an awareness of a change in their identity and report anxieties about end-of-life and dying (Kåhlin et al, 2015; McEvoy et al, 2012; Newberry et al, 2015). Furthermore, people with a learning disability appear to experience barriers to access end-of-life care (Hunt et al, 2020). Although research indicates that people are aware of the concept of dying, often professionals seem to avoid talking to people about death as they are concerned that it will upset the person (Tuffrey - Wijne and Rose, 2017). This can result in people with a learning disability not knowing that they themselves or their family members are dying (Tuffrey - Wijne et al, 2020). Research in the context of dementia furthermore shows that people with a learning disability can worry about changes in their life such as needing to leave their current homes to move into nursing homes for older people or dementia specific settings (Sheth et al, 2021). People describe that they experience little control over, and involvement in, decisions that are being made about their care and support (Lloyd et al, 2007; Watchman, 2016). Where people with a learning disability live is also often different to the general population. Few people with a learning disability own their homes. Many continue to live with family members into old age supported by siblings or ageing parents (Finkelstein et al, 2010; Knox and Bigby, 2007), an increasing number live in their own flats with support, others live in group homes or flats that are owned by social care services (Larson et al, 2017; Scottish Consortium for Learning Disabilities, 2022) or in life-sharing communities (Scottish Government, 2013). Life-sharing communities exist across the world and offer people alternative models of care (Jackson, 2022; McDonald and Keys, 2006). The most common life-sharing settings include L'Arche and Camphill communities. Those settings differ from other service models as staff and people with a learning disability typically live alongside each other. The communities usually comprise of several houses and workshops within one big estate, where people with learning disabilities work during the day, such as farms, bakeries, and craft workshops.

Allowing people with a learning disability to 'age in place' is now regarded as best practice and associated with higher levels of quality of life (Araten-Bergam and Bigby, 2021) but it has been shown to depend largely on the skills and knowledge of staff and available

resources, instead of the wishes of the person with learning disabilities (Webber et al, 2010). Services can struggle to support people in their home as their needs increase. The identification of people's wishes, and preferences can be difficult, particularly in the presence of severe learning disabilities or dementia. As people might be unable to make many decisions themselves, others, such as carers and professionals, make choices on their behalf in many aspects of life. While services for older people can struggle to meet the needs of individuals with learning disabilities, learning disability specific services can find it difficult to meet age-related health needs (NICE, 2018). Yet, studies in the UK and the Netherlands have shown that services can support people with a learning disability to stay and die at home (Bekkema et al, 2015; Bernal et al, 2021). There are increasing, but still few studies, which explore the views of social care staff in how to best support adults with learning disabilities in old age and towards the end of their life. Studies have been conducted in learning disability services such as group homes and supported living services (Araten-Bergman and Bigby, 2021; Johansson et al. 2017), as well as palliative care services (Foo et al, 2021), but there is little research on life-sharing settings. The first author had previous experience of working in a variety of learning disability services across Scotland, including working in a shared living setting for a number of years, albeit with children and young people. Learning about the lack of research on life-sharing settings the authors were interested to explore the practices and experiences of these settings as they are often founded on a philosophy that stresses reciprocity (Jackson, 2022). Both L'Arche and Camphill have a history of engaging with questions of spirituality and how values shape interpersonal relationships (McDonald and Keys, 2006). It was hoped that the study could add to an understanding of how people are supported in the two settings towards the end of their life and how staff navigate ethical decisions around enabling people to stay within the communities until their death. The study was particularly interested in the way staff experience care-relationships and how their relationships to the people they support influences care practices and decision-making towards the end of life.

Research aims

The project aimed to explore the views and experiences of social care professionals who support adults with learning disabilities in old age in two life-sharing settings in Scotland. We were particularly interested in the care practices, values, wider culture and resources which enabled staff to support people in old age and how staff viewed their relationships to people who they had often known for many years.

Terminology

In interviews participants referred to adults with learning disabilities as people they support and explained that they preferred not to use labels that might other people. We have used the term 'people who receive support' throughout the findings section but needed to add 'people with a learning disability' in places to avoid confusion and clarify meaning. The settings will be referred to as 'communities'.

Recruitment and background to settings

Recruitment took place through two life-sharing communities for adults with a learning disability in Scotland. Both settings were very similar, comprising of a large estate with houses where people with learning disabilities and staff live together. Both settings also offered vocational placements to people on site, such as working on the farm, garden and craft workshops. The first setting was slightly smaller and set in a rural area of Scotland, while the second one was bigger and part of a city local authority. Both settings explained that they had experiences of supporting people in old age and both settings described that they had an aging population and that questions around how to support people towards the end of their life were becoming more frequent and pressing.

