

Exploring the lived experiences and care challenges of formal paid caregivers for people with intellectual disability and dementia

Introduction

People with intellectual disability are living longer due to advances in healthcare and services meeting their physical needs more effectively (Cleary & Doody, 2017). As people grow older, considerations of age related health and social support becomes increasingly critical. The ageing process increases the risk of developing age related health conditions, with dementia posing an additional risk (Victor, Williams, Kinnear, & Ryan, 2018).

The prevalence of dementia is greater in people with intellectual disability than in the general population, however the risk of developing dementia is further increased in people with Down's syndrome (Fortea et al., 2021; McCarron et al., 2017; Strydom et al., 2013; Strydom et al., 2010). Down's syndrome or chromosome 21 trisomy is both a genetic cause of intellectual disability and early onset dementia (Fortea et al., 2021). The association between Down's Syndrome and early onset dementia is partially explained by mutations in the gene for amyloid precursor protein (APP) located on chromosome 21. Alzheimer's Disease, a common form of dementia, is characterised by an accumulation of amyloid plaques. Amyloid plaques are aggregations of beta-amyloid protein that occur due to an imbalance in the processing of APP (O'Brien & Wong, 2011).

Triplication of the APP gene is sufficient to cause early onset Alzheimer's Disease (Doran et al., 2017). Exacerbating the increased prevalence and early onset, the progression of dementia is also more rapid amongst people with intellectual

disabilities in conjunction with age related health needs (Axmon et al., 2016; Strydom et al., 2013).

General physical health issues arising with dementia can often include a decline in mobility, increased susceptibility to infections, difficulties with eating and nutrition, and challenges in managing chronic conditions such as diabetes or cardiovascular disease (Haveman et al., 2010). Despite the increased prevalence rates, service provision has been slow to respond to the changing health and care needs and the increased caregiving responsibilities (Chapman, Lacey, & Jervis, 2018; McCarron, McCallion, Reilly, & Mulryan, 2014).

Caregivers often report many complexities in caring for people with intellectual disabilities following a diagnosis of dementia (Furniss, Loverseed, Lippold, & Dodd, 2012). As the disease progresses, the challenges of caring for a person with dementia increase, underlining the need for more responsive and tailored support (Perera & Standen, 2014, McLaughlin & Jones, 2011, Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014).

Early signs of dementia are often more subtle, and identifying dementia symptoms can be particularly challenging in individuals with intellectual disability (Cleary & Doody, 2017). Behavioural changes can serve as key indicators of cognitive decline in this population, although they can be easily overlooked or misinterpreted, resulting in diagnostic overshadowing. Diagnostic overshadowing is characterised by the assumption that a specific behaviour presentation is associated with a person's intellectual disability, without health and care professionals investigating any other possible causes for change in presentation (Jamieson & Mason, 2019; Krinsky-

McHale & Silverman, 2013). The consequences of late diagnosis of dementia can include, delays in a person receiving anti-dementia medication (acetylcholinesterase inhibitors, often shortened to 'cholinesterase inhibitors') and NMDA receptor antagonists) (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Sheerin et al., 2020) or other post diagnostic non-pharmacological interventions aimed at slowing progression (Acton, Jaydeokar, & Jones, 2023a; MacDonald & Summers, 2020).

Despite the increased prevalence rates, service provision has been slow to respond to the changing needs and increased caring responsibilities (Chapman, Lacey, & Jervis, 2018; McCarron, McCallion, Reilly, & Mulryan, 2014). Caregivers often report many complexities in caring for people with intellectual disabilities following a diagnosis of dementia (Furniss, Loveseed, Lippold, & Dodd, 2012). As the disease progresses, the challenges of caring for a person with dementia increase, underlining the need for more responsive and tailored support (Perera & Standen, 2014, McLaughlin & Jones, 2011, Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014).

In the United Kingdom, the National Institute for Health and Care Excellence (2018) recommended guidelines and emphasised the unique challenges of growing older with intellectual disability. However, despite these recommendations, several studies have highlighted the lack of available post diagnostic supports aimed at assisting caregivers in managing the complex changes associated with caring for such individuals (Acton, Jaydeokar, & Jones, 2023b). These challenges encompass a range of factors, including navigating behavioural changes, accessing appropriate medical care, ensuring social inclusion, and addressing the evolving needs of aging individuals with intellectual disabilities. The absence of tailored support services exacerbates the burden on caregivers and can lead to increased stress and burnout.

