

# Health and social care practitioners' understanding of the problems of people with dementia-related visual processing impairment

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## Abstract

It has been highlighted that health and social care staff need a greater awareness of the needs and problems of those people with young onset dementia in the UK. Symptoms of Alzheimer's disease are relatively well known (memory loss, disorientation, language difficulties and behavioural problems). However, there is less awareness of dementia-related visual processing impairments in Alzheimer's disease, Dementia with Lewy Bodies or rarer dementia syndromes such as posterior cortical atrophy (PCA), leading to delayed assessment, diagnosis and management. This qualitative study explored health and social care practitioners' opinions of the needs of people with dementia-related visual processing impairment (such as individuals with PCA) and identify any training that these practitioners might need. Social workers, occupational therapists, care home staff, rehabilitation workers (visual impairment), optometrists and admiral nurses participated in focus groups or one-to-one semi-structured interviews. All participants were shown video clips of people with dementia-related visual impairment to facilitate discussion. Sixty-one participants took part in focus groups or interviews between November 2014 and December 2015. Participants' experiences and understanding of dementia were explored and thematic analysis of the data identified two major themes. Theme 1 explores participants' understanding of dementia-related visual impairments. Theme 2 recounts how participants address and support people with dementia-related visual impairment and their families. Participants discussed, reflected and critically analysed the video clips during data collection. Most considered new perspectives of their own clients' difficulties and those participants working with people with rarer dementias consolidated their experiences. However, some participants seemed hesitant to accept the existence of visual processing impairment arising due to dementia, rationalising novel information to existing understanding of memory loss or behavioural problems. This study highlights that health and social care practitioners want more training and better understanding of less well-recognised symptoms of dementia and rarer syndromes (including PCA) to ensure appropriate, evidence-based assessment and intervention.

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**KEYWORDS**

dementia training and education, dementia-related visual processing impairment, health and social care practitioners, posterior cortical atrophy

**1 | INTRODUCTION**

The increasing numbers of people diagnosed with dementia as a consequence of the globally ageing population is well documented. Current estimates are that there are 850,000 people with dementia in the UK (Alzheimer's Society, 2017), and 47 million people worldwide (Alzheimer's disease International, 2016). In the UK, there are approximately 45,000 people with young onset dementia, where symptoms arise before the age of 65 (Alzheimer's Society, 2017).

Although dementia is an umbrella term for a variety of progressive neurodegenerative diseases, the majority of people living with dementia have Alzheimer's disease (AD), where a decline in memory is the predominant leading symptom. Symptoms such as problems in reasoning, communication, disorientation and behavioural problems are also recognised. However, other symptoms such as dementia-related visual impairment (arising from damage to the posterior cortical areas of the brain responsible for visual perception and object identification) in Alzheimer's disease are less recognised. The lack of understanding and knowledge of less common symptoms in dementia often leads to delayed or incorrect assessment, diagnosis and management by health and social care professionals (Care Quality Commission & CQC, 2013) of PCA and of other uncommon dementias such as Dementia with Lewy Bodies or corticobasal degeneration.

Visual impairment in dementia has recently received increased attention, particularly regarding the syndrome known as Posterior Cortical Atrophy (PCA). PCA is most commonly caused by AD pathology and tends to be young onset in presentation (Crutch, Yong, & Shakespeare, 2016). It is estimated that around 5% of patients with AD have PCA (Crutch et al, 2012), but this is likely to be an estimate because of low general awareness of the syndrome's existence. In contrast to typical, memory-led AD, PCA (also known as Benson's syndrome) presents initially with dramatic and progressive impairment of visual processing (which is dependent on intact posterior cortical functioning) rather than impairments of memory, as experienced by the late Terry Pratchett and described in his BBC documentary "Living with Alzheimer's" in 2009 (Pratchett & Russell, 2009). Cortical visual impairment can contribute to challenging behaviours, hallucinations and delusions in people with dementia (e.g. agitation because curved patterns on curtains are misperceived and misinterpreted as snakes slithering down the wall). Less florid symptoms include difficulties with everyday tasks such as reading, way-finding, recognition of familiar people, use of cutlery and other activities needing preserved spatial cognition.

