“Forgetting familiar faces”: Staff perceptions of dementia in people with intellectual disabilities

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1 | INTRODUCTION

Dementia is characterised by a progressive deterioration in memory, cognitive capacity and impairments in everyday living skills. The prevalence in the general population is between 5 and 7% for people over 60 years (Prince et al., 2013), but as much as five times higher for people with an intellectual disability (Strydom, Chan, King, Hassiotis, & Livingstone, 2013). There is also a significant risk of “diagnostic overshadowing”: functional decline going unremarked and being treated as just part of the learning disability (Holland, 2000). Other common symptoms of dementia include mood disturbance, agitation, personality changes and other socially inappropriate behaviours. These symptoms are strongly associated with the stress of carers (Kales, Gitlin, & Lyketsos, 2015).

Attention has been drawn to the applicability of Tom Kitwood’s model of dementia care (Kitwood, 1993) and the challenges of applying it to services for people with intellectual disabilities (Cleary & Doody, 2017). Specifically, the aim to age in place (Scharlach, Graham, & Lehning, 2011) may be more difficult to achieve for adults with intellectual disabilities, when behaviours associated with dementia may trigger care providers to move the person to a more supported (and sometimes more restricted) environment. Although government policy in the United Kingdom has attempted to make services accessible to all citizen, including those who may have relied on specialist services, through measures such as “reasonable adjustments” (Equality Act, 2010), in Ireland, older adults with intellectual disability are still most likely to live with parents and family or within intellectual disabilities residential services (Doyle, Hourigan & Fanagan, 2017). The quality of these services is to some degree dependent on the skills and knowledge of the staff, in addition to the availability of resources. Lack of staff knowledge of dementia has been highlighted in previous studies (Furniss, Loverseed, Lippold, &
Dodd, 2012; Herron & Priest, 2013) as well as a lack of confidence among staff in dealing with dementia in services that had received no specific training on working with older adults with intellectual disabilities (Whitehouse, Chamberlain, & Tunna, 2000). The care needs of people with intellectual disabilities and dementia are significant (Furniss et al., 2012; McCallion, McCarron, & Force, 2005), and recent research has identified risks of comorbidities such as epilepsy and hearing problems which are more common in people intellectual disabilities and dementia (Mc Carron, McCallion, Reilly, & Mulryan, 2014).

Many studies have focused on the knowledge and skills of staff working with people with intellectual disabilities and dementia (Fahey-McCarthy, McCarron, Connaire, & McCallion, 2009); fewer have explored the emotional impact on staff (Wilkinson, Kerr, & Cunningham, 2005). In this study, we wanted to explore the experience of staff in supporting persons with intellectual disabilities and dementia, how they coped with the emotional impact of this work and to identify support needs for the staff, before offering dementia training to the staff group.

2 | METHOD

Focus groups are particularly useful for the creation and exploration of shared meaning relevant for staff teams (Beck, Trombetta, & Share, 1986). Two focus groups were moderated by an experienced clinical psychologist, who encouraged an open debate among the participants about their experiences of working with older adults with intellectual disabilities, their experiences of dementia and the diagnostic process, and the support needs of service users. Each focus group lasted approximately 1 hr. Two members of the research team drafted the moderator’s guide, following consultation with a steering group, and identical questions were asked in both focus group sessions. All participants were encouraged to contribute to each question, and the psychologist encouraged interaction between participants and the exploration of differing views. The groups were audio-recorded.

2.1 | Participants

A purposive sample was recruited from frontline staff members in both day and residential services, at various levels of training, from a large voluntary organisation that provides services to people with intellectual disabilities (Palinkas et al., 2015). Two focus groups were conducted with 18 staff, nine in each group. Participants completed a short demographic questionnaire. The mean age of participants was 40.8 years (ranging from 30 to 54 years). Typical of the care staff population, the sample was mainly female with one male participant. Fifty per cent of the participants had a degree (n = 9), primarily a nursing qualification, and 39% had completed a diploma (n = 7). Staff indicated that they had worked on average 15 years in the field of intellectual disability, with a range of 5 years to 35 years. Nearly three-quarters of the participants (72%, n = 13) worked in a day service with the remaining five staff working in a residential setting. The majority of staff (n = 16) had not received dementia training previously, with one staff member receiving dementia training specifically in the area of intellectual disability. Eighty-three per cent (n = 15) of the participating staff indicated that they were key workers for clients, suggesting strong familiarity with their clients.