The recognised lack of caregiver knowledge and the increased burden in caring for a person with dementia has been acknowledged as factors contributing to this phenomenon as highlighted in various studies (Cleary & Doody, 2017; Furniss, Loverseed, Dodd, & Lippold, 2012; Herron, Priest, & Read, 2020).

We wanted to understand the challenges in caring for a person with intellectual disability and the barriers of obtaining a diagnosis of dementia. Therefore, we explored the lived experiences of formal caregivers in order to understand the barriers of obtaining a dementia diagnosis, the care challenges and necessary adjustments required in caregiving. Understanding the emotional impact on caregivers will help to provide a comprehensive understanding of the multifaceted aspects involved in providing care to people with intellectual disability and dementia.

Method

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2022) was used to allow a greater understanding of formal caregivers lived experience of caring for a person with intellectual disability and dementia. The principle objective of IPA is to examine how people make sense of their experiences and connect meanings they use to interpret them (Smith et al., 2022). IPA provides a framework for in depth exploration of the individuals experiences (Holloway & Galvin, 2016). The lived experience of caring for a person with dementia requires an in-depth exploration to understand the complex and multifaceted aspects of the disease and the effect this has on those who provide care. IPA is particularly useful in stimulating discussion to understand the nuances in individual stories and how people make sense of caring for a person with intellectual disability and dementia (Lord, 2015). This approach was

used to enable a deeper understanding of the diverse range of perspectives and experiences within the context of caring for a person with dementia.

Procedure

Participants were recruited to the study from private sector organisations providing residential and supported living services within North West England. Purposive Sampling was used, whereby managers of care providers were identified from NHS community intellectual disability services and approached by clinicians from the memory service. Information about the study was provided to formal caregivers by members of the community team. Participants who requested further information about the study were provided an opportunity to discuss participation in the study with the lead member of the research team (DA).

Participants were required to have prior formal caregiver experience, specifically providing care to a person with intellectual disability and dementia. All participants in the study who agreed to take part in the individual interviews were asked to sign a consent form.

Participants

A total of 14 participants attended one individual interview session. Demographic information of formal caregivers is provided in table 1 (insert table).

A topic guide was created based on a focused review of peer-reviewed literature. Initially, the principal author conducted this review, which included both peer-reviewed literature, national policy and clinical guidelines. Subsequently, the findings of this review were deliberated upon by all authors. Through this discussion, a topic guide for the interviews was formulated, encompassing questions regarding the experiences of providing care to individuals with intellectual disability and dementia.

Confidentiality and data protection

All data collected by the NHS Trust was treated with utmost confidentiality.

Information was only accessed by authorised personnel for research purposes.

Personal data underwent rigorous protection measures, including encryption and restricted access, ensuring the preservation of data integrity and privacy. Participants were assured of their privacy rights throughout the data handling process.

Ethical Approval

The study received approval from the Research Ethics Committee and Health Research Authority (22/SC/0230) through the Integrated Research Application System (IRAS ID: 310648) in August 2022.

Analysis

IPA was used for data analysis of transcribed individual interviews. This was completed manually and the data was analysed using the seven step process of IPA (Smith et al., 2022). The analysis commenced with reading and re-reading transcripts of the individual interviews. A detailed analysis of each individual transcript was completed and coded before moving onto the next interview transcript. Coding was an iterative process with discussion between the researcher (DA) and a second researcher (SLJ) at each stage of the inductive cycle. To minimise interpretation bias both the researchers (DA & SLJ) completed the initial coding independently. The process allowed for examination of the researchers own interpretation to ensure this was consistent with the second researchers understanding and clarify that data was in agreement with analytical interpretations made.

Experimental statements were subsequently formulated by initial noting of key points and frequently referring to the original text. This process promoted the accuracy and fidelity of the experimental statements and capturing the essence of the data.

Personal themes were grouped together to search for connections and organised into a table of experimental themes. Personal experimental themes were developed through analysis and meaning to each individual (Smith et al., 2022). This process was completed separately for each of the interviews. Personal experimental statements that contained a similar meaning were manually stacked to assist data management and cluster statements.