A letter was sent to key-professionals in both communities outlining the research, followed by a phone conversation. Once both communities had reviewed the proposal and decided to take part, we forwarded Participant Information Sheets to the organisations by post. To be interviewed for the study, social care staff were required to have experience in supporting people at the end of life and to have lived in the community alongside people for at least three years. Participant Information Sheets were shared with staff and eight participants agreed to take part in the study (three in setting one and five in setting two). While this is a relatively small number of participants, all participants that took part had accompanied people at the end of life in key-roles, supporting them for several years until their death. All participants had been involved in making key-decisions about people's care and support and thus our sample of participants were very homogenous, allowing us to describe the experiences of participants in depth, while being transparent about the specific context and characteristics of participants (Patton, 2002). While this study only presents an initial exploration of the topic, all participants had detailed experiences of the phenomena being studied and the collected data had great depth and was able to give a profound insight into the ethical dimensions of accompanying people at the end of their life (Creswell, 2013).

Participants

Most participants had lived and worked in their communities for over ten years, some for over twenty and thirty years. Thus, participants drew on their experiences of supporting people in the past and present and within different roles they had had in the communities. All

participants continued to live within the communities, and all had lived together in one house with people with learning disabilities at one point. An overview of the eight participants and their background can be found in the table below (Table 1, pseudonyms used).

Data collection

Data was collected in the form of semi-structured individual interviews and group discussions. The combination of both individual interviews and group discussions has been highlighted as an advantage to offer more nuanced data (Lambert and Loiselle, 2008; Gill et al, 2008). While individual interviews allow the researcher to listen to individual stories and experiences in depth, group discussions provide space to examine and explore differences and similarities in opinions and views, giving participants space to comment on each other's experiences (Lambert and Loiselle, 2008). Furthermore, in this project we used group discussions to have a stronger focus on exploring external influences, the set-up of both settings and collaborative practice, while individual interviews gave space for people to share their personal experiences. Additionally, seeing participants more than once allowed us to clarify and further explore themes of interest that had started to emerge.

Individual interviews and group interviews took place at the two communities between May and September 2018. The lead researcher conducted all interviews and transcribed them after. During her visit to the communities, she was invited to join meals and see people's different workplaces.

Ethics

Ethical approval was obtained from the University of Edinburgh. Ethical considerations related to potential issues regarding care of vulnerable adults, anonymity and sensitivity of the topic. Given the nature of the topic area, there was a possibility that participants could become distressed. Plans had been in place to stop the interview, only continuing if participants felt able to do so. Additionally, details of support were provided to participants. During one face to face interview a participant became visibly distressed talking about the death of people she had supported. The interview was stopped shortly but she asked to continue. After the interview she reflected that she was surprised how strong she still felt about her experiences but that it had been positive to talk about it in more depth, and she remarked that sadness was part of the process of remembering.

Analysis

Reflexive thematic analysis (Braun and Clarke, 2006; Braun and Clarke, 2019) guided the process of data analysis. All transcripts were uploaded to NVivo qualitative data analysis software (version 11). The coding moved from descriptive line-by-line coding to identify

broader themes and explore similarities and differences across the data in more depth. Lastly, reflecting back on our research aims and questions we moved beyond descriptive themes towards a deeper analytical understanding of our data (Braun and Clark, 2019). For this last step of the process we considered the developed themes in light of our interest to better understand how care-relationships were experienced by participants and what practices, values and resources appeared to allow or hinder people with a learning disability to stay within the communities till the end of their life.

Findings

Participants described that people's journeys through old age as very individual. However, aging was described as happening at an earlier age for people with a learning disability compared to the general population. Most participants spoke of a gradual slowing down process with people needing longer for tasks, being more tired or preferring more time by themselves. Overall participants identified many similarities between the aging processes of people with and without learning disabilities. However, participants described that people's understanding of those changes often needed a different kind of support. Additionally, as people had always depended on the 'care system' their choices had always been limited and the transition into old age often involved a further decrease of choices and possibilities.

***JOAN:** Maybe the way old age limits anybody's choices has more of an impact on them, but I think that is something that happens with anybody, sort of life closing down and becoming more limited in scope. It is accentuated by the fact that for many people their scope hasn't been as much as you would want it to be anyway.*

Four main themes were identified across the data that highlighted different dimensions of care, which were seen to influence how people were supported in old age and at the end of their life. This included an emphasis on relational care, responsive and respectful care, collaborative care, and lastly an acknowledgment of barriers in/within care and caring.

Relational care

Most participants had known the people they supported for many years. Participants felt that there was a lot of detailed knowledge of people and help from colleagues to support people at the end of their life.

***MIA:** People here just knew him so well and I think that makes it easier, even when his dementia was so advanced, to really make a connection.*

Knowing people they supported well and in many cases having shared their everyday life with them for several years helped participants to notice small changes in routines and abilities. This was discussed from a perspective that included both participants knowing the person well, but also people knowing participants well and feeling safe around staff.