The difficulties brought about by PCA need to be distinguished from visual problems caused by pathologies of the eyes which affect the quality of the information relayed to the visual processing areas

**What is known about this topic**

- People with rarer dementias (such as posterior cortical atrophy [PCA]) often experience delayed diagnosis, assessment and intervention.
- Visual impairment in Alzheimer's disease, dementia with Lewy Bodies and rarer dementias (including PCA) is poorly recognised.
- People with PCA can often articulate their everyday difficulties and respond to intervention, providing potential insights of dementia-related visual impairments experienced in later-stage typical Alzheimer's disease.

**What this paper adds**

- Memory loss, disorientation, language and behavioural problems are well recognised. However, many practitioners regularly working with people with dementia lack of awareness of dementia-related visual impairment.
- Training and education of practitioners about rarer dementias and problems including visual impairments are needed for timely and appropriate assessment and management.

of the brain. For example, in Charles Bonnet syndrome (Plummer, Kleinitz, Vroomen, & Watts, 2007) people experience vivid hallucinations due to macular degeneration in the eye's retina which causes the information fed back to the brain's visual areas to be much degraded. The brain's attempts to interpret such degraded information lead to bizarre hallucinations, such as little men dancing on the table. In contrast, PCA symptoms typically cannot be explained by peripheral pathologies of the eyes, but rather are due to pathology at the cortical level.

Core features of PCA cases include relatively well-preserved memory and language, and some insight into the difficulties they encounter in the earlier stages of the disease (Ahmed et al, 2016; Crutch et al, 2012). People with a diagnosis of PCA are therefore more likely to be able to articulate their problems with everyday activities, and may demonstrate increased responsiveness to interventions such as simple environmental changes (Shakespeare, Crutch, & Fox, 2012; Shakespeare et al (2015). Effective support from health and social care professionals can only be given if the professionals have an informed understanding of the problems of people with PCA. Many people living with PCA are proactive in making their own environmental

changes, often because of lack of involvement from health and social care professionals (Harding et al., 2018). Understanding of the problems for people with PCA could also inform management and intervention of visual impairment occurring secondary to memory impairment in people with typical Alzheimer's disease, and which may undermine functional independence at a point where people may be less able to articulate or recognise their visual difficulties.

In view of national and international strategies on dementia care, and recent evaluations of health and social care practice by the CQC (2013) and the Royal College of Psychiatrists (2017), it was considered timely to explore the understanding of health and social care workers about the needs of people with dementia-related visual processing impairment as there was an awareness that this group of people were receiving inappropriate management prior to their definitive diagnosis. The second objective of the study was to explore what training and support would help health and social care workers assess and respond to the needs of people with dementia-related visual impairment.

## 2 | MATERIALS AND METHODS

A qualitative research approach independent of any tradition (such as phenomenology or grounded theory) was taken in this study. This approach is commonly used in health and social care research to explore subjective experience in the real world, especially where the phenomenon has not been fully investigated before (Braun & Clarke, 2006; Morrow, 2007). Consistent with a subtle realist position (Ritchie & Lewis, 2003), the researchers adopted a neutral stance towards data collection, interpretation and presentation of the findings, whilst recognising that a totally objective position is never completely achievable. In line with this approach, a heterogeneous sample was sought so that a wide range of views and variation in experiences could be explored. The experiences, opinions and beliefs reported by participants were assumed to get close to the truth of what these participants had understood about the topic but the findings were not considered to represent all possible views and opinions, and will necessarily be influenced by the participants' particular social, experiential and cultural contexts. A semi-structured interview guide was developed. Key topics for exploration during data collection were identified but participants' experiences and perceptions were privileged and sufficient latitude was built into the guide to permit the introduction of new and unanticipated topics.

As participants' understanding and experiences of working with people with dementia-related visual impairment were sought, focus group discussion was the method of choice. It was considered that these would provide the opportunity to access individuals' personal ideas and understandings, and to debate, discuss, challenge or modify opinion through group interaction (Acocella, 2012; Kidd & Parshall, 2000; Krueger & Casey, 2004; Wilkinson & Breakwell, 2004). The majority of the focus groups were face-to-face with two members of the research team carrying these out at the participants' place of work in the London area and South East England. So that

experiences could be shared, the focus groups were discipline or organisation-specific. A pragmatic approach had to be taken to facilitate recruitment with some disciplines. Not all participants worked in uni-disciplinary teams in the same geographical location. Therefore, methods of data collection other than face-to-face focus groups were considered. Online focus groups were also offered using the GotoMeeting software, which enabled individual participants to take part in an online video or audio focus group, in real time, from different parts of the UK (Tates et al, 2009). Where appropriate, individual online interviews also took place, so that the experiences of those who offered to participate in the study were captured. These occurred when coordinating timings of online focus groups with participants were problematic, if Internet connectivity (or software usage) was difficult, where interview was the preferred option, or by default when participants failed to attend the online focus groups. All participating individuals received a certificate of contribution for their Continuing Professional Development portfolios.

