

Supporting people with an intellectual disability and dementia: A constructivist grounded theory study exploring care providers' views and experiences in the UK

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Abstract

Background: There is a need to better understand the experiences and support needs of paid and family carers of people with an intellectual disability and dementia, and the role of Intellectual Disability Dementia Care Pathways (IDDCCPs). This study explored the experiences of carers, and IDDCCPs and other support structures within those experiences.

Methods: A constructivist grounded theory methodology was implemented. Data were obtained through 23 semi-structured interviews with two family carers, eight paid carers and eight healthcare professionals.

Findings: The study's theory produced five interrelated categories: Impact of Dementia, Challenging the Diagnosis Process, Continuum of Support, Continuity and Continuum of Understanding.

Conclusions: Findings have demonstrated the importance of planning and supporting carers' holistic needs; the role of an IDDCCP in the post-diagnostic support (or lack of it) for carers; and the importance of a timely diagnosis of dementia. Recommendations for practice are offered.

KEYWORDS

care, carer, dementia, intellectual disability, care pathway, qualitative research

1 | INTRODUCTION

People with an intellectual disability have experienced increased life expectancy (Emerson, Glover, Hatton, & Wolstenholme, 2014), resulting in changing healthcare needs, including age-related mental health conditions, such as dementia (Whitehouse, Chamberlain, & Tunna, 2000).

Dementia is an umbrella term used to describe a group of symptoms and includes a wide range of diseases and disorders of the brain. Although with differing fundamental causes, they all result in

progressively deteriorating intellectual functioning and loss of daily skills (Prasher, 2005). Nevertheless, how the dementia is experienced is informed by a combination of neurological impairment, psychological factors such as health and individual psychology and socio-environmental factors (Kitwood, 1997). In almost all aspects, dementia presents in a similar fashion for people with an intellectual disability as for those without; however, two striking differences are that people with an intellectual disability, particularly people with Down syndrome, are at an increased risk of dementia, which is likely to have an earlier onset (Strydom, Chan, King, Hassiotis, & Livingston, 2013).

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Paid carers are formal caregivers employed to support people with an intellectual disability and dementia, often in group residential settings; whilst family carers are informal caregivers who support a member of their family, unpaid, usually in the home. Carers are essential in facilitating a good quality of life for the people they support with an intellectual disability and dementia (Cleary & Doodly, 2017; Watchman, 2014), making it important to understand carers' holistic needs.

A small but growing body of empirical research has provided some insight into how carers experience supporting the changing needs and increasing dependency of someone with an intellectual disability and dementia; for instance, illuminating experiences of physical (e.g. increased duties), emotional (e.g. grief), social (e.g. loss of someone to talk to) and financial (e.g. hiring carers) burden, which negatively impacts on carers' well-being (Cleary & Doodly, 2017; Furniss, Loveseed, Lippold, & Dodd, 2012). Carers' lack of knowledge and understanding of the symptoms and progression of dementia are also reported in previous studies (Herron & Priest, 2013; Whitehouse et al., 2000) and contribute to delay in referral to services, diagnosis, post-diagnosis support and planning for life with dementia (Herron & Priest, 2013).

Carers may experience challenges with delivering person-centred dementia care and meeting the individual's changing needs; consequently, person-centred approaches (Kitwood, 1997) are not always available to people with an intellectual disability as dementia presents and worsens (Cleary & Doodly, 2017). In the absence of dementia training, carers can feel unprepared to provide person-centred dementia support across the stages of dementia (McCarron, McCallion, Fahey-McCarthy, Connaire, & Dunn-Lane, 2010); instead, providing reactive rather than planned care (Iacono, Bigby, Carling-Jenkins, & Torr, 2014), and commonly feeling uncertain and lacking in expertise to provide the best care and support (Wilkinson, Kerr, & Cunningham, 2005).

Given the prevalence of carer burden and challenges with delivering care, it is of the utmost importance that carers' own knowledge, physical, psychological, and social needs are planned for and met (BPS, 2016; BPS & RCP, 2015). This is recognized by UK government strategies (e.g. "The Prime Minister's Challenge on Dementia 2020"; Department of Health, 2015), and NICE's (2018) clinical guidance which emphasize the importance of meeting the holistic needs of carers alongside the person with dementia, within the care planning process. This is important, as well-supported carers are "better able to provide support over a longer period" (BPS, 2016).

In reality, the type and level of support received by carers may not reflect that recommended by the guidance, as their full range of needs are not always assessed (Heller et al., 2018). Family and paid carers of people with an intellectual disability and dementia often have to rely on informal sources of support, such as peers, to manage the additional stresses (Ryan, MacHale, & Hickey, 2018), emotional burden (McLaughlin & Jones, 2010; Perera & Standen, 2014), and to help with practical challenges (McLaughlin & Jones, 2010). Formal sources of support are not always easily accessible, especially for family carers. Carers may be unaware of available services, uncertain

which services to approach for support and how to access them (Furniss et al., 2012; Iacono et al., 2014).

Dementia care pathways (DCPs) are a recommended framework in the UK (BPS & RCP, 2015) for the planning and delivery of person-centred services and support for people with dementia and their carers. In their simplest form, DCPs are documents which state the patient's pre-determined journey through services. DCPs have been described as an effective tool to assist "in streamlining a system of care to ensure patients with dementia receive equal, effective, evidence-based treatment and support which is timely and responsive to the needs of the individual and their carers" (Sullivan, Mannix, & Timmons, 2017, p. 189).