Findings

The set of grouped experimental themes generated four super-ordinate themes and 13 sub-ordinate linked themes highlighting the unique experience of caring for a person with intellectual disability and dementia. Super-ordinate themes were; (1) recognising early indicators and diagnosis, (2) post diagnostic support, (3) coping with change and (4) need for future development. Findings are summarised and presented in the following categories supported with transcript data used to illustrate key insights.

Recognising early indicators and diagnosis

Identifying signs of cognitive decline

Formal caregivers reported the difficulty they experienced identifying the subtle signs and symptoms of dementia in the person they provided care toward. Caregivers recounted a sense of uncertainty when observing changes in the person:

'We first thought the decline in skills was part of his Intellectual disability and getting old, but we had to help him more and more every day. After a while we thought something is just not right' (P3).

Whilst reflecting on the length of time taken before seeking professional support to investigate functional changes, one participant explained:

'Thinking on the last seven years the changes were massive. She used to go out on the bus on her own, but started to get lost coming home. We didn't really think at the time her getting lost coming home was actually part of her forgetting where she lived. Little did we realise it was the early stages of dementia, we just put it down to her being a bit stressed' (P8).

This pattern continued with other participants reporting similar difficulties. Formal caregivers identified limited dementia awareness was a key factor in supporting them to identify signs of cognitive decline:

So I'd say it was for five years, maybe longer before we realised the changes in mood and personality were caused by dementia (P13).

'We had noticed a decline for a while, I would say a few years. It's the little things we started to notice. She would seem to get confused when in the home, not seem to know where she was' (P14).

Identifying the signs of dementia can be more difficult in people with intellectual disability. The early signs of dementia are often more subtle, which was reflected in participants experiences:

'We didn't know what we were really looking for, we notice things had changed, but did not understand why and what we do about it. What would help is a tool and training, to help us spot the early signs' (P6).

'We need a simple checklist or tool for carers to help recognise the early signs of cognitive decline, so people can get an earlier diagnosis'(P13).

Formal caregiver's recognised that a lack of dementia awareness was a key factor in their ability to identify signs of dementia in people with intellectual disability.

Therefore, fostering education and equipping caregivers with effective tools to identify early and subtle signs of cognitive decline was considered a priority area from the data.

Sense of blame

Caregivers felt a considerable amount of personal responsibility for people they supported receiving late diagnosis, often attributing a proportion of blame towards themselves due to this apparent lack of dementia awareness:

'If I had only known more about dementia, I should have known more as a carer and got her help sooner' (P7).

'I just didn't spot the signs, it's obvious now, he was getting lost when coming back from the shops and going into other people's rooms. I blame myself for not getting help sooner. His decline has been so fast he's not recognisable anymore' (P5).

Caregivers considered late diagnosis a significant factor when reflecting on their feelings of not responding earlier when noticing functional changes. This was evident in one particular caregiver where a rapid progression of dementia and subsequent decline had occurred:

'I often think back and blame myself, if only had I talked to the Doctor about some of the changes, she could have received a diagnosis and medication earlier to slow the progression' (P11).

Formal caregivers reflected on the deterioration in activity of daily living skills and how they had been slow to react, initially associating decline as a natural ageing process for people with intellectual disability. Feeling of shame and guilt amongst caregivers featured highly for not recognising features of the decline earlier. This in turn only served to compound blame in the care offered.

Obtaining a diagnosis

The difficulty obtaining a diagnosis of dementia provoked a sense of frustration in many of the caregivers. Several caregivers reported when they had raised concerns these were often disregarded by healthcare professionals. One caregiver explained:

'I believe people are quick to fob off us carers. Both General Practitioners and specialist services tend to attribute early signs of dementia to getting older and don't see or listen to people who provide care' (P2).

Formal caregivers consistently highlighted the challenges accessing professional support. This became apparent as caregivers started to recognise differences in an individual's daily presentation. However, their concerns were not always acknowledged, despite proactive efforts. One caregiver vividly captures the ambivalence felt by many participants via their subjective experiences:

'We repeatedly expressed our concerns to the doctor. We persisted for nearly a year highlighting her cognitive decline to the GP, sometimes visiting weekly. Finally after several months they referred her to the learning disability team, leading to a dementia diagnosis' (P6).