SOFIE: *I have lived with the people I support for a very long time, some of them for nearly twenty-three years. They know me and I know them.*

Six participants discussed how a belief in mutuality influenced their practice. Mutuality was defined as the appreciation of the unique contribution each person brings and to understand relationships as reciprocal. This seemed to help participants to conceptualise old age as a time in life where people continued to contribute despite an increase in support needs, even during their last weeks of life.

JOAN: *He was like a sort of anchor and other things would go on around him because he was there and it almost drew people to the sitting room. Because somebody was there so that was a lovely side of life and it was missed when they died by the other people in the house.*

Yet, while viewing care-relationships as reciprocal, all participants also showed an awareness of the power imbalance between themselves and the people they support. Participants emphasised trying to involve people in daily decision-making but also felt that they had a responsibility to guide or facilitate bigger decisions around medical care and to some extent also smaller everyday decisions around food-choices or remaining active as their duty of care. All participants described tensions between respecting people's independence and their duty of care, as people were becoming more dependent.

BETH: *That was quite a big step then to realise that we actually have to hold the fork and feed him and we were always resisting taking that step because it is obviously taking someone's independence completely but it was necessary otherwise he wouldn't have eaten anything.*

Taking a relational perspective by acknowledging their role in facilitating independence meant that participants conceptualised independence mostly in relation to access to activities and engagement in community life rather than as doing things alone. In this way participants felt that independence could be achieved relationally, through the support of others.

ROSIE: *We have an activity we do together and so I can enable them to feel good about themselves and that they have something valuable to give.*

While participants stressed the importance of being aware of boundaries and needing to adhere to professional codes of practice, participants seemed to feel that there was a more profound human quality to their work. Participants often used the words friend or family to explain how they felt about the people they supported.

MIA: *I mean it is something between friend and family I don't know. There is a closeness there that care just isn't the right word.*

JOAN: *It is more tricky if we are trying to think well who do I think what is my experience of what I am in relation to people who I have really shared my life with for the last 34 years or something.*

Responsive and respectful care

Both settings only had a small number of employed staff and most did not work in a shift system, as they lived on site. Participants felt that this allowed them to be more flexible to meet the needs of individuals and respond to changes in people's routines such as needing longer to get ready in the mornings or needing longer rests in the afternoons. Continuing to offer people opportunities in situations as they were occurring and then observing their responses seemed to be a helpful way to promote an involvement that was situational and did not only rely on verbal comprehension.

MIA: *It is trying something out and then seeing, seeing then how people respond and how happy they are with the change.*

Supporting people through the process of losing areas of independence was described as requiring time and sensitivity.

All participants discussed that older age also marked a change in people's identity. Participants described that many people strongly identified with their work and workshop settings. The loss of, for instance, working on the farm could be difficult for people and participants described the importance of involving people in finding new meaningful activities. Respecting people's identities was a strong theme across interviews and included an awareness of people's life histories. Valuing people's past lives by creating photo albums or memory boxes and remembering their passions and interests at funerals were striking examples of how both settings attempted to uphold people's life histories.

JOAN: *There is a double decker red bus that you can hire in the area and we hired it for two funerals (...) because both people absolutely loved buses and so the whole community went to the funeral in the red bus.*

All participants described how it was important to honour that both communities were not care settings but people's homes. And all participants described the importance to honour people's sense of belonging when it came to decisions around potential moves to nursing or palliative care homes out of the communities. Participants spoke about a feeling of guilt and how it was emotionally challenging to make those decisions.

BETH: *It is the kind of dilemma and decisions very similar to when a family supports someone, an elderly parent, and at some point you can't do it anymore. It is hard, it is not easy.*

In both settings it was stressed that death was not a taboo and that they tried to engage people in thinking about the end of life. Participants described that it helped people to visit those who had moved to nursing homes and to attend funerals. Additionally, two participants spoke about having photographs and items around to remember people and support others to remember them in everyday life.

Collaborative care

While a commitment to involve and engage people was clearly visible across interviews, all interviews also included a feeling of never being able to fully know what the person would have wanted, nor knowing how much the person was able to understand or comprehend changes and decisions that needed to be made at the end of their lives. Having doubts seemed to be an integral part of participants' work and this seemed to result in a reflective and collaborative approach that attempted to stay closely attuned to the behaviour of the person, while acknowledging own and wider limitations.