To address the dual needs of intellectual disability and dementia, some NHS services in the UK have developed specialized intellectual disability dementia care pathways (IDDCCPs), where existing intellectual disability staff are employed specifically in multidisciplinary teams to provide services for those service users developing dementia alongside their other non-dementia services. Though some guidance on dementia services and supports for people with an intellectual disability and their carers are available within the UK (BPS & RCP, 2015), to the authors' knowledge, the literature does not report on a standardized IDDCCP service, with individual services developing their own protocols in collaboration with other relevant services such as social work and end-of-life care.

Within the intellectual disability and dementia field, there is a dearth of literature exploring the role of IDDCCPs for carers and people with an intellectual disability and dementia. The little that exists largely describes developing or newly implemented IDDCCPs (Cairns, Lamb, & Smith, 2010; Jenkins et al., 2008; Kalsy et al. 2005), with few studies providing insight into how IDDCCPs are viewed or experienced.

The little amount of research which has explored IDDCCP services and supports has illustrated their usefulness for carers, who are able to access support and training (Chapman, Lacey, & Jervis, 2018; Jenkins et al., 2008); though uptake of training has been reported as low for family carers (Chapman et al., 2018). IDDCCP teams can be integral to ending the uncertainty carers and people with an intellectual disability and dementia experience without a diagnosis.

Chapman et al. (2018), through one focus group with eight health and social care practitioners from a community intellectual disability service which delivered an IDDCCP, explored the usefulness of IDDCCPs in the screening and diagnosis process, and post-diagnosis interventions. Services and supports consisted of dementia screening, assessment, diagnosis and interventions; training (e.g. dementia awareness and interventions); and resources (e.g. dementia intervention checklist). The authors reported that the dementia screening and assessment elements of the IDDCCP provided a "common framework" and "shared understanding" which enabled an improved "consistent, efficient, coordinated, multidisciplinary approach" (Chapman et al., 2018, p.38). However, Chapman et al. also found that participants may not always adhere to the processes outlined within the IDDCCP, such as actively involving people with an intellectual disability and dementia in their reviews; this

negatively impacts the personhood of the person they are supporting. Other research has illustrated that paid and family carers lacked awareness and understanding of a newly implemented IDDCP (Jenkins et al., 2008).

There is a paucity of research which has explored the role and/or evaluated the effectiveness of care pathways for people with an intellectual disability, who may have comorbid conditions and require the use of multiple pathways (Powell & Kwiatek, 2006; RCP, 2014; Wood et al., 2014).

There is, therefore, a need to improve knowledge of how family and paid carers experience supporting people with an intellectual disability and dementia (e.g. their needs, stressors and mediators), and the role of IDDCP teams in these experiences; therefore, this research aimed to:

1. Explore family and paid carers' views and experiences of supporting someone with an intellectual disability and dementia.
2. Explore the role of healthcare professionals and support systems, with a focus on one Intellectual Disability Dementia Care Pathway, in the support of family and paid carers and people with an intellectual disability and dementia.
3. Construct a useful theory to explain the experiences of family and paid carers when supporting people with an intellectual disability and dementia.

Three primary research questions were identified:

1. How do family and paid carers view and experience supporting someone with an intellectual disability and dementia?
2. What support systems and strategies are in place for carers, and how do these strategies contribute to support for carers?
3. What is the role of an Intellectual Disability Dementia Care Pathway (IDDCP) service, and its healthcare professionals, in the support of carers and people with an intellectual disability and dementia?

2 | METHOD

2.1 | Study context

An Intellectual Disability Dementia Care Pathway (IDDCP) was developed and implemented in the West Midlands by a small NHS intellectual disability multidisciplinary team, which included psychiatrists, community nurses and occupational therapists. At the time of data collection, the IDDCP team delivered a care pathway which had been developed over several years and focused on providing a diagnosis of dementia and post-diagnostic support for people with an intellectual disability. The IDDCP was developed using the British Psychological Society and Royal College of Psychiatry (2015) guidelines for people with dementia and an intellectual disability.

The pathway started once a referral was made to the IDDCP team; this referral usually came from the GP of the person with an intellectual disability but could also be made by the person's carer and/or family if they were known and had access to the local NHS intellectual disability service. Once referred, the person is screened for dementia and assessed for other possible physical and mental health causes of the observed changes. These data are collated and discussed by the IDDCP team, who provide one of three outcomes: a diagnosis of dementia; dementia is excluded; or dementia is suspected. Where there is a suspected case of dementia, assessments are repeated up to a year later and compared with the initial dementia screening (baseline) to observe any changes. If/ when a diagnosis is given, the IDDCP's team plan and provide post-diagnosis medication and support; for carers, this may involve basic training, information around what dementia is and its symptoms, and advice (e.g. on how to respond to behavioural changes).