Many formal caregivers shared their experiences with medical professionals as a first port of call. They noted professionals frequently associated behavioural changes with intellectual disability, disregarding concerns even when caregivers explained that the presentation was uncharacteristic or relatively new change for the person.

Liaising with professionals

Caregivers expressed frustration when discussing professionals, sensing a general lack of clinical responsiveness when expressing concerns about changes in a person's presentation:

'I think there is a general barrier to getting a diagnosis of dementia for people with a learning disability' (P1).

'Remembering the whole system of obtaining support just infuriates me now. During the early stages, it felt like none of the Doctors or nurses truly listened to us. They constantly put changes in his behaviour to his learning disability, despite us repeatedly expressing concerns and disagreement. It seemed to fall on deaf ears' (P12).

Behaviour and personality changes in older adults with intellectual disability can indicate early signs of dementia. However, formal caregivers noted a general reluctance from professionals to investigate possible causes for changes in mood and personality. These changes were often attributed to behaviour of challenge and associated with a person's intellectual disability.

'General Practitioners and healthcare professional often focus solely on a person's only disability, attributing everything to the person's behaviour' (P3).

Formal caregivers expressed their concerns regarding diagnostic overshadowing, describing this as a significant factor for people receiving a diagnosis of dementia.

This was attributable to a lack of intellectual disability awareness training particularly, within General Practice medicine from data evidence. The following extract captures a formal caregivers own personal feelings:

‘General Practitioners are the front door to healthcare services, but if they can’t recognise what we tell them as being a decline in cognitive and adaptive functioning, then what hope is there in people receiving timely diagnosis and treatments for dementia’ (P13).

Several caregivers expressed similar frustrations noting that they had repeatedly communicated their concerns to a person’s GP, particularly as functional decline had progressed. However, formal caregivers experienced frustration when referrals to specialist services resulted in variations in clinical knowledge about dementia:

‘It depend on who picks up the referral from the community team, some have a lot of knowledge, others a lot less’ (P5).

There was a prevailing ambivalence amongst formal caregivers towards healthcare professionals. Caregivers frequently articulated the challenges in communicating with healthcare professionals, attributing the notable impact diagnostic overshadowing had on people receiving a timely diagnosis of dementia:

‘Accessing the healthcare system and professionals is not easy. Once you manage to see a professional the diagnostic process is very long. I think it took over 18 months to get a diagnosis’ (P6).

Caregivers displayed a noticeable lack of confidence in their ability to identify signs of dementia and distinguish them from symptoms arising from a person’s intellectual

disability. Consequently, the effective communication of these signs and symptoms was considered equally pivotal in enabling an accurate dementia diagnosis.

Post diagnostic support

Limited available information

The aim of post diagnostic support should be to provide information that assists people navigate the daily challenges following a dementia diagnosis. However, caregivers acknowledged general lack of accessible post-diagnostic support from specialist services. The general consensus amongst caregivers was they were often 'just left to cope' (P5). Several caregivers perceived a gap in service provision, identifying a pressing need for improvements.

Reports from formal caregivers indicated a sparsity of available information on dementia and intellectual disability, with none of the caregivers having accessed any dementia training or educational resources. When identifying aspects requiring post diagnostic improvement, caregivers raised concerns on the absence of dementia related information from clinical services. They considered the need for future service provision to include widespread dissemination of dementia information and training support within the care sector:

'Post diagnostically, it would have been of benefit for us carers to receive a lot more information, tell us what we can do, just the basics really. Leaflets and more information resources after diagnosis is crucial in assisting us provide care' (P6).

'Receiving post diagnostic information would have been valuable as it would have helped us keep him preserve and maintain his skills. Subsequently, I have used my own initiative to obtain information about dementia. It's really frustrating to think no one provided us with any information to help us care for him' (P9).

Conversely, when formal caregivers did receive information, its quality was deemed 'not fit for purpose' (P1). Moreover, the information often focused narrowly on specific areas of concern, such as dysphasia guidance or advice on moving and handling. This approach was deemed limited, as it neglected to encompass a broader range of essential areas, including understanding the illness, symptom management, psychosocial interventions and identifying available resources for monitoring an individual's physical health.