2.1.1 | Data analysis

The digital audio files from the groups were transcribed verbatim. Data analysis was guided by principles of thematic analysis (Braun & Clarke, 2006) with two cycles of coding were used for data analysis (Miles, Huberman, & Saldaña, 2014). First, two of the authors did a naïve reading of the transcript to become familiar with the data set, checking the transcript for accuracy and then coding by hand, line by line. The two team members coded independently to foster interrater reliability. Each coder reviewed the focus group transcript to identify emerging keywords (or codes) that captured mutually exclusive dominant themes (Corbin & Strauss, 1990). Initial codes, categories and subsequent themes were analysed and compared for consistency. An inductive approach to thematic analysis meant that codes and themes were data-driven and did not necessarily fit within a preexisting coding frame (Braun & Clarke, 2006). Secondly, all three researchers reread the transcripts individually, and refined, collapsed and ordered the categories and themes during a series of face to face meetings. Discrepancies between the coders were generally resolved by consensus, following discussions and modification of coding category definitions, and dependability was achieved when the authors found that they had reached a consensus about the key themes to be reported (Lincoln & Guba, 1985).

2.1.2 | Ethical considerations

Ethical approval was obtained from the relevant local research committee, and the staff gave written, informed consent to participate in the study. Confidentiality was discussed with the participants when the group began. All procedures were performed in accordance with the 1964 Helsinki declaration and its later amendments.

3 | RESULTS

Participants’ perspectives on working with ageing clients with intellectual disabilities are organised into four main themes and categories.

3.1 | Theme 1: Recognising symptoms associated with dementia

This theme explores participants’ experiences of recognising symptoms associated with dementia in older adults with intellectual disability. The categories within this theme were grouped as follows: changes in behaviour, cognitive decline, emotional lability and decline in daily living skills and physical health.
3.1.1 | Changes in behaviour

Behavioural indicators of dementia were the predominant symptoms observed and discussed by participants. Changes in service users' behaviour over time were noted by participants, with before and after comparisons being common and disengagement from social activities was noted as an important symptom associated with dementia.

...sitting stuck...they would have always come straight back from the canteen...now they're just sitting there

...reluctance to interact anymore...their reluctance to go out

Participants reported that these behavioural deficits can be replaced by behavioural excesses such as fixations, stereotyped behaviours and engaging in old routines which are no longer applicable.

Repetitive movements now, circling, constantly circling and a little bit of aggression

Other behavioural excesses described were wandering, sleep disturbance and shouting out or vocalising.

3.1.2 | Cognitive decline

Frontal lobe-related symptoms such as forgetfulness and confusion were the most prominent cognitive deficits described by participants. The group discussed symptoms associated with agnosia in dementia; an impaired ability to process sensory information and recognise people (prosopagnosia).

Forgetfulness, forgetting familiar faces that they should have known

It took her a few days to remember who I was, days later she said my name...

One participant described visuoperceptual difficulties as another cognitive symptom noted.

...the disorientation between day and night

As a result of these visuoperceptual changes, some service users can experience what participants perceive to be hallucinations and/or distortions in their environment.

Seeing shadows, hearing voices

3.1.3 | Emotional lability

Participants reported some heightened emotional sensitivity and changes in mood.

Unexplained crying

...as the day progresses and she gets tired, she gets weepy

Participants described this change in emotional regulation as a loss of personality; service users respond differently to people...

You're losing people...they're just totally different

3.1.4 | Decline in daily living skills and physical health

The deterioration in service users' ability to perform activities of daily living was another symptom of dementia discussed by participants in both day and residential services. They described symptoms of apraxia.

Their personal care sometimes slips...

she'd only use a fork now...everything has to be mashed together

Participants discussed the implications of dementia on the service users' physical health.