BETH: *It was emotionally challenging because this man, he was just very often very upset, out of confusion, and it didn't leave you cold. You were so concerned about what might be wrong, are we doing everything we could be doing? He wouldn't be able to say and one needed to learn a certain confidence that we actually really tried everything, we can't really do more but it is hard to see.*

Decisions that involved a change in care setting or substantial changes to people's support packages were made in reviews together with health and social work professionals and relatives. If possible, people were part of those meetings, but a number of participants reflected that often people's ability to be involved was limited at

this stage, as meetings often took place once a crisis had developed and the person's cognitive abilities had deteriorated. Being proactive was described as best-practice and participants described that they tried to involve people when they were still well in conversations around how they would like to be supported in old age.

All participants spoke about the importance of involving families but stressed that in many cases of older people there could be very little or no family involvement.

Additionally, some of the older residents were not local and came from local authorities further away, which could complicate contact with families or social work.

OLIVER: *There is a small elephant in the room here with regards to (...) the cultural change that has been in regards to attitudes towards people with learning disabilities over the last thirty years. Many of the people we have in later life might not have a lot of relationships simply because they were cut off from family ties particularly in the 50s and 60s. You slowly see that there are stronger family relationships and I think it will change in the future.*

In cases where there was family involvement, parents had often passed away or were less able to be involved in the lives of their children. Towards old age siblings were described as taking on advocating and guardianship roles and becoming a main point of contact for staff.

Experiences of working with social work were mixed. A number of participants remembered close relationships to social workers or specific local authorities and how this had been helpful to get extra funding agreed and to quickly respond to the changing needs of people in old age. Others spoke about having little contact to social workers and finding it difficult to get hold of people to come and see the person, to attend review meetings and respond to requests for extra funding. Accessing health professionals seemed to be easier and participants spoke about receiving support from specialist cancer or palliative nurses who had come regularly to care for people within both settings. Additionally, both settings had established relationships to local GP practices, which was described as a big advantage, as the GPs and people knew each other. GPs were also described as visiting people within the community if this was easier for them.

Barriers in/within care and caring

The impact of internal and external resources on decision-making processes were widely discussed by all participants. Participants spoke about in how far their actions and decisions had consequences for the person and themselves. Their own needs and the needs of people were discussed as interdependent. A sentence that was repeated in group discussion in relation to enabling people to stay within the communities was

'We do it as long as we can'. While participants stated that they tried to be flexible in responding to needs, they sometimes reached limits due to lack of staff and caring tasks becoming more time-consuming or needing specialist medical expertise. In group discussions participants suggested that it was at times down to one person being committed to care for someone till the end of life that allowed them to die within the community.

OLIVER: *We do our utmost to make that possible [for people to stay] and we will do that up to the point where it is either not safe or in the best interest of the person. That is a constant tug of war between the emotional relationship and the practical, the pragmatic side of things.*

Risks to people themselves and others were referred to in the context of dementia and absconding, aggressions, rejection of medicine, food or drink and an increase in physical needs that required specialist medical care such as the development of systemic infections or pressure sores. The need to consider all other people who lived in the communities was mentioned, albeit briefly and mostly in the context of aggression.

ROSIE: *We rather try and support within the community. Unless they turn aggressive and are a danger to others. Because for some the transition [into old age] is not easy and there is a lot of aggression, a lot of temper.*

Additionally, participants expressed an awareness of the complexity of the wider service provision context and scarcity of resources. The physical set-up of the houses people lived in was described as a barrier and of increasing concern with an aging population.

BETH: *We realised we have very little rooms downstairs on the ground floor that are suitable for people who need an ensuite bathroom and all that. That is where a limitation is.*

All participants discussed that there was a lack of medical and nursing training for staff. This was more prominent in interviews in the second setting. Getting specialist equipment and the support from specialist nurses and healthcare professionals towards later stages in old age seemed to allow some people to stay. Additionally, in the first setting participants described how they had relied on support through the NHS to avoid crisis situations while waiting for funding from social care to come through to employ extra staff. At the same time recruiting social care staff to cover additional hours seemed to be complex with often limited interest.

This seemed to be connected to funding being attached to only a few hours daily and living in a rural area.

***MIA:** There was no interest. All the local companies were either full or don't cover this area because we are so rural it is quite difficult. I imagine it happens a lot that healthcare services need to step in because of how difficult it was to find care through the social sector.*

All participants described tensions between acknowledging their own limitations to provide the right care and support for people, while also having concerns about the ability of nursing care homes to support people, where people would not have established relationships to staff. This was one of the major dilemmas identified by participants: Seeing great value in consistent relationships, while at times coming to a point where they felt that people's needs could no longer be met in the communities. There were differences in opinion if nursing homes were better able to address physical care or dementia-specific needs and participants stressed that it was impossible to know where people would have been better looked after.