Professional support

It is important to recognise that formal caregivers identified the demands placed on clinical services caused by the impact of COVID-19 and the limited availability of clinical support during this period. However, whilst reflecting on their personal experiences post COVID-19, one caregiver highlighted the challenges experienced in obtaining an outpatient review:

'Accessing and receiving support from health services has proven difficult. I know COVID has played a part, but she's only just now seeing the psychiatrist after 12 months since diagnosis. We haven't had any review of her healthcare needs or any offer of support' (P1).

Formal caregivers widely acknowledged the general accessibility of specialist dementia services. However, specialist services were perceived as reactive, offering limited proactive support. Notably, intellectual disability services provided effective support when requested by caregivers. Although the repeated assessments resulted in additional waiting times, heightening frustration amongst caregivers due to subsequent delays in post diagnostic support.

There was an overarching ambivalence towards specialist intellectual disability services. The perceived quality of service delivery was contingent on the expertise of the professional involved, with one caregiver noting:

'It often depends on who completes the assessment, as professionals from different disciplines don't always have enough knowledge of dementia to provide us with adequate advice' (P8).

Conversely, some formal caregivers expressed satisfaction with the support received for these services feeling well supported by services, emphasising the positive influence of professional guidance on addressing challenges in caregiving. In particular, managing associated behavioural incidents.

Coping with change

Managing emotions

The diagnosis of dementia clearly had an emotional impact on formal caregivers. As they reflected on their personal experiences, caregivers highlighted the challenges encountered in sustaining ongoing support, especially as the disease progressed. A pervasive sense of loss permeated amongst caregivers, coupled with emotional strains in coping with the cognitive and physical deterioration:

'It's an awful disease, witnessing the deterioration is increasingly difficult. I struggle every day and often get upset because it's so hard to watch, to think what he was like and to see him now, it's absolutely heart breaking' (P4).

'I just muddle through day by day. Each day I learn something new, but its difficulty seeing him decline. I notice his decline every time I'm back in work and it's so difficult and upsetting to watch' (P9).

Although, many formal caregivers adopted a positive outlook, one participant described how the initial shock of diagnosis created a paternalistic outlook amongst the care team:

'I noticed early following her diagnosis, we all started to do everything for her, I would say we deskilled her out of affection and care. We struggled after diagnosis as we felt the need to nurture and protect her' (P3).

Fears for the future

A common theme among caregivers indicated the need for periods of self-reflection. Although, caregivers often reflected positively, they expressed concerns and anxiety about the future, particularly regarding their ongoing capacity to provide care as the disease progresses:

'I am frightened about the future and continuing to be able to look after him, this is his home, but we do have to think of the other people living here' (P4).

'It's a worry watching him decline, you don't see the dementia then all of a sudden you see the decline and it's so upsetting. I often cry thinking about how long we can continue to safely look after him' (P2).

Although, formal caregivers demonstrated their commitment to keep the person in their own home for as long as possible, they were acutely aware of the challenges inherent with this commitment. Openly discussing their apprehensions, caregivers expressed fear regarding their ability to meet the person's future care needs. This included the daunting prospect of potentially making challenging decision in the future, such as relocating the person to an older adult residence. Despite this emotional weight, the topic was something every formal caregiver had started to seriously contemplate:

'This is their home; we'll do everything to keep him here'. We've begun making changes to the environment to keep him safe and thinking about the suitability of the current placement' (P3).

'We are an important part of her life and she's integral to ours'. But I'm uncertain how much longer we can adequately care for her; I find this very upsetting to say' (P13).

Some caregivers expressed concern that the suitability of environments and increasing needs posed challenges for providing long-term care. However, the commitment and flexibility in care approach demonstrated a readiness to adapt the home environment and change care practices, aiming to accommodate the person's changing needs.

Learning to cope

Self-guided learning and peer support emerged as the most frequently cited approach of acquiring post diagnostic knowledge. Caregivers established systems for sharing information, finding this method particularly beneficial in enhancing dementia awareness within the staff team. A caregiver emphasised the need to 'find our own solutions to overcome care challenges and learn to cope' (P10).

This sentiment was repeated by numerous caregivers who frequently found themselves having to improvise and modify care strategies based on individual's lived experiences. Two formal caregivers shared:

'I was winging it in the early days, but because I knew her, I was learning with her. There were things I could transfer from my own family experiences of dementia to share with my colleagues' (P13).