...they don't drink as much, get dehydrated...

Neurological symptoms of dementia such as seizures, typically associated with more advanced stages of dementia, were highlighted.

A client recently that has had an epileptic seizure...his health has deteriorated...

3.2 | Theme 2: process of diagnosing dementia

This theme refers to the process of detecting dementia, the rapid decline in functioning and the referral pathway available to staff when seeking a diagnosis.

3.2.1 | Differential diagnosis: early detection

Participants spoke of the difficulty they initially encounter when determining if a change in behaviour is attributable to dementia, considering various possibilities when observing behaviour changes, such as mental health difficulties, bereavement and typical ageing.

It could be depression; someone could have died. A lot of things might have changed for someone if a parent has died, or family circumstances might have changed

Some participants reflected that they initially think of challenging behaviour when they notice a change in behaviour that is unusual for a client.
We think behaviour before we think dementia. I think we go down the behaviour route before we go down the dementia route.

Participants spoke of the challenges of diagnosing dementia with people with intellectual disabilities.

She started off presenting with mental health problems, well, what everyone thought was mental health problems... It came to light she had dementia but it was sidelined by mental health problems.

### 3.2.2 Progress of symptoms: rapidity of decline

In general, participants identified a pattern of decline once a diagnosis of dementia was made.

It seems to be following a pattern. People with Down's Syndrome seem to be following similar steps.

Participants showed an awareness of the risk factors of ageing, particularly those clients with Down's syndrome.

When you think of the people with Down Syndrome, they do age at a different rate.

A subtheme discussed by participants was the speed with which they observe the deterioration in clients.

the change has been quite rapid, you're talking 12 months, definitely 2 years, there's a huge change and suddenly we're regressing, and losing the skills.

### 3.2.3 Referral pathway

Participants discussed ways of highlighting their concerns by reporting their observations of client changes to family, nurses on duty or making referrals to psychology and psychiatry. Staff reported involving family members immediately.

As soon as you start seeing it, you would highlight it.

You'd be asking are they seeing something like it.

Participants of the focus group worked in both day and residential centres, and their discussion highlighted the different referral routes for clients in both settings. Participants observed that clients attending residential services have direct access to specific supports that staff can manage, while clients attending day services rely on family to refer to community services.

I suppose because they're day service, we'd contact their families and probably encourage families to seek some sort of medical advice.

As a result, participants generally felt that the referral pathway for clients attending residential services was more straightforward.

### 3.3 Theme 3: challenges of dementia for clients

This theme explores the challenges of dementia for service users, from participants' perspective. The findings within this theme were organised as follows: loss of independence, need for routine and familiar staff and ageing in place.

#### 3.3.1 Loss of independence

Participants described the difficulty service users face when their independence becomes limited as a result of a decline in their ability.

...they were so independent...they don't acknowledge or realise that they can't do what they used to and still go and do it.

Service users with dementia may not be able to recognise their need for more support and may be at risk of putting themselves in danger inadvertently. This higher level of monitoring can limit service users' opportunity to make personal choices.

They should have their choice but sometimes...we make the decisions for them.

...he has no freedom himself.

Overall, it was clear that participants found it difficult to reconcile service users' need for more support and assistance with their right to choose. The discussion highlighted participants' struggles with the concepts of normalisation and social role valorisation versus their duty of care to the service user.

#### 3.3.2 Need for routine and familiar staff

Participants believed that service users experiencing symptoms of dementia responded better and more positively to familiar staff in both day and residential services.

...that (familiarity) helps...especially if you're working somewhere with challenging behaviour, you're able to identify that this isn't a behaviour, that this is actually a change for them.

...it's very important to have regular, long term staff...they can see changes...changes can be very subtle.

Participants discussed the importance of maintaining a regular routine with service users as they age. Older service users rely on daily structure as a coping mechanism.

Routine is really important to them.
3.3.3 | Ageing in place

As older service users’ value routine and familiarity, participants emphasised the important role ageing in place plays in care provision.

...it (changing environment) goes against the whole principle, then, that you need to know your person.

...it’s awful that they can’t be maintained where they live...