***JOAN:** He got pneumonia in the care home which, I mean the amount of care that he had once he had gone there, although he went there because he needed more than we could manage here, was obviously he had in a sense much less (pause) personal care and one to one I don't think existed at all*

However, while moves outwith the communities were at times seen to be necessary, all participants described instances where staff maintained relationships to people who had moved to nursing or palliative care settings. This included regular visits, people coming back to the community for visits and participants maintaining an involvement with professionals and family members. Six interviews included portrayals of participants being with people during their last moments in life or organising their funerals.

***HELEN:** We sat once more altogether around her bed and she was not even fully conscious anymore but we were just sharing memories just also for ourselves but hoping that she would hear it.*

Discussion

Participants described their commitment to people, stressing the importance of continuity in relationships to uphold people's identities and facilitate a sense of belonging. There has been an increased interest in the concept of belonging when conceptualising what good lives or good care mean for people with a learning disability in the wider literature (Nind and

Strnadova, 2020; Power, 2013). The concept of belonging has been used to facilitate a deeper understanding of social inclusion, one which stresses the presence of close relationships to others and the attainment of valued social roles within people's local environments (Power, 2013). Although people were described as needing more support in old age, participants emphasised that values of choice and participation continued to inform their practice. Involvement was facilitated through consistent and attuned relationships between staff and the person and both communities described supporting people through changes in their routines and identities by creating more flexible and slower-paced routines. Staff needed to interpret behaviour, notice changes and facilitate new opportunities and routines for people based on knowing about their preferences and likes. The dilemma of not being able to fully know about the wishes and views of people was discussed. Close collaborative practice and supervision seemed to be one way to discern the wishes of people. Values discussed by participants bore great similarities to practices and values identified by Dossa (1990) in her study on the importance of meaningful relationships in the lives of people with learning disability in old age. Drawing on Bogdan and Taylor's (1989) 'sociology of acceptance', she identifies the importance of staff to (1) appreciate non-verbal communication and to be sensitive to intuitive elements within communication, (2) to view people as unique individuals and to have an understanding of their biographies, (3) to view relationships as reciprocal and (4) to value people's roles within their communities. Similarly, other studies have shown that an emphasis on shared humanity is linked to better quality of care, including staff and people with a learning disability sharing meals and staff enjoying the company of people they support (Bigby et al, 2015,; Johnson et al, 2012). Additionally, Bogdan and Taylor (1989) identified that believes in social justice or religious principles help staff to form reciprocal relationships and in this study both communities did promote an engagement with spiritual beliefs and the meaning of human relationships among their staff. Overall, practices and views of staff were connected closely to an understanding of care as relationship-based work, as it is defined in the tradition of Social Pedagogy, which is widely practiced in many mainland European countries (Hatton, 2013; Kirkwood et al, 2019) and which participants themselves referred to, describing how values of Social Pedagogy influenced training and practice in both settings. Social Pedagogy has been called a 'pedagogy of relationships' (Stephens, 2009). It describes how care-relationships take place in shared social spaces and acknowledges the emotional sphere of those relationships, recognising that the quality of relationships that professionals and people build over time, will have a significant influence on practice and outcomes (Stephens, 2009).

Increases in behaviour that challenges, absconding and medical needs were difficult to manage for both settings. In such instances tensions were identified between (i) ensuring

that people were well and safe and (ii) making it possible for the person to stay within the environment, tensions that are reported within both the dementia and wider learning disability literature (Elliott et al, 2009; Lord et al, 2016; Webber et al, 2010). Participants highlighted how they struggled to make the decision for someone to leave the community, feeling that often people's quality of life was negatively impacted by the move to a new setting. There are different opinions if learning disability specific or general health services are best able to support people in old age. Todd et al. (2019) call for the need for future research to clarify the role of both learning disability-specific and generic healthcare professionals to support people in old age. Participants in this study stressed the need to have both: professionals with specific knowledge of physical and medical care, as well as professionals with learning disability knowledge to support people's communication. Close collaborative practice between learning disability professionals and those with specific knowledge about dementia, primary healthcare or palliative care has been identified as crucial to meet the needs of people (Cleary and Doody, 2017; Holst et al, 2018). Yet, participants suggested that of maybe even higher importance is the involvement of people who have close relationships to the person with a learning disability and know them well. This seemed to be linked to worries about new staff not knowing the person, not understanding their unique way of communicating and for people's identity to be lost. Those risks have been reported in other studies (Watchman, 2016; Middleton and Hewitt, 1999). In her study on dementia in people with a learning disability, Watchman (2016) describes the case of a woman with learning disability and dementia who moved to a care home for older people and whose verbal abilities rapidly declined. Watchman observed how staff seldomly engaged with her and seemingly had assumed that she had always been unable to speak. Similarly, others have emphasised the importance of understanding and knowing about people's life stories, their preferences and ways of communication to provide person-centred care (Middleton and Hewitt, 1999; Lloyd et al, 2007).