'Helping each other was key, by passing on what worked and didn't work in managing challenging situations, helped us manage and cope with many of the changes' (P8).

Caregivers adopted a self-directed learning approach, deeming the adapting approaches as 'trial and error' and emphasising the value of 'working together as a team help us change how we managed care situations' (P4). Caregivers derived considerable support from ongoing communicating with each other throughout the person's dementia journey using platforms like WhatsApp for assistance and idea exchange: 'we use WhatsApp to not only support each other, but to share ideas of how to better manage situations' (P7). Additional strategies included communication diaries, staff meetings and debriefing sessions, particularly following challenging situations.

Acknowledgement of feelings of isolation were prevalent, with caregiver frequently working alone in their care provision. To help alleviate feelings of isolation many of the caregivers established a variety of ad hoc systems to mutually support one another in addressing the person's needs. These systems were considered integral in supporting formal caregivers in coping with the emotional impact of observing the cognitive decline of the person they care for. At this stage it is imperative that caregivers are supported and educated in the challenging roles they undertake to provide better care for the person with dementia, and their family network.

Finding solutions

A key aspect of formal caregivers' experiences of caring for a person with dementia was the commitment to discovering effective solutions to navigate care challenges.

The resilience caregivers demonstrated towards overcoming care management difficulties, highlighted their commitment to delivering high-quality care:

'We found by talking to each other, having regular staff meetings to discuss what works best to manage certain situations really helps in providing day-to-day support' (P11).

Formal caregivers recognised that adopting a self-directed learning approach improved their own knowledge, often arising from the limited information provided post diagnosis:

'I always look things up on the internet to help me provide care, but it's still very much trial and error (P3).

'Understanding more about dementia can change people's outlook to be more positive. Sharing knowledge on what worked and what didn't prove valuable in finding solution to some care challenges' (P5).

This approach provided a sense of unity amongst staff teams. Caregivers reported feeling closer with colleagues, fostering an environment where ideas and solutions could be openly discussed. Similarly, one caregiver described forming meaningful connections, enhancing their confidence in delivering person-centred dementia care.

Making memories

The care and compassion demonstrated by all formal caregivers was evident in all individual interviews, consistently emerging as a repeated theme in discussions about the future:

'Always remember the good times and focus on the positives' (P1).

Caregivers generally displayed optimism in their approach to future planning, showing empathy towards the evolving needs of people they cared for. There was a cumulative sense of optimism for the future, aiming to enable the person to continue to live the fullest life possible:

'My aim is to keep making memories; doing the things we both love doing together and helping him enjoy life (P4).

'It's about making the best of the time you have with the person, before things start to decline' (P2).

There was a sense of acknowledging the person they cared for had started to decline. However, there remained a positive outlook towards remembering past events and shared experiences:

'We created a memory book after his dementia diagnosis, filled with pictures of family friends and our trips. I love sitting with him, looking through the pages and reminiscing about the past' (P5).

Need for future development

The value of professional support

Regarding future development, there was an overarching emphasis placed on the pivotal role intellectual disability professionals have in guiding caregivers to improve care practices:

'Professionals, like nurses and psychologists, have valuable knowledge that should be shared with caregivers to enhance our support plans to enable improved care quality' (P11).

Some caregivers reported limited engagement with specialist services following diagnosis, only seeking support when they felt overwhelmed. The primary reason for limited post diagnostic engagement was attributed to limited understanding and a lack of information about dementia. When support was obtained from services caregivers valued the collaborative approach of the multi-disciplinary team approach to support changes to care strategies:

‘Professionals played a crucial role in helping us adapt our approaches to respond to the changing needs, which has improved our management of her dementia and her quality of life’ (P13).

‘During a challenging period of dementia progression, we waited a long time before getting support from healthcare professionals, perhaps from our lack of knowledge. Once we engaged with them, their advice was invaluable and significantly helped us in managing his dementia’ (P9).

Caregivers noted that receiving guidance from specialist intellectual disability services, positively contributed towards their ability to provide person centred dementia care. Furthermore, the support provided by these services played a crucial role in providing emotional support to the caregivers themselves.