### 2.1 | Participants

Health and social care workers that were in regular contact with people with dementia, and/or those with visual impairment as part of their working routine were recruited to the study. Purposive sampling of social work teams, occupational therapists, optometrists, Visual Impairment Rehabilitation Officers (ROVIs), nursing home care workers and dementia specialist community (Admiral) nurses took place. All participants had to have worked in their discipline and in dementia care for at least 1 year.

Participants came from a range of services such as the public sector (NHS, Local Authority), private sector and charities. Permission was granted by the Head of an Older People's Services in one local authority for their social workers, occupational therapists and key workers to take part in the research. Participants were recruited via an email invitation sent by their line manager. Other occupational therapists were recruited via the Royal College of Occupational Therapists' Specialist Section for Older People's database of members. Nursing Home workers were recruited via the Enabling Research in Care Homes (ENRICH) local network and were invited to attend via an email invitation sent by the care home managers. Optometrists were invited to participate via an article in their employers' newsletter, ROVIs were invited via the Rehabilitation Workers Professional Network and Admiral Nurses were invited via the Dementia UK network. In these three instances, a brief recruitment invitation email was sent to the coordinators of the networks to circulate to members and interested individuals were asked to email the research team directly.

Where face-to-face focus groups were carried out, participant information sheets, demographic information and consent forms were emailed to the line manager/local organiser to distribute to participants prior to the actual focus group. Participant information sheets and consent forms were also taken by the research team to focus groups so that participants could give written consent prior to data collection taking place. Where online focus

**TABLE 1** Demographic information

	Profession/Discipline	Interview/Focus group	Number of participants	Online/Face to face
NHFG1	Nursing/care staff	Focus group	5	Face to face
NHFG2	Nursing/care staff	Focus group	9	Face to face
SWFG3	Social work	Focus group	10	Face to face
SWOTFG4	Social work/occupational therapist	Focus group	9	Face to face
OTFG5	Occupational therapist	Focus group	10	Face to face
ROVIFG6	Visual impairment rehabilitation officers	Focus group	7	Face to face
OTFG7	Occupational therapist	Focus group	2	Online
AC1	Activities coordinator	Interview	1	Face to face
OP1	Optometrist	Interview	1	Online
OP2	Optometrist	Interview	1	Online
OT1	Occupational therapist	Interview	1	Online
OT2	Occupational therapist	Interview	1	Online
OT3	Occupational therapist	Interview	1	Online
ROVI1	Visual impairment rehabilitation officer	Interview	1	Online
ROVI2	Visual impairment rehabilitation officer	Interview	1	Online
AN1	Admiral Nurse	Interview	1	Online
AN2	Admiral Nurse	Interview	1	Online

Note. (One occupational therapist took part in both a focus group and an interview so appears twice in this table).

groups and interviews were carried out, participants were emailed the participant information sheet, demographic information and consent forms in advance. Where these had not been returned prior to the focus group, a reminder for attendees to return the consent and demographic form was given. All participants were also asked for their verbal consent to participate and pertinent demographic information at the beginning of the focus group and/or interview.

## 2.2 | Data collection

Data collection occurred between November 2014 and December 2015. Each focus group and interview lasted approximately 60 min using the same semi-structured topic guide. Two members of the research team were involved in data collection and focus group discussion as facilitator and co-facilitator. A total of 61 people participated in six face-to-face focus groups carried out in the participants' workplace, one online focus group of two people, one face-to-face interview (planned as a focus group) and nine online interviews (Table 1). One focus group member subsequently asked if they could be interviewed for a second time and separately because of logistical issues within the focus group, impacting upon participation. All focus groups and interviews (including those online), were audio-recorded.