Participants took a relational perspective when discussing their actions and decisions made, highlighting the specific and unique context of each individual and their relationship to them. The study highlighted that it was often close personal relationships that had formed between participants and people that allowed someone to stay living in the community. Thus, participant's descriptions of care-relationships seemed to align closely to an ethics of care perspective (Kittay, 1999). Ethics of care is concerned with particular relationships and specific contexts, highlighting the human dimensions of ethical decision-making (Dunn and Burton, 2008). Participants explored care not only in relation to the practical activity of providing care or support, the realm of caring **for**, but also thought about care in relation to caring **about** people, which Rogers (2016) and Noddings (1999) identify as the emotional

realm, the realm that describes being concerned about someone, feeling responsibility and commitment. When people needed to move out of the communities into nursing or palliative care settings, it appeared that relationships between the communities and the person often continued, further highlighting the emotional dimension of the care-relationship between participants and the people they supported.

Overall, findings are more positive and stand in contrast to other research that illustrates the difficulties of services to adequately support people with learning disability during the end of their lives (Lord et al, 2017; Todd et al, 2020). Studies show that staff often feel uncomfortable to speak about death with people with learning disabilities (Tuffrey - Wijné et al, 2020). However, in both communities death was not seen as a taboo. Although participants stressed that it could be difficult to speak directly about individual people themselves or those close to them dying, both communities tried to create a culture that normalised death. It was evident that death was seen as a part of life, and people who had died were still part of the life of the communities through photos of them being on mantle pieces and people regularly sharing memories of them.

Limitations

Our study only involved interviews with social care professionals living in both communities. Combining the perspectives of social care staff with experiences of people with learning disabilities living in the communities, alongside their families, could provide a deeper and more multi-faceted account of practices and lives in life-sharing communities. Additionally, it would have been an advantage to combine our interviews with observations of participants interacting with the people they support. Participants reflecting on and talking about their work experiences in interviews does not necessarily describe how they act in practice and researchers should be cautious about inferring from one to the other (Broadhurst and Mason, 2014; Ferguson, 2014). It is important to be aware that the findings from this study are context-dependent and cannot be generalized. Previous studies have shown that quality of care between services of the same model can vary widely, and attitudes of staff, organisational culture and available resources are significant influences (Emerson et al, 2000a, 2000b; Bigby and Beadle Brown, 2016). The two settings will not be representative of all life sharing communities, nor will the views of staff be representative of all staff who work there but the uniqueness of both settings might offer an interesting contrast to existing research findings.

Conclusion

In 2019 the Scottish government started a campaign to attract more people into careers in adult social care, which saw posters placed across Scottish cities, citing the slogan 'There is more to care than caring'. This reflects an understanding of caring as something quite ordinary, something that does not require skill, that is not professional. The emphasis seems to be placed on providing care for, rather than caring about. In a UK context social care is often described using professional language. Emphasising choice and personalisation, care relationships are portrayed to be between 'clients' and 'service providers' (Clarke, 2006; Glendinning, 2008). Such a consumerist view to social care stands in contrast to the narratives of participants in this study. In interviews participants spoke about their emotional ties to people, highlighting the central role caring about people played in facilitating involvement and belonging and acknowledging their own emotional ties towards people. Care-relationships were experienced as deeply personal and relationships between staff and people with a learning disability influenced decision-making and practice. While acknowledging the small sample size of our study, we believe in the value of future research which focuses on the relationships between social care staff and the people they support, and this should include life-sharing communities. We believe this has the potential to better help us understand complexities that are inherent in care-relationships, promoting a relational understanding of care and gaining deeper insights into the emotional realm of caring.

References

- Araten-Bergman, T. and Bigby, C., (2021) Ageing in Place in Group Homes: An Australian Context. *Handbook on Ageing with Disability*, pp.337-349.
- Bekkema, N., de Veer, A. J. E., Wagemans, A. M. A., Hertogh, C. M. P. M., & Francke, A. L. (2015). "To move or not to move": A national survey among professionals on beliefs and considerations about the place of end-of-life care for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 59 (3): 226-237.
- Bernal, J., Hunt, K., Worth, R., Shearn, J., Jones, E., Lowe, K., and Todd, S. (2021). Expecting the unexpected: measures, outcomes and dying trajectories for expected and unexpected death in adults with intellectual disabilities in social care settings in the UK. *Journal of Applied Research in Intellectual Disabilities*, 34(2): 594-605.
- Bigby, C. and Beadle-Brown, J. (2016). Culture in better group homes for people with intellectual disability at severe levels. *Intellectual and Developmental Disabilities*, 54: 316-331.