Training and education

Formal caregivers shared their experiences in caring for a person with intellectual disability and dementia. The main aspect of this approach was to gain valuable insight from people with lived experience to transfer key learning into the development of educational resources to improve care delivery. The topic was emotive, promoting caregivers to freely share personal experiences as a catalyst to transfer knowledge to identify areas of future training development.

Formal caregivers emphasised the general lack of available dementia information and acknowledged the need for bespoke dementia education:

'If I could turn back time, we needed education. Dementia education, especially in the early stages would have helped us a lot. It would have helped our caregiving, improved our understanding of the disease and guided us towards post diagnostic interventions to engage him. I still think training will help us now' (P7).

'To say the need for dementia education amongst us carers is a huge need, is an understatement. Simply put, training is crucial for improved dementia care and providing strategies for addressing the challenges and engagement' (P13).

Formal caregivers often independently pursued dementia training months after diagnosis. The reported benefit emphasised how improved knowledge positively impacted and improved care practices.

'We received dementia training a year after diagnosis. It was so enlightening, it changed how we managed situations, how we communicated, how we engaged her in meaningful activities and responded to her needs' (P11).

However, there were clear variations in the quality of training, highlighted by a caregiver:

'I attended dementia training which was all about behaviour not so much about dementia. On reflection, it was all about behaviour management. I think they used the word dementia three times' (P1).

Caregivers suggested that future education and resource should offer practical strategies for behavioural management. They also stressed the importance of guidance on minimising environmental risks and maintaining a consistent approach:

'It really helps to keep things the same and keeping people busy. Develop a daily routine and try stick to the same routine as much as possible' (P7).

Recognising the need for information on physical health, there was a general consensus that post diagnostic stimulation activities were essential to promote person-centred care practices.

Improving physical health awareness

People with intellectual disability often struggle to communicate symptoms of pain as dementia progresses. Caregivers have an important role identifying pain and physical distress. Formal caregivers emphasised their pivotal role in ensuring the person is supported to receive good quality healthcare. However, a key finding of this study is the limited awareness of the physical health needs of people with intellectual disability.

'He can't communicate he's feeling unwell anymore. We lack training and knowledge about his physical wellbeing' (P3).

'I have limited knowledge of physical health, difficulties with communication is a big factor, as people can't always tell you they are unwell, so often things don't get treated quickly enough' (P9).

The lack of physical health knowledge amongst formal caregivers was a repeated theme. Awareness or use of physical health surveillance tools to monitor a person's daily health and alert caregivers to changes in health status was limited. When caregivers were provided with information about available monitoring tools, the value of resources was clearly recognised:

'We will be using these tools to monitor his physical health. I can see how these will help us recognise changes and direct us to seek faster medical support' (P11).

'Identifying pain in someone with limited communication is crucial. Who wants to live in pain? Carers are often not told about available tools for monitoring physical health to direct our response when someone is unwell' (P12).

Moreover, caregivers recognised the correlation between progressing dementia and decline in communication skills was a key factor in recognising pain and distress in people with intellectual disability. One caregiver expressed their uncertainty stating:

'She can't communicate pain or illness anymore, we do feel lost at times and need something to help us recognise ill-health, so we can get medical help straight away' (P8).

Confidence in recognising changes in a person's behaviour as potential indicators of physical issues was lacking. One caregiver describes their personal experience:

'He became very aggressive which we thought was due to his dementia. However, something was just not right, we didn't know what was wrong, it went on for weeks. We eventually went to the GP and he was treated for a urine infection. Basic education could stop unnecessary suffering' (P7).

Caregivers learned from experience, improving their response to physical health needs. They acknowledged a lack of awareness and confidence impacting on obtaining appropriate medical support. There was a consensus that training should be provided which includes resources, including guidance on using health monitoring tools. Information on common health conditions was considered essential towards raising awareness and prompt caregivers to effectively respond to a person's healthcare needs.

Discussion

This study explored the lived experience of fourteen formal caregivers of people with intellectual disability and dementia. Their reports highlight the uncertainties of a dementia diagnosis and the challenges in providing future care. The aim was to capture valuable insights into caregiver's experiences and difficulties following a dementia diagnosis. Caregivers openly shared their individual experiences, with similar finding from other studies that emphasised limited available resources for improving dementia care practices (Carling-Jenkins, Bigby, & Iacono, 2014; McLaughlin & Jones, 2011).