2.2 | Methodology

Owing to limited previous work in this area, a Grounded Theory methodology was appropriate, as it seeks to generate new knowledge and arrive at a clear theoretical explanation addressing the research aims and questions. Grounded theory has multiple variations, but a constructivist grounded theory methodology (Charmaz, 2014) was deemed most appropriate. Constructivist grounded theory shares many original grounded theory strategies but challenges the notion that there is a single truth about the topic of interest, waiting to be discovered. Instead, constructivist grounded theory argues that there are likely to be multiple truths or possible explanations of a phenomenon and that these will be affected by the researcher's own history, knowledge, experience and system of beliefs. Constructivist grounded theory provided an approach which focused on understanding experiences; and was well aligned with the researcher's own beliefs about the construction (interaction between the researcher and participant) and constraints (situated in time and context) of the data. The final output of this methodology is a theory, which is composed of categories (groups of similar concepts) and the category's properties (characteristics of a category).

2.3 | Participants

A total of 18 participants, consisting of two family carers, eight paid carers and eight healthcare professionals (six IDDCP healthcare professionals [including a psychiatrist, community nurses and an occupational therapist] and two working in a housing and care organization [community nurses]; see Table 1), were recruited through purposive sampling. Participants were recruited from two sites: an IDDCP and a housing and care organization in the West Midlands, UK. The housing and care organization is a not-for-profit

Participant Pseudonym	Age range	Sex	Role	Number of interviews
Alex	40–49	F	HCP	1
Ash	40–49	F	HCP	1
Brook	50–59	F	HCP	1
Carroll	50–59	F	HCP	1
Dale	50–59	F	HCP	1
Frankie	50–59	F	HCP	1
Jesse	40–49	F	HCP	1
Morgan	50–59	F	HCP	1
Pat	30–39	F	PC	2
Sam	50–59	F	PC	1
Shawn	50–59	F	PC	2
Stevie	50–59	F	PC	1
Taylor	50–59	F	PC	2
Glen	40–49	F	PC	1
Kelly	50–59	F	PC	1
Kennedy	30–39	F	PC	1
Lee	60–69	F	FC	2
Robin	50–59	F	FC	2
Total number of interviews				23

TABLE 1 Demographics for all participants

Participant group	Inclusion criteria
Healthcare professionals (HCP)	18 years old or over, currently or have recently been on the care team of an individual with an intellectual disability and dementia.
Family carers (FC)	18 or over, a family member (immediate or extended family, blood related or related by marriage) of someone with both an intellectual disability and dementia, providing or having provided care and support for that individual.
Paid carers (PC)	18 or over, currently or previously employed as a caregiver to an individual with an intellectual disability and dementia without professional qualifications.

TABLE 2 Inclusion criteria

organization which specializes in dementia care, and supported living for people with an intellectual disability.

All participants were identified, using inclusion criteria (see Table 2) and contacted by a gatekeeper (the IDDCP clinical lead for the six participants recruited from the IDDCP; a senior manager within the housing and care organization for the remaining two healthcare professionals; and IDDCP healthcare professionals, or senior management staff working within the housing and care organization for paid and family carers). Gatekeepers provided potential participants with information about the study and asked them to contact the lead author if they were interested in participating. Once contacted by the potential participant, the lead author addressed any questions or concerns and organized an interview.

2.4 | Data collection

Data were collected through 23 digitally recorded, face-to-face, semi-structured interviews over a 24-month period (2014–2016) with DH, a psychologist and experienced qualitative researcher. None of the authors were known to the participants prior to their interview/s. The combination of having some pre-determined questions, which helped to ensure that the research questions were answered, and the flexibility to change and introduce questions to better understand participants' views and experiences, made a semi-structured interview a useful and appropriate tool when exploring the experiences of carers.

Family carers took part in two interviews each to capture any change over time. The first three paid carers participated in two

interviews each, which was reduced to one interview for subsequent paid carers, as little new insight was being produced. Healthcare professionals took part in one interview each. Interviews took place in the person's home or workplace.

A topic guide was used for each of the three participant groups and provided a set of questions and prompts to be asked within interviews. Questions were developed through a collaborative process with the three authors and were informed by the research aims, questions and findings from the literature review (see Table 3 for sample questions from the three topic guides). New questions that were introduced to the topic guides of later interviews were informed by the developing analysis and introduced following discussions and agreement between the authors. Interviews were transcribed verbatim by DH and were then checked against the audio-recording for correctness. All transcripts were anonymized.

2.5 | Ethics

NHS ethical approval was obtained. All participants were made aware that participation was voluntary and provided written informed consent prior to participating in an interview. Participant names have been replaced with pseudonyms.

2.6 | Trustworthiness

Procedures were implemented to better ensure their trustworthiness (Lincoln & Guba, 1985). For example, investigator triangulation helped to promote credibility. The lead author led the analysis whilst every stage of the analysis was reviewed, discussed and agreed between all three authors. To better ensure transferability, details of the study sites were described, and illustrative quotes used to support interpretations. Additionally, a clear audit trail from data collection to data analysis, and the interpretation of data, was recorded to help ensure confirmability.

2.7 | Analysis

The analysis was performed by DH. Transcribed interviews were processed manually and analysed using constructivist grounded theory. Analysis commenced as soon as data were collected and was revisited through a non-linear iterative process, as more data were collected. It was underpinned by constant comparative methods; data, codes and tentative categories were constantly compared with one another within and across transcripts to develop more abstract categories and to illuminate the relationships between properties of categories within the constructed theory.

The data were analysed through different stages, starting with initial coding of a transcript, where segments of data were labelled; staying inductive by describing what was happening in each segment, and avoiding being too interpretive. To be thorough and consistent, segments were restricted to a line or short sentence of the transcript.