Reassurance was given to participants that the focus was their insights and opinions rather than testing their knowledge. They were asked general scoping questions about their experiences of working with people with dementia, what visual problems they had noticed in their clients, how they had noticed them and how they addressed them. Participants were asked about their familiarity

with the term "PCA" or terms such as "Benson's syndrome," "Terry Pratchett syndrome," "Biparietal Alzheimer's" and where they might have come across these (e.g. television, a service user, training session). Participants were shown video clips of people with DLB and with PCA demonstrating and discussing visual problems (such as complex visual hallucinations, difficulties reaching to objects or perceiving faces and scenes), and were asked if these clips provided any resonance with their own clients' experiences. These video clips had been collected (with permission) for the purposes of dementia research. Possible or suggested assessment, management and assistance for those people in the video clips were also discussed.

## 2.3 | Data analysis

All interview and focus group audio files were transcribed verbatim by a professional transcriber, with participant and place names replaced with pseudonyms to ensure anonymity. Transcripts were stored in password-protected folders on password-protected computers. Notes, consent forms and other written material were stored securely on university premises. Transcripts, written field notes and online discussions were uploaded to ATLAS.ti 7 software. Focus group transcripts were parsed to establish and attribute data to specific individuals (where possible). A thematic analysis was then undertaken according to Braun and Clarke's framework (2006) and discussed by members of the research team. Our subtle realist position (Ritchie & Lewis, 2003) informed our analysis to prioritise participants' perspectives and to identify the most common perspectives. In the first instance data were analysed in turn, first the parsed focus group data and face-to-face interview data and then the online interview data.

The inclusion of focus group data, face-to-face interview data and on-line data inevitably complicated the data analysis process and some accounts were more richly detailed than others. This is not unusual in qualitative research due to uneven participation and the salience of certain topics for individual participants (Ritchie & Lewis, 2003). Each individual contribution was then analysed as a single data unit. While focus groups were chosen deliberately as a means of data collection, the interaction component was used to facilitate the development of the discussion therefore the type of interactions and range of non-verbal communications were not considered in the data analysis.

Codes were generated only after immersion in and familiarisation with the data, through listening, checking and correcting the transcriptions, rereading, and noting initial impressions. The ATLAS.ti software enabled the research team to stay close to the data and allow for comparison of initial codes and subthemes across all transcripts. Where initial impressions had highlighted codes and subthemes in one or two transcripts, the remaining transcripts were returned to in an iterative way, to establish if these appeared elsewhere. Codes were then organised and re-organised into themes and major themes.

### 3 | FINDINGS

Firstly, more descriptive findings that arose in response to initial scoping questions, appertaining to participants' experience and understanding of dementia are presented and then the two major themes that came from the data. The first of these themes "where does dementia end and visual problems begin," explores participants' understanding of visual problems for people with dementia. The second theme "my experience and my gut feeling and my ability to problem-solve," recounts how participants address and support people with dementia-related visual impairment and their families.

The majority of participants had experience of working with older people with dementia and had received some form of dementia training. However, few had personal experience of working with people with younger onset or rarer forms of dementia. Participants identified that their clients were mostly diagnosed with Alzheimer's disease, DLB and vascular dementia. Where participants did work with younger clients, they identified that these individuals tended to have alcohol or substance abuse-related dementia or fronto-temporal dementia (FTD) (SWFG3, OTFG5, OPT2). Few participants recognised terms associated with PCA, such as Benson's syndrome or Terry Pratchett syndrome.

The complexity of dementia was highlighted by the reported behaviours of clients. Participants described behavioural problems, memory loss, poor concentration, loss of independence in everyday activity and mobility. Many changes in people with dementia were perceived as illogical and therefore provided a great deal of complexity when working with clients. In the main, changes in behaviour were attributed to memory loss or poor motivation.

Participants often worked with clients without a definitive diagnosis (or a delayed diagnosis), especially those participants working

in social care (SWFG3, SWOTFG4, OTFG5, OPT1). Participants identified that knowing the client's diagnosis and impairments were useful for long-term planning, including decisions about provision of major adaptations (such as stair lifts) and why clients might be experiencing problems. They all identified that it was more important to know how dementia manifested in everyday life. When participants were referred clients with unfamiliar dementia diagnoses, information was not always easy to find. Many participants used the Alzheimer's Society, Dementia UK websites or the Google search engine to obtain information (SWFG3, SWOTFG4, OT3, ROVI1, OPT2).