However, participants recognised that the service users’ old environment may no longer be suitable for more complex, high support needs:

They’re ageing...their needs are changing

...at this stage now, this person is no longer safe for themselves within their environment

Many participants reported a lack of forward planning when changing a service user’s living environment due to symptoms of dementia. The service user is forced to cope with a sudden change in their living circumstances, conflicting with their need for familiarity and routine:

...she can no longer use the stairs and that’s awful. And she literally then had to leave her own house on that day...

...this individual has to be catapulted straightaway because we’re at crisis and they’re coming into a whole new team of people who are working with them who (don’t know them at all)

Participants empathised with how difficult this change can be for service users who can no longer stay in their current residence:

...you just expect them to go along with it. We mightn’t be so accepting if it was us, and our home was no longer there do you know...

3.4 | Theme 4: challenges of dementia for others

The challenges of dementia identified in this theme are grouped as follows: staff, peers and family.

3.4.1 | Challenges of dementia for staff

Participants acknowledged the challenges staff face when caring for people who are experiencing accelerated ageing and dementia. The challenges are twofold: the emotional reaction to seeing a person change and lose skills, and the burden of caring with limited resources, supporting a person who needs more supervision. When sharing their experiences, participants expressed the worry and sadness they feel as they watch a person lose their personality and skills.

I think it’s very upsetting for staff. These are people you’ve had great ‘caic’ with and then suddenly they don’t even remember you

It’s awful, it’s very hard, it’s sad, it’s very, very sad...you’re losing people, you’re losing their personality, they’re just totally different

It’s heart-breaking

Participants also shared the challenges of supporting people with dementia and intellectual disability with limited resources.

There’s a constant worry as well, especially if you are short-staffed

It’s very stressful on the staff that you keep highlighting it and even the working environment for the staff, for a client to get to that stage is actually quite stressful

The attitudes of participants demonstrated their motivation and commitment to supporting and caring for people with an intellectual disability despite the worries and challenges. Participants avail of peer support to manage the stresses of caring for people with dementia and intellectual disability.

I think one of the nice things is being able to work with staff who have worked there quite a while is to actually hear the nice stories about people you may not know from years ago. Just bits about them, it’s nice to be able to hear that

Given the difficulties encountered with limited supports available, participants noted important staff traits to manage the challenges, including the importance of patience and appropriate skills in working with difficulties associated with ageing.

3.4.2 | Challenges of dementia for peers

The impact of dementia on peers was acknowledged by participants in both focus groups, particularly the difficulty experienced by peers who often do not understand the changes in the relationship. Staff demonstrated an awareness of the need to spend more time with peers as they can be upset and annoyed with the person with dementia.

They get upset sometimes because they can’t understand it. They’re inclined to isolate them a little bit because if they’re shouting or if they’re doing behaviour that is causing staff to spend a lot of time, maybe fixing a problem, they’re inclined to change friendships
This mirrors the findings that people with intellectual disabilities living with those with dementia, who require one-to-one time with staff, experience this as a negative impact on their own access to staff (Forbat & Wilkinson, 2008).

Peers sometimes develop a helping role in the day centres.

*Their peers are kind of minding them, they notice that there is something wrong.*

*The clients are minding each other really.*

Overall, participants felt that the impact of dementia is emotionally upsetting for the service user’s peers and the resulting changes pose many challenges, including making changes to accommodate the person with dementia.

*It’s not fair on peers because they have no quality of life.*

### 3.4.3 | Challenges of dementia for family

Staff made frequent reference to the impact of dementia on the client’s family members. They recognised that discussing dementia can be very upsetting for families. It can be hard to process the information, particularly as many parents are elderly. Participants showed an awareness that the diagnosis can be frightening for families.

*For the families it is devastating. It’s like a walk into the unknown. There’s just not enough information out there.*

*I suppose they’ve tried for so long to make them as independent as they can be, and then the next thing...they are regressing.*

However, the participants also reported experience of families seeking support from staff due to the difficulties they encounter at home.

*Sometimes family will come to you yourselves because they’re in difficulty at home and they can’t cope any longer.*

While parents are the primary advocates for the person with intellectual disability, many of them are elderly. Participants frequently support extended family members such as siblings and cousins. They recognise the difficulty for siblings to take over the care.