Focused coding was implemented once the authors were satisfied with the thoroughness, accuracy, and inductiveness of the initial coding. Focused coding entailed organizing and managing the developing analysis. This equated to raising and/or synthesizing initial codes, which were underpinned by the same or similar meaning; or where initial codes were pulled together to build a picture; or single codes which added a unique perspective or were central to the research questions.

Once satisfied that focused codes provided an understanding of each participant's experience, data were categorized. This process entailed selecting focused codes which held overriding significance or clustering focused codes together based on a common underlying theme. Across the analysis, memo-writing was used to reflect upon, note and analyse the comparisons and connections made across codes and categories, whilst raising focused codes to categories.

3 | FINDINGS

The findings are discussed in relation to four categories and the core category (*Impact of Dementia*). The four categories underpin and

TABLE 3 Sample of topic guide questions for all three participant groups

Participant group	Sample of questions
Healthcare professionals	<ul style="list-style-type: none"> • Could you describe the process that people with intellectual disability suspected of dementia go through to get a diagnosis? • Could you describe what you think are the most important services and/or support for PWID and dementia, and their carers?
Family carers	<ul style="list-style-type: none"> • Could you describe a typical day for you when you are caring for _____? • Have you heard of the [name of geographical location] intellectual disability dementia care pathway?
Paid carers	<ul style="list-style-type: none"> • Could you describe what made you first ask for advice about _____? • What other services, if any, have you experienced since caring for_____?

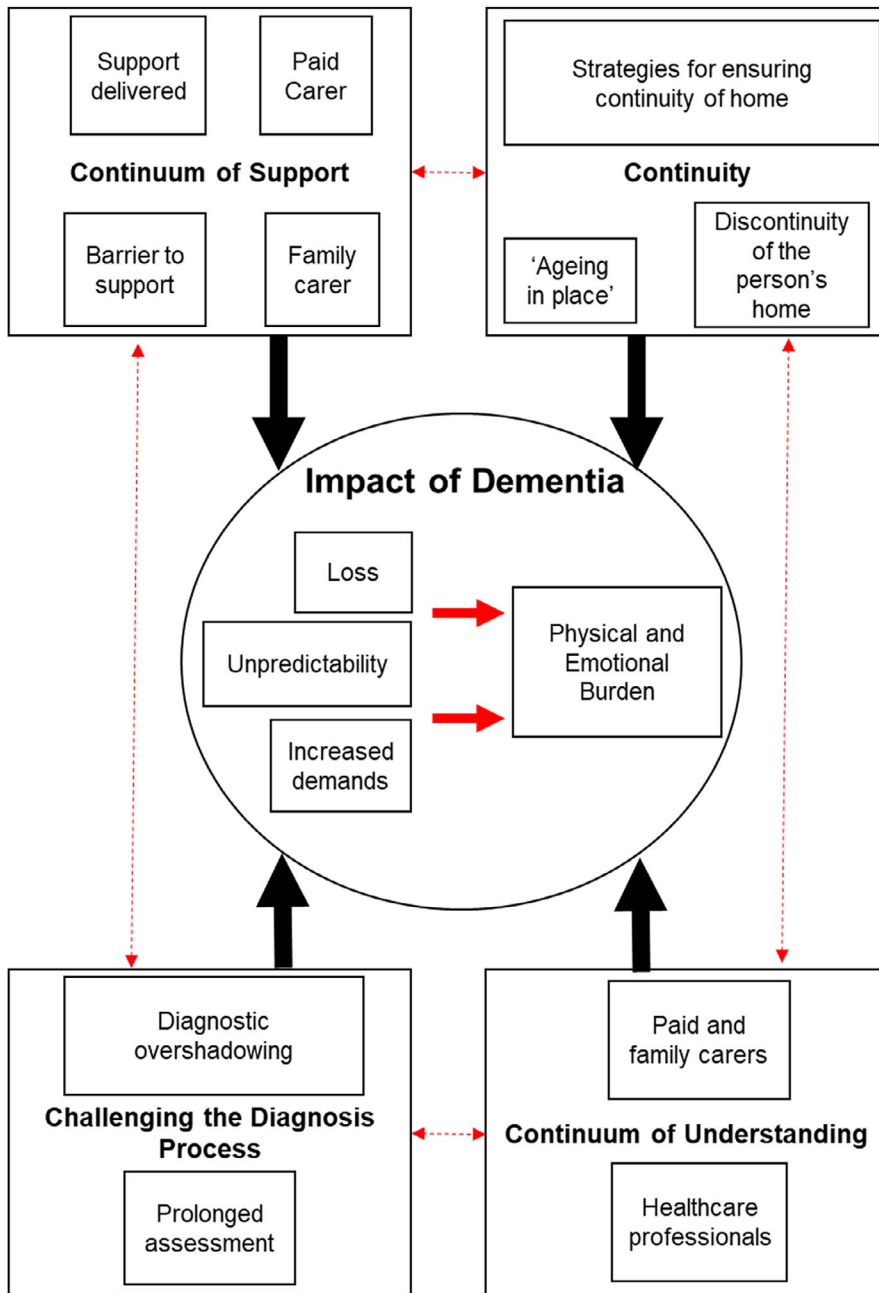


FIGURE 1 Visual representation of the constructivist grounded theory. The black arrows indicate that the categories influence the core category. The red arrows between the categories highlight how they influence each other [Colour figure can be viewed at wileyonlinelibrary.com]

inform the core category. The constructed theory, the interrelated relationships between the categories and core category, is then explicated and visually presented in Figure 1.