The difficulty formal caregivers had in recognising the early signs of cognitive decline in the absence of any training or identification tools is a key area to focus development. Without identifying the signs, the chances of early diagnosis are minimal, potentially leading to delayed interventions and a lack of appropriate support for people experiencing cognitive challenges.

The development of an early signs detection tool aiding caregivers in identifying early signs of cognitive decline holds the potential to not only support early diagnosis but also enhance the well-being of people with intellectual disability. This imperative lies in the need to develop practical and accessible resources such as the aforementioned detection tool, which can empower caregivers to more effectively recognise the subtle signs of cognitive decline.

An administrative screening tool developed by the National Task Group on Intellectual Disabilities and Dementia for Early Detection and Screen for Dementia (NTG-EDSD) enables caregivers to more effectively document functional changes related to dementia in people with intellectual disability (Esralew, Janicki, DiSipio,

Jokinen, & Keller, 2013). This proactive approach aligns with the broader ambition of facilitating early interventions and promoting more timely access to care and support services (National Institute for Health and Care Excellence, 2018).

Caregivers' understanding of dementia varied. However, when dementia was suspected, there were often barriers towards obtaining a diagnosis. The response from services and professionals to the concerns of caregivers encompassed three key factors; the attitudes of professionals towards caregivers, professionals own lack of knowledge and skills, and a significant emphasis towards positive behavioural support with resultant diagnostic overshadowing. Addressing these issues requires a focussed approach to find solutions. For instance, the implementation of dementia informed care training for all professionals, including local authority staff, could significantly contribute to enhancing their understanding (Herron & Priest, 2013; Krinsky-McHale & Silverman, 2013; Strydom et al., 2010). This dementia training could not only foster a more empathetic and supportive attitude among professionals, but also provide them with the necessary knowledge and skills to understand the complexities of providing dementia care.

Comprehensive dementia care should extend beyond individualised person-centred care by including significant individuals within the person's support system or circle of support in the care planning process. This crucial aspect is currently underemphasised, leading to a lack of sensitivity among professionals to the needs of caregivers. The widespread mindset often confines the issues solely to the person with dementia, thus neglecting the pivotal role of formal caregivers in the care process. To address this gap, it is essential to incorporate solutions into care plans which recognise and detail how the needs of caregivers will be met, whether through direct support or appropriate signposting. Additionally, there is considerable potential

in establishing support groups facilitated by third-sector organisations, fostering a sense of community and shared experience among caregivers.

Educational resources are needed to enhance caregivers' awareness and understanding of aging and dementia in people with intellectual disability. Providing education to caregivers is essential to improve the confidence of all caregivers to deliver person centred aged care. Therefore, it is vital that caregivers are provided with more adequate awareness to both inform earlier diagnosis and enhance the well-being of older people with intellectual disability. A key area of prioritisation is the development of education and resources in aging and dementia. Empowering caregivers through education will enhance their confidence in providing person centred aged care.

The difficulties encountered by formal caregivers in recognising, addressing, and responding to the physical health needs of people is a particular area of concern. Alarming is the limited allocated resources towards enhancing caregiver knowledge of the physical health needs of people with intellectual disability (Totsika, Hastings, & Vagenas, 2017). Evidence suggests this knowledge gap impacts on the confidence of formal caregivers in supporting people with intellectual disability in accessing and receiving healthcare (Webber, Bowers, & Bigby, 2016). Therefore, enhancing caregiver's knowledge through education is essential to meet the needs of an ageing population to support the delivery of high quality care and reduce health inequalities in this population group.

It's essential to stress that conventional resource packs, paper leaflets, and flyers are insufficient; a more dynamic and interactive approach is imperative for truly effective caregiver support and education.

Conclusion

The experiences of caring for a person with intellectual disability and dementia described by formal caregivers highlights the challenges in providing individualised physical, emotional and behavioural supportive care. The lack of knowledge of the physical health needs of people with intellectual disability and dementia amongst caregivers emphasises that improvements are needed in education and resources to improve outcomes and wellbeing. Resources to more effectively identify the early signs of dementia are needed and are a key area for future investigation that requires urgent attention in caregiver training programmes.

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