#### 3.1 | Theme 1

"We don't know where one [problem] sort of begins and the other stops"

This quote indicates how participants had difficulty differentiating visual problems from behavioural or memory problems, when their clients with dementia had difficulties with everyday activities such as washing their hands or using the toilet (OTFG5). For those participants working with people with younger onset dementias, the consequences of slow or absent diagnosis (especially PCA or FTD) were raised as having life-changing consequences for clients such as inappropriate mental health assessment for depression or bipolar disorder, problems with the police, early retirement or job loss:

"Especially if medics aren't paying much attention to it, so it's hard to know why they left that job, you know - 'I left that job because they kept shouting at me' is the kind of thing you might hear, and the reason they might have been shouting at them is the dementia..." (OT2, l.199)

When asked why they thought people with dementia had difficulties seeing things, most participants cited problems such as glaucoma, macular degeneration, cataracts, lack of spectacles or wrong prescriptions. One participant acknowledged that in some dementias the visual cortex of the brain was affected but considered that many problems could still be explained by poor memory and interpretation (OTFG6). Few others considered problems with visual impairment. When participants were shown video clips of people with different visual impairments in dementia, they began to think more deeply about what they had observed. Most participants were familiar with clients with dementia experiencing hallucinations but had not necessarily considered why these were experienced. One participant said:

"I come across a lot of people with hallucinations and I'm sort of now wondering whether they are seeing a shape, light, something, and the brain translates it into something that's tangible like a person..." (SWOTFG4, l.333)

Not all participants changed their opinions and perceptions after observing video clips, especially those where people with PCA had difficulty identifying famous faces, or a picture of Brighton pier (Crutch et al, 2012). These participants rationalised the difficulties observed as being memory problems, poor eyesight, word finding difficulties, lack of knowledge, interest or cultural relevance rather than visual impairment (SWFG3, SWOTFG4, OPT2). Participants were not surprised that recognition of other people would be difficult when clients were not able to recognise their relatives' faces (ROVI1, ROVI2). In two instances, participants observed that difficulty with recognising faces was inability to differentiate the gender of the individual rather than poor memory of famous people (for example, identifying former president Bill Clinton as a woman) (SWFG3, OTFG6). Nevertheless, within one focus group (SWFG3) a participant consistently rationalised this, saying:

"Yeah, but you have to also put it in perspective that there are a lot of women out there, just like there's a lot of men that look either very feminine or very masculine. And so you have to put it in perspective.... these men had long hair" (SWFG3, I.464)

Although some participants did not change their opinion, discussion within interviews and focus groups enabled other participants to reconsider problems as visual-processing problems, rather than pathologies of the eyes, memory problems or lack of knowledge. When discussing the video clip showing how a person with PCA had difficulties identifying a picture of Brighton pier, some participants observed how the individual pieced the picture together in fragments or by association (SWFG3, OT3, OT1). One participant said:

"I think its like as if seeing snippets of the picture and they were just able to see little, little bits and then put the picture together like a jigsaw puzzle" (SWFG3, I.533)

The content of the video clips also prompted some participants to wonder if problems that they had encountered with their own clients—such as getting lost in their home, not being able to see all of their food on their plate, losing belongings, difficulty climbing stairs were due to similar visual impairment issues (NHFG2). One participant said:

"I was working with a lady that was never diagnosed... we were doing a route from her flat to the shop. And her landmark was a lamppost. There was only one lamppost and she missed it every time. Every single time. And she'd walk back to it and she'd go 'there it is'. And she would walk on, and she missed it every time..." (ROVIFG6, I.863)

Other participants likened visual impairment difficulties seen in the video clips to those of clients following a stroke (SWFG3, OTFG5). For those participants who had experience of working with people with rarer forms of (as yet undiagnosed) dementia, the video clips resonated with their own clients. One participant said:

"You know, when we have people with PCA, they initially present with bad eyesight, but it's sometimes its things like not being able to fit a key into a lock... because they are trying to fit it in sideways... (OT2, I.66).