3.1 | Category 1: Challenging the Diagnosis Process: The difficulty of obtaining a timely diagnosis and its impact on care

Challenging the Diagnosis Process illustrated the multitude of factors which contributed to a lengthy, challenging process underpinned by uncertainty for people with an intellectual disability and

their carers. A timely diagnosis enabled understanding, planning and timely post-diagnostic interventions:

...I think if the staff had got that diagnosis earlier, we could have tailored our support a bit better.

(Glen, PC)

Diagnostic overshadowing was a prominent obstacle to obtaining a timely diagnosis; this is where behaviours and actions which may be indicative of the dementia are instead attributed or misinterpreted as the person's intellectual disability or comorbid condition/s (Mason & Scior, 2004):

...it's hard to know whether it's just a problem with their [intellectual] disability...or it's the start of dementia. I think we had a few years where we were very unsure.

(Robin, FC)

Paid and family carers did not always have the appropriate knowledge to identify dementia-related changes; consequently, referrals to the IDDCP were usually at a progressed stage of the dementia.

Acquiring a diagnosis was a lengthy process. There are many conditions which may mimic some of the symptoms of the dementia, making it a challenge to provide certainty of the underlying cause. This required healthcare professionals spending time ruling out such conditions, as encapsulated by Alex, a healthcare professional from the IDDCP:

A community nurse will be allocated first because we want to rule out any physical causes such as a UTI (urinary tract infection) or an audiology problem so we try to rule out any physical health before then they come on to the pathway.

(Alex, HCP)

Only when other conditions were ruled out were people with an intellectual disability registered on the IDDCP; though this did not necessarily mean they would receive a diagnosis of dementia.

Having a baseline of the person's capability, whilst healthy, was an important tool in the diagnosis of dementia. A baseline provided information of their capability which could then be compared with repeated assessments to check for dementia-related declines. However, baselining in this service had to be reactive, as initial assessments were only carried out once a referral came into the IDDCP team.

When dementia could not be confirmed or excluded, these assessments became the baseline against which repeated tests could be compared. However, a reactive baseline brought challenges when assessing the person for dementia-related decline:

It's very difficult because the dementia is often not seen until quite late...then you can't get those baselines when they're at their best really. It's important to get those baselines when they're at their best, especially people with Down Syndrome.

(Carroll, HCP)

A reactive baseline meant carrying out assessments once deterioration in functioning had already occurred. This made it challenging to gauge premorbid functioning and therefore to judge dementia-related deterioration through a one-off set of assessments. Where a repeated assessment was needed for a confirmed diagnosis, there was time-lapse:

At the moment we do a baseline and then we say probably repeat in a year.

(Alex, HCP)

A year without a confirmed diagnosis meant a long period of uncertainty. Whilst the IDDCP had input during this time, a year without a confirmed diagnosis meant a long period of uncertainty for the person with intellectual disability and their carers.

3.2 | Category 2: Continuum of Support: Carer support needs

This category illustrates the support delivered and received by participants, to carry out their caring roles. They highlighted the importance of maintaining a person-centred approach to ensure a fulfilling life for the person with dementia, underpinned by compassion, and adapting support to meet their individual needs:

With caring with dementia, making sure that they have their life to the full, that's the main thing, and what they need, cause obviously they've all got different needs.

(Taylor, PC)

Some participants found it challenging to apply some of the principles and approaches advocated within dementia support, as they felt they sometimes conflicted with their experience of intellectual disability support:

...Coming from an intellectual disability background, when somebody believes or thinks something that's not true, you try to explain to somebody that it's not true...it kind of goes against the grain [not correcting the person]...that's a totally different way of supporting somebody...it's something I found quite hard.

(Glen, PC)

Support structures were important to carers. Paid carers were supported throughout their role which alleviated their burden and enabled them to provide the necessary dementia support. Paid carers described how they would support each other, as colleagues, through difficult emotional situations:

...knowing what they are capable of and you know what they can't do now, it's heart breaking and it's good to know that you've got somebody there that you can let some steam off (to)...

(Shawn, PC)

Healthcare professionals from the IDDCP, organizations and managers all played a central role in ensuring paid carers were dementia

trained and sufficiently prepared to carry out their role, as demonstrated by Alex:

We give them the skills to be able to say that they can make the clients' lives meaningful.

(Alex, HCP)

When paid carers were unable to provide the necessary support, or needed guidance, they drew on support from healthcare professionals from the IDDCP:

We just do as much as we can for them and get as much support and help ourselves really.

(Shawn, PC)

Support for paid carers was also about accessibility during uncertainty of actions. Six out of eight paid carers discussed how IDDCP support enabled them to provide better support. However, some paid carers also experienced a lack of support or loss of support, for example due to funding cuts. This had adverse consequences both for the carer and the person with an intellectual disability and dementia.

Family carers experienced many challenges in accessing support and had few support structures to draw upon; consequently, they relied on the support of each other and family members, to support their family member with dementia:

We just stick together as a family, we help each other, have a moan, have a tear, or just, you know, it's what you do....