Bigby, C., Knox, M., Beadle-Brown, J. and Clement, T. (2015). 'We Just Call Them People': Positive Regard as a Dimension of Culture in Group Homes for People with Severe Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 28: 283-295.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2): 77-101.

Braun, V. and Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, 11(4): 589-597.

Bogdan, R. and Taylor, S. J. (1989). Relationships with severely disabled people: The social construction of humanness. *Social problems*, 36: 135-148.

Broadhurst, K. and Mason, C. (2014). Social work beyond the VDU: Foregrounding co-presence in situated practice—Why face-to-face practice matters. *British Journal of Social Work*, 44: 578-595.

Clarke, J. (2006). Consumers, clients or citizens? Politics, policy and practice in the reform of social care. *European Societies*, 8: 423-442.

Cleary, J. and Doody, O. (2017). Nurses' experience of caring for people with intellectual disability and dementia. *Journal of Clinical Nursing*, 26: 620-631.

Creswell, J. W. (2013). *Qualitative Inquiry and research design choosing among five approaches*. Thousand Oaks, CA: Sage Publications.

Dossa, P. A. (1990). Toward Social System Theory: Implications for Older People with Developmental Disabilities and Service Delivery. *The International Journal of Aging and Human Development*, 30: 303-319.

Dunn, C. P. and Burton, B. K. (2008). Ethics of care. *Encyclopedia of Business Ethics and Society*. Thousand Oaks, CA: Sage Publications: 803-806.

Emerson, E. and Hatton, C. (2008). Estimating Future Need for Adult Social Care for People with Learning Disabilities in England.

Emerson, E., Baines, S., Allerton, L. and Welch, V. (2011). Health inequalities and people with learning disabilities in the UK. Learning Disabilities Observatory.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Jaerbrink, K., Walsh P. N. and Netten, A. 2000a. Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation*, 105: 81-102.

Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., Hallam, A., Knapp, M., Jaerbrink, K., Netten, A. and Linehan, C. 2000b. The quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities. *Journal of Intellectual and Developmental Disability*, 25: 263-279.

Elliott, B. A., Gessert, C. E. and Peden-Mcalpine, C. (2009). Family decision-making in advanced dementia: narrative and ethics. *Scandinavian journal of caring sciences*, 23: 251-258.

Ferguson, H. (2014). Researching Social Work Practice Close Up: Using Ethnographic and Mobile Methods to Understand Encounters between Social Workers, Children and Families. *The British Journal of Social Work*, 46: 153-168.

Finkelstein, A., Tenenbaum, A., and Bachner, Y. G. (2020). "I will never be old": Adults with down syndrome and their parents talk about ageing-related challenges. *Ageing and Society*, 40(8): 1788-1807.

Foo, B., Wiese, M., Curryer, B., Stancliffe, R.J., Wilson, N.J. and Clayton, J.M. (2021). Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews. *Palliative Medicine*, 35(4): 738-749.

Gill, P., Stewart, K., Treasure, E. and Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British dental journal*, 204: 291-295.

Glendinning, C. (2008). Increasing choice and control for older and disabled people: a critical review of new developments in England. *Social Policy & Administration*, 42:451-469.

Hatton, K. (2013). *Social pedagogy in the UK: Theory and practice*, Russell House Publishing Ltd.

Holst, G., Johansson, M. and Ahlstrom, G. (2018). Signs in people with intellectual disabilities: interviews with managers and staff on the identification process of dementia. *Healthcare, Multidisciplinary Digital Publishing Institute*, 103.

Hunt, K., Bernal, J., Worth, R., Shearn, J., Jarvis, P., Jones, E. and Todd, S. (2020). End-of-life care in intellectual disability: a retrospective cross-sectional study. *BMJ Supportive & Palliative Care*, 10(4): 469-477.

Jackson, R. (2022). Karl and Tilla König and the creation of the Camphill Movement. *British Journal of Learning Disabilities*, 50(2): 188-198.

Johansson, M., Bjoerne, P., Runesson, I. and Ahlstrom, G. (2017). Healthy ageing in people with intellectual disabilities from managers' perspective: a qualitative study. *Healthcare, Multidisciplinary Digital Publishing Institute*, 45.

Johnson, H., Douglas, J., Bigby, C. and Iacono, T. (2012). Social interaction with adults with severe intellectual disability: Having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities*, 25: 329-341.

Kahlin, I., Kjellberg, A., Nord, C. and Hagberg, J.-E. (2015). Lived experiences of ageing and later life in older people with intellectual disabilities. *Ageing & Society*, 35: 602-628.

Kirkwood, S., Roesch-Marsh, A. and Cooper, S. (2019). Evaluating social pedagogy in the UK: Methodological issues. *Qualitative Social Work*, 18: 8-23.

Kittay, E. F. (1999). *Love's Labor: Essays on Women, Dependency, and Equality*, New York, Routledge.