### 3.2 | Theme 2

"Myexperienceandmygutfeelingandmyabilitytoproblem-solve"

This quote comes from an interview with one participant (OT2, I.221) who identified a lack of evidence-based assessment and interventions for people with rarer dementias such as PCA. Other participants had a pragmatic approach to assessment and intervention because of a lack of diagnosis, which was a needs-based approach establishing what clients could, could not do or want to do. One participant described a focus on function first and cause second (OT3). Nursing home participants said that establishing a relationship with clients, enabled them to become more intuitive and responsive to their moods and behaviours. This intuitive approach was also echoed by other participants, when observing clients and their home environment. They described recommending the elimination of glare or reflection for clients who had distressing hallucinations of perceiving strangers in their home. One participant said:

"...we couldn't remove all the mirrored wardrobes... Their room was a huge problem because she'd have heated debates with all these unseen people. So they were all covered over and every glass and patio door..." (AN1, I.683)

Minimising patterns in curtains, wallpaper and also carpets was common advice given by participants. Most participants identified flooring as problematic, and therefore reduction in shiny floors, patterned carpets and limited changes in floor colour were advised. Participants recounted that where practicable, they recommended removing contrasting rugs or mats, as clients thought that these were steps or holes in the floor that they would fall through (ROVI, AN2, OT3). Contrast between objects was deemed to be highly important for clients with all kinds of dementia by the majority of participants. For many this related to doors on wards and in residential care in contrasting colours, the use of bright signs on doors or differing coloured tape in the home to signpost bathrooms and bedrooms. The use of contrast was also advocated so that objects or furniture could be more easily identified from surroundings; for example toilet seats, chairs, plates or tablecloths or mats. Although people talked about the use of the colour red as a contrast, most participants felt that the contrasting colour should be determined on an individual basis for each client and their surrounding environment. Whereas some participants suggested the use of coloured plates in providing contrast with food at mealtimes, others also suggested the use of plate guards or using the clock principle of identifying food on the plate at mealtimes (ROVI1, OT2). The use of contrasting colour on relevant control panels of equipment—such as microwaves, remote controls and switches, colour-coded speed dial on phones were suggested. The use

of good lighting was advocated by participants (OP2, ROVI1 & 2, OT2), to ensure that there were no shadows in rooms to reduce hallucinations and also to provide good luminance within the environment for safe manoeuvres around furniture and on stairs. One participant highlighted how important lighting was to some clients:

"I've got someone who would be happy if I was to install so much lighting in the house that you could land a plane in it..." (ROVI2, I.98)

The need to "declutter" clients' environments was also identified as a key intervention to promote independence and safety. Participants related this back to the video clip of a lady struggling to identify Brighton pier. They considered that the difficulty with identifying the picture was an issue with figure-ground perception (difficulty discerning foreground from background). They suggested that such an individual would need to reduce clutter in their home and probably require help when in the outdoor environment (OT2, ROVI1, OT3). One participant explained the issue further:

"The more items there are... they might not be in your path but your brain's seeing them, so you're brain's saying oh, there's five chairs in this room and you're thinking oh, blimey, five chairs, but if there are only two chairs, there's one of them that's in your way, remember, but there's only two of them anyway, then it's easier because you don't feel so intimidated by all the chairs in the room..." (OT2 I.266)

As well as making environmental changes, participants considered education of the family as an important intervention to enhance their understanding, help and support. Although aware of the lack of evidence base for their practice, and noting that a definitive diagnosis was not crucial, the need for timely recognition and robust identification of clients' presenting problems was seen as important to determine the advice given to clients and their families.

In this theme, participants were aware of the lack of evidence base for their practice. Although a definitive diagnosis was not crucial to all participants, the need for timely recognition and robust identification of the clients' presenting problems was seen as important to determine the advice given to clients and their families as well as appropriate interventions.

## 4 | DISCUSSION

This study aimed to explore the understanding of health and social care workers about the needs of people with dementia-related visual processing impairment and secondly to explore what training and or support would help health and social care workers assess and respond to the needs of people with dementia-related visual impairment. Participants came from a range of disciplines and professional education in different organisations and

geographical areas of the UK. However, they all had day-to-day experience of working with people with dementia. Participants provided insights and perspectives from their own areas of practice and experience, with many commonalities (regardless of profession or level of education). Where experiences differed, were with those practitioners who worked with people with rarer dementias such as PCA.