(Lee, FC)

Family carers were unaware of the existence of the IDDCP, as they were referred to generic mental health services, where support was limited in comparison to the IDDCP. Due to this lack of awareness, they could not access the specialized skills and knowledge of the IDDCP healthcare professionals in times of uncertainty, to answer any queries, to alleviate concerns or reduce the burden of support as dementia worsened:

It was frustrating because we knew there was things wrong. We knew that he was vulnerable at home, but we couldn't get any of the social workers until things got really bad...that was the frustrating part because you don't know what help, else you can do really...it was just a constant strain and worry...we were always on pins.

(Robin, FC)

Equally, the IDDCP team was sometimes unaware of the existence of a particular person with an intellectual disability in their community, and thus unable to intervene.

3.3 | Category 3: Continuum of Understanding: Carer knowledge and training needs

This category describes the importance of understanding dementia and intellectual disability, in order to provide effective support. IDDCP healthcare professionals had a good understanding of how to meet the needs of people with an intellectual disability and dementia, as exhibited through their actions, and the positive experiences described by paid carers:

Nurses [IDDCP] come in and do bloods in here, which is less distressing for him. They treat them like an individual. They've always adapted to their individual needs...They explain things to them

(Kennedy, PC)

Though paid carers showed a developing understanding and ability to support the person's dementia needs after training, prior to training, their poor understanding of the dementia, and how this translated into supporting the person's dementia needs, had possible implications for support:

I didn't understand much about dementia...in our heads it was just something that happened to old people, not younger people with learning disability and Down syndrome...I think we just managed.

(Glen, PC)

Family carers, who received no support from the IDDCP, had an even poorer understanding of dementia, reflected in their struggle to understand how to support their family member's changing needs and increase emotional burden.

3.4 | Category 4: Continuity: Achieving "ageing in place"

Continuity referred to enabling consistency in the lives of people with an intellectual disability and dementia by maintaining them in their home, where possible. There was a sense that well-being was best achieved through "ageing in place"; where care and support is adapted to the individual's changing needs within their home (Watchman, 2008). Participants believed that moving the person from their home could compound their dementia, as they would encounter the challenges of navigating a new environment:

...it's not home for them [dementia home]...they've all said it would have such a dramatic negative effect on their well-being, it's likely to increase the deterioration.

(Pat, PC)

Participants showed a particularly strong commitment to maintaining continuity in the person's home, through their desire to support the individual until the end of life or for as long as possible with the dementia:

the first response that (paid) carers, when we say 'you know, so and so, we think there's a possibility of a diagnosis of dementia', 'well they're not going to move him are they, he's going to be able to stay here, we're going to be able to care for him until the end of his dementia', yeah, why not, why shouldn't we, you know.

(Jesse, HCP)

Many of the healthcare professionals and paid carers had long-established, strong relationships with the people they supported. This attachment strengthened their commitment to ensure the person with an intellectual disability, and dementia was supported in their home until the end of life. Thoughts of being unable to maintain continuity induced negative emotions for carers:

It's hard because everyone was very fond of her because she lived there for a long time, and it's difficult to think you can't manage or support her.

(Glen, PC)

Continuity in the person's home came to be viewed somewhat differently by family carers. After initial reservations, both family carers saw a residential home as a suitable option to meet their family member's increasing support needs:

It was the best thing for them, you know. [Family member] was much better off.

(Robin, FC)

Family carers felt they did not have the ability to safely support their family member in their home, which meant moving them into a residential home with 24 hr support.

There was an awareness that continuity was not always possible or desirable. Decisions on moving the person out of their home revolved around the well-being of fellow residents, the suitability of their current environment, and the abilities of the care team. For example, Pat (PC) discussed moving the person if their dementia had too much of an impact upon the person's fellow residents:

If we felt the incidents were becoming too frequent or they're having too much of an effect [upon the other residents]...we'd look at a suitable alternative placement.

(Pat, PC)

Strategies were implemented to keep people in their home. For instance, healthcare professionals from the IDDCP and care

organizations provided paid carers with training or sent them on training course to increase knowledge and understanding about dementia, allowing paid carers to support the person with dementia and ensure they remained in their home. For instance, as Sam (PC) stated:

The college course, it just made me question everything I was doing with the person with dementia... and we've got an old lady now with dementia, and we just go into her world, which we do now, we make the needed changes to meet her additional needs.

(Sam, PC)

However, many paid carers lacked training in end-of-life support, which meant it was not always possible to provide a home for life. Where the necessary end-of-life support could not be accessed, the person had to be moved to where this expertise was available.

3.5 | Core Category: Impact of Dementia

Impact of Dementia represents the multiple forms of burden which carers experienced as dementia presented and worsened in the individual they were supporting. All carers experienced loss, unpredictability and increased demands. As carers supported the person and the worsening dementia, elements which made the person unique to carers, such as their behaviours and personality, changed, which carers perceived as loss of who the person used to be:

Their dementia's quite bad now...now they've got the blankness in their eyes and nothing really. I don't know, nothing excites them anymore.

(Robin, FC)

These changes impacted upon carers psychologically, as they felt more concerned, worried, heart-broken, helpless and felt grief:

Staff have found it a little bit hard emotionally because each week we see a little bit less of that person because the dementia's changing him.