*A sibling doesn’t know because if they haven’t actually been primarily the people who have been looking after them, it’s very difficult to come in then.*

*A lot of parents don’t want to have to pass it onto their siblings because it’s another burden on their child.*

### DISCUSSION

The participants in this study offered a vivid perspective on their experiences of working with adults with intellectual disabilities who have begun to develop dementia. They highlighted the importance of shared history with the person with an intellectual disability, in being able to understand, evaluate and make judgements about potential changes in behaviour and how these may reflect the early stages of the dementia process. Cognitive and behavioural changes, decline in the ability to engage in activities of daily living and emotional lability were all identified as key warning signs by the participants. Behavioural excesses and deficits are strongly associated with cognitive deterioration in the early stages of dementia (Adams & Oliver, 2010). Likewise, participants foregrounded the dilemma of interpreting challenging behaviour in the context of an older adult with intellectual disabilities. Challenging behaviours are common in adults with dementia (Bell, Turnbull, & Kidd, 2009), but they are also common in adults with intellectual disabilities. A total population study found 62% of adults with intellectual disabilities had a behaviour problem (e.g., self-injury, aggressive or destructive behaviours), and the intensity of those behaviours peaked in those over 70 years of age (Lundqvist, 2013). Therefore, any attempt to differentiate between challenging behaviours which may have environmental, social or behavioural aetiologies, from those that may indicate the early stages of dementia require careful consideration.

Participants highlighted the challenge of dementia for clients, their peers, the family and the staff themselves, reflecting on both the behavioural and support challenges, as well as the significant emotional impact that working with dementia brings. Some spoke about the dilemma of balancing normalisation practices with reduced choice making in the context of dementia care. Early work on developing dementia services for people with intellectual disabilities has highlighted the positive impact that carer knowledge has on dementia care (Cairns, Lamb, & Smith, 2011), and the importance of staff education and flexibility of service provision (Janicki, 2011). However, the emotional impact of dementia on peers has rarely been explored. Udell (1999) articulated the emotional impact of watching “dearly loved housemates die” and drew out some of the implications for service structure from the anguish this can cause. Forbat and Wilkinson (2008) highlighted the need to consult people with a learning disability who live with someone with dementia about their views and argued this should influence policy development. Some intervention projects have focused on the understanding of people with intellectual disabilities of the impact of dementia (Kerr & Innes, 2001), without necessarily addressing the emotional impact that the dementia of a housemate or friend may have on them as a person. An exception has been Lynggaard and Alexander (2004) in their group work with adults with intellectual disability living with others with dementia. Participants in our study highlighted how important they think developments and potential interventions would be in this area.

Many participants talked about the impact of working with a service user with dementia on them. This theme resonates with a point
made by Udell (1999) that staff are trained to think about their role in supporting learning and growth, but in dementia care, there needs to be a change in focus to maintaining skills and managing increasing dependence. However, participants in this study also highlighted the strong emotional impact that these changes have on them. This raises a number of issues about how organisations support staff engaged in emotionally taxing work, such as this, particularly in the light of the research on burnout in dementia care in mainstream older adult care (Duffy, Oyebode, & Allen, 2009).

Limitations of this study include that the participant age profile may be somewhat older than other service settings, and this may have an impact on perceptions of ageing and dementia. We did not control for experience of working with services users with dementia, and staff working in the older adult service for people with intellectual disabilities may have very different experiences.

5 | CONCLUSION

This study adds to the emerging literature on the challenge of recognising dementia processes in adults with intellectual disabilities, differentiating the causes of challenge behaviour as symptoms of dementia, understanding the impact of dementia on people with intellectual disabilities and elaborates on previous work examining the impact dementia has on the peers and support staff. The younger age of presentation of dementia in people with intellectual disabilities may make the emotional impact on peers, family and carers more profound than in other groups. Further research to investigate how to work with the emotional impact of dementia on others would be of great benefit.

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CONFLICT OF INTEREST

The authors have no conflict of interest.

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