Kittay, E. F. (2009). The ethics of philosophizing: Ideal theory and the exclusion of people with severe cognitive disabilities. *Feminist ethics and social and political philosophy: Theorizing the non-ideal*. Springer.

Knox, M., and Bigby, C. (2007). Moving towards midlife care as negotiated family business: Accounts of people with intellectual disabilities and their families "just getting along with their lives together". *International Journal of Disability, Development and Education*, 54(3): 287-304.

Krahn, G. L. and Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: what do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities*, 27: 431-446.

Lambert, S. D. and Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of advanced nursing*, 62: 228-237.

Larson, S. A., Eschenbacher, H., Anderson, L., Pettingell, S., Hewitt, A., Sowers, M., ... Agosta, J. (2017). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2015. Residential Information Systems Project Report. *Institute on Community Integration*.

Lloyd, V., Kalsy, S. and Gatherer, A. (2007). The subjective experience of individuals with Down syndrome living with dementia. *Dementia*, 6(1): 63-88.

Lord, K., Livingston, G., Robertson, S. and Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: Development of a decision aid, a qualitative study. *BMC Geriatrics*, 16: 1-8.

McDonald, K.E. and Keys, C.B. (2006). L'Arche: The successes of community, the challenges of empowerment in a faith-centered setting. *Journal of Religion, Disability & Health*, 9(4): 5-28.

Mcevoy, J., Machale, R. & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 56: 191-203.

Middleton, D. and Hewitt, H.L. (1999). Remembering as social practice: Identity and life story work in transitions of care for people with profound learning disabilities. *Narrative inquiry*, 9(1): 97-121.

Newberry, G., Martin, C. and Robbins, L. (2015). How do people with learning disabilities experience and make sense of the ageing process? *British Journal of Learning Disabilities*, 43: 285-292.

NICE (2018). Care and support of people growing older with learning disabilities. National Institute for Health Care Excellence.

Noddings, N. (1999). Response: Two concepts of caring. *Philosophy of Education Archive*, 36-39.

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage.

Power, A. and Bartlett, R. (2019). Ageing with a learning disability: Care and support in the context of austerity. *Social Science & Medicine*, 231: 55-61.

Rogers, C. (2016). *Intellectual Disability and Being Human: A care ethics model*, Routledge.

Scottish Consortium for Learning Disabilities. (2022). *My home, my community*.

Scottish Government (2013). The keys to life - Improving quality of life for people with learning disabilities. Edinburgh: The Scottish Government

Sheth, A.J., Kramer, J.M., Magasi, S., Heller, T., Nishida, A. and Hammel, J. (2021). "It's not the same without you:" Exploring the experience and perception of transition for people with intellectual disabilities and dementia. *British Journal of Learning Disabilities*, 49(3): 365-372.

Stephens, P. (2009). The nature of social pedagogy: an excursion in Norwegian territory. *Child & family social work*, 14: 343-351.

Todd, S., Bernal, L. J., Hunt, K., Brearley, S. and McCarron, M. (2019). Forgotten lives, hidden Deaths: people with ID living in and dying in non-ID care settings. *Journal of Intellectual Disability Research*, 63: 646-646.

Todd, S., Bernal, J., Shearn, J., Worth, R., Jones, E., Lowe, K., Madden, P., Barr, O., Forrester Jones, R. and Jarvis, P. (2020). Last months of life of people with intellectual disabilities: A UK population-based study of death and dying in intellectual disability community services. *Journal of Applied Research in Intellectual Disabilities*, 33(6): 1245-1258.

Truesdale, M. and Brown, M. (2017). People with learning disabilities in Scotland: 2017 health needs assessment update report. *Edinburgh: NHS Health Scotland*.

Tuffrey-Wijne, I., Finlayson, J., Bernal, J., Taggart, L., Lam, C. K. K. and Todd, S. (2020). Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A UK-wide survey of intellectual disability support staff. *Journal of Applied Research in Intellectual Disabilities*, 33(5): 927-938.

Tuffrey-Wijne, I. and Rose, T. (2017). Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study. *Journal of intellectual disability research*, 61: 727-736.

Watchman, K. (2016). Investigating the lived experience of people with down syndrome with dementia: Overcoming methodological and ethical challenges. *Journal of Policy and Practice in Intellectual Disabilities*, 13(2): 190-198.

Watchman, K. (2018). The intersectionality of intellectual disability and ageing. In *Ageing, Diversity and Equality: Social Justice Perspectives* (pp. 245-258). Routledge.

Webber, R., Bowers, B. and McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes. *Disability & Society*, 25: 657-671.

Welshman, J. and Walmsley, J. (2006). *Community care in perspective: Care, control and citizenship*, Springer.