(Pat, PC)

The changes associated with the worsening dementia also produced increased and varied demands on carers:

...everything changes with her now...care plans, risk assessments, all that's been changed. Support levels have been changed with her, it's a whole new routine with her depending on what day she's having....

(Shawn, PC)

Dementia compounded existing support needs, but also introduced new demands, such as supporting meal times, and unpredictability. A

combination of increased time spent on pre-existing support needs, increased management of behaviour changes, new demands, and taking it day-by-day, meant providing more time and focus to the individual with dementia, which caused physical and emotional burden as carers attempted to meet the increasing needs of the person they were supporting.

3.6 | The Constructivist Grounded Theory

Figure 1 provides an overview of the theory that has been constructed through the analysis process. The outer squares represent the four interrelated categories that inform and underpin the core category (**Impact of Dementia**), as represented by the middle circle, and acted as stressors (compounding the **Impact of Dementia**) and/or mediating factors (alleviating the **Impact of Dementia**). The inter-related relationship between the four categories is represented by the two-way dotted arrows in the diagram, whilst the impact these categories have on the core category is represented by the solid arrows. The properties of all categories are presented in the smaller squares within the categories. Within the core category, the red arrows represent how the properties of loss, unpredictability and increased demands inform physical and emotional burden.

The support, or lack of support, received by carers could alleviate or compound the **Impact of Dementia**. Support, such as training, provided carers with greater knowledge of the symptoms of dementia, which informed a timelier start of the diagnosis process.

When carer understanding was supported, carers implemented strategies and environmental changes to better ensure continuity in the home. Where there was a lack of support, carers struggled to understand the dementia, how to support the individual's changing needs, and ensure "ageing in place."

4 | DISCUSSION

This study set out to explore carers' experiences of supporting people with an intellectual disability and dementia, and the role of support structures, such as an IDDCP. The findings have highlighted important stressors (e.g. increased demands, lack of support) which informed and compounded the burden of the dementia, and mediators (support, IDDCP) which alleviated this burden.

This constructed theory has highlighted how increased, varied, unpredictable demands, and the perception of losing who the individual was, caused physical and emotional burden within carers. To alleviate this burden, carers utilized available sources of support, including peers (paid carers), other family members (family carers), and healthcare services (paid carers). This support also helped carers better use appropriate strategies to meet the needs of person with an intellectual disability and dementia.

Though current guidance advocates assessing, planning and supporting the holistic needs of carers (NICE, 2018), the findings have

shown that support was not always available or planned. A unique element of this study was the exploration of the role of an IDDCP. Building on previous qualitative research (Chapman et al., 2018; Jenkins et al., 2008), this study has drawn on the experiences of both healthcare professionals and carers, to provide a more holistic understanding of the IDDCP's usefulness. The IDDCP was an invaluable source of support and services for paid carers. It was responsive to paid carers' ongoing informational needs and in doing so, helped to develop dementia capable carers. Carer training and information was a planned post-diagnostic support, embedded within the IDDCP. The IDDCP also acted as a central contact point for paid carers to have their queries addressed. Both strategies alleviated paid carers' concerns and uncertainty and helped them feel more confident in providing appropriate person-centred dementia care (Kitwood, 1997) and implement adaptations to ensure a more dementia-friendly home (Strydom, Al-Janabi, Houston, & Ridley, 2016).

In contrast, family carers in this study reported receiving no services and support from the IDDCP. It is difficult to conclude whether this is a wider issue, as the findings only represented two family carers, from the same family, who appeared to draw dementia support from generic rather than specialist services. Experiences may have been different for family carers whose family member was already known to intellectual disability services. However, these findings illustrate the challenges services, such as the IDDCP, may have when trying to provide an inclusive supportive structure, and provide support to individuals cared for by families with little contact with services.

4.1 | Implications

An important implication of these findings is the need for local services to develop inclusive specialized IDDCPs. Having IDDCP healthcare professionals, who have expertise in both intellectual disability and dementia, allows support, advice and information to be tailored to both the person's intellectual disability and dementia. This may also help to address some of the challenges people with an intellectual disability and dementia, and their carers, experience when encountering generic services without the appropriate expertise in intellectual disability care (Bouras & Holt, 2004). Additionally, IDDCPs could support the assessment and planning of the full range of carers' needs, where applicable in collaboration with other services and organizations, strengthening and formalizing the support they offer (including training), and providing an inclusive, accessible central source of contact for both family and paid carers.

Knowledge and understanding of both intellectual disability and dementia are essential to initiating the diagnosis process and providing person-centred support. In agreement with the previous literature (Herron & Priest, 2013), carers, without sufficient, appropriate training, found it challenging to differentiate symptoms of dementia from the individual's intellectual disability and struggled to apply elements of dementia care and maintain continuity in the individual's home.

The findings suggest there should be a comprehensive, accessible training package, informed by this study and the notion of person-centred care (Kitwood, 1997), to address carer needs, and ensure the personhood and quality of life of people with an intellectual disability and dementia until end of life. Carers highlighted the need for both a theoretical understanding of dementia and how to address dementia-related changes through dementia training courses, but also hands on experience where they could apply this training. Therefore, any training package should be underpinned by a strong theoretical and evidence-based approach and if possible, include role play to ensure a clear understanding of the symptoms of dementia, how dementia is experienced by people with an intellectual disability and dementia, and the role carers and care organizations can have in these experiences. This may help to better ensure a timely referral and implementation of services and support. Paid carers also illustrated the usefulness and need of on-the-job training, information and advice around dementia symptoms and person-centred care, provided by IDDCP healthcare professionals; such support should be provided alongside, and be complementary to any training package. This study has highlighted a need to address the reactive approach to care planning, which was sometimes, perhaps inevitably evident.

A timely diagnosis can better inform the care planning process, ensuring carers and the people they are supporting receive the necessary holistic support to meet their needs from an early stage of the dementia (Chapman et al., 2018; Watchman, 2003). The findings illuminated the extra considerations of diagnosing dementia in people with an intellectual disability. The IDDCP healthcare professionals' expertise in both intellectual disability and dementia allowed them to implement the necessary processes to accurately identify, assess and diagnose dementia, through a thorough assessment process which was informed by a package of assessments.

The IDDCP used a reactive approach to the assessment of dementia, which relied on carers and others noticing changes, and then referring the person to the IDDCP for an assessment. However, reactive assessments may reduce the reliability and usefulness of assessments when baseline information is not available to compare the assessments against (BPS & RCP, 2015; McKenzie, Metcalfe, Michie, & Murray, 2018). Consequently, within the IDDCP, as baseline assessments had not been proactively obtained, it was sometimes difficult to make a clear diagnosis of dementia. Where dementia was suspected, the initial assessments needed to be compared against longitudinal repeated assessments, which could be up to a year later. This meant a period of uncertainty and delay in important post-diagnostic planning and delivery of support and services. It is important to note that the IDDCP team in this study was in the process of implementing proactive screening every two years for people known to them with Down syndrome aged 40–49 years old, or annually for people with Down syndrome aged 50 years or older.

The literature has illustrated the benefits of using a combination of a reactive and proactive approach to assessing dementia in people with an intellectual disability (Strydom et al., 2016). A proactive approach means delivering a battery of tests whilst dementia is not present and repeating these assessments on a regular basis. Proactive baselining

and assessments better allow for a timely diagnosis of dementia and early dementia care planning (Janicki, 2011). A strong implication from the constructed theory is the further development and implementation of guidance and policy which advocates the application of both reactive assessments and proactive baselining and screening. This will better ensure a reliable, timely diagnosis, and early dementia care planning which actively involves people with an intellectual disability and their carer/s. Decisions will need to be made around how regular repeated assessments are, with more frequent assessments for at risk groups, such as people with Down syndrome (BPS & RCP, 2015). Importantly, people with an intellectual disability and their carers should be involved in any decisions around whether they want baseline assessments and future monitoring.

4.2 | Limitations of the study

A limitation of this research was small size of the family carer participant group. Only two family carers (4 interviews in total) were recruited, and these participants were siblings to the same person with an intellectual disability and dementia. Challenges with recruitment may have been underpinned by the IDDCP and housing and care organization teams having less contact with family carers compared with paid carers, as many people with an intellectual disability were at the advanced stages of dementia and lived in supported accommodation. Additionally, the extent to which these findings can be transferred beyond the geographical area the IDDCP covers needs to be considered. IDDCPs may be idiosyncratic, differing between parts of the country, and dependent on available expertise, infrastructure, and financial resources. Furthermore, they may not exist in this format beyond the UK.

This study has provided an interpretive theory, which is situated in time and context (Charmaz, 2014). The aim was never to provide a theory which could be generalized to populations, but instead could be transferred to other similar settings and contexts. Only exploring one IDDCP limited the transferability of the findings to other contexts. However, the theory contributes new knowledge to the limited available empirically informed understanding of the use of IDDCPs.

4.3 | Future research

Future research needs to build on the findings of this study and overcome the challenges with recruitment, to further explore the experiences of family carers. It may be necessary to recruit participants from multiple IDDCPs across the UK, to ensure more family carers, who have experience of caring for their family member with dementia, are recruited. This will also provide a better understanding of the processes implemented by multiple IDDCPs teams and help to ensure the findings are more transferable across settings.

The findings have captured the need for effective dementia care planning, where carers are supported in a timely manner, and stressors are planned for and addressed. However, this research study did not explicitly explore this across the different stages of

dementia. Future research needs to explore the changing needs of carers across the stages of dementia, and how dementia care planning can proactively address the stressors within their supportive role and better ensure carers are prepared to provide person-centred dementia care.

5 | CONCLUSIONS AND RECOMMENDATIONS

This paper has provided a theoretical explanation that highlights stressors and mediators which inform, compound or alleviate the impact of the dementia on carers. This qualitative study contributes knowledge to a small amount of literature exploring carers' experiences of supporting people with an intellectual disability and dementia and the role of an IDDCP and provides recommendations for future research and practice including:

1. the need for local health services to develop inclusive specialized IDDCPs
2. the development of a comprehensive, accessible training package, informed by these findings and the concept of person-centred care (Brooker & Latham, 2016; Kitwood, 1997)
3. the need for organizations and services to address the reactive culture sometimes seen, and implement procedures for effective dementia care planning
4. the need to ensure a reliable, timely diagnosis and early dementia care planning, through reactive assessments, proactive baselining and screening, and associated guidance.

CONFLICT OF INTEREST

No conflict of interest.

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