The majority of participants worked with older people with dementia and had received dementia training as part of their employment. They were fully aware of memory and behavioural problems in their clients, but were less aware of other problems including dementia-related visual impairments, or of rarer or young onset forms of dementia. Lack of, or slower, diagnosis of rarer and predominately younger onset dementias (such as PCA) were reported by participants. Many participants were concerned that they lacked the knowledge and skills to appropriately meet the needs of their clients who might have dementia-related visual impairments. They wanted more training and a stronger evidence base to support their practice. These findings support the recently published report by the CQC (2013) and the national audit by Healthcare Quality Improvement Partnership (2017) in the UK, which highlighted the need for hospital and care home workers to have better training and understanding of less common dementias for appropriate help, timely and more accurate assessment and diagnosis.

Participants relied on their practice experience and intuitive reasoning, when assessing and responding to the needs of clients, in the absence of a diagnosis. Key features they described were observing and understanding their clients' difficulties, observing their clients' interaction with their environment, and their everyday activities. In the absence of an evidence base specifically for clients with visual processing problems with or without a definitive diagnosis (such as PCA or DLB), participants identified the need for environmental adaptation and the use of good lighting and colour contrast with clients to alleviate problems, as recommended by Greasley-Adams, Bowes, Dawson, and McCabe (2014) for those people with dementia and visual impairments caused by pathologies of the eyes. When a diagnosis was available, those participants working with clients with PCA or visual processing problems also highlighted a lack of standardised assessments and a strong evidence base to inform their practice, as gaps in their professional "toolbox."

All participants were highly engaged in discussion of the video clips and for some, the video clips and discussion provided new perspectives of their own clients' difficulties. They were able to reflect and critically analyse novel information, in relation to what they saw, clients they had worked with previously and their knowledge of visual impairments in other health conditions such as stroke. For those participants working with people with younger onset dementias, participating in the study confirmed and consolidated their clinical reasoning and practice. These behaviours concur with Bannigan and Moores (2009) concept of professional thinking, where critical reflection and analysis of existing and (more importantly) new knowledge and information are incorporated with research evidence into clinical reasoning and decision-making.

Conversely, a lack of understanding of visual processing impairments meant that some participants struggled in their evaluation of what they witnessed in the video clips. They found it difficult to accept new knowledge or understanding of dementia-related visual processing impairments, preferring to reason that the poor task performance observed in the video clips was due to their existing understanding of memory loss and behaviour changes in dementia. Bannigan and Moores (2009) suggest that reliance upon familiar knowledge rather than reflecting upon, and exploration of, new knowledge impacts upon health and social care professionals' decision-making and interventions with clients. Once again these findings confirm the reports by the CQC (2013) and HQIP (2017) by highlighting the need for further training, better assessments and information of rarer dementias. Such training would facilitate understanding and management of visual processing problems in dementia.

#### 4.1 | Strengths and limitations

This study does not purport to generalise its findings but to represent the perceptions and understanding of the study participants. Recruiting participants from different areas of health and social care provided a comprehensive range of experiences. Even though a pragmatic approach to data collection (i.e. face-to-face and online) was taken, some participants were more difficult to recruit, which meant that some professional groups are represented more than others. However, it is considered that many of the experiences, support and training needs were common across the groups and not discipline-specific (nor related to level of professional education), which suggests that the study managed to capture a collective view across participants.

The majority of the focus groups were carried out face-to-face in participants' work place with colleagues, so that participants could have provided socially desirable or guarded responses (Krueger & Casey, 2004). Although the aim was to use focus groups for all online data collection, this proved problematic because of difficulty in coordinating times between participants, with a few requesting interview only. The quality of participants' Internet connections impacted upon them joining (and remaining in) focus groups or on the flow of conversation within the session. Nevertheless, the software allowed the team to share the video clips with participants and for dialogue to occur in the same way as in face-to-face sessions.

## 5 | CONCLUSION

Although dementia awareness is a requirement within pre-registration health and social care education (Health Education England, 2014) and health and social care staff training (DH 2016), the findings from this study support the CQC (2013) report and Healthcare Quality Improvement Partnership (2017) audit that health and social care practitioners require further and better training and understanding of less common and younger onset dementias. The need for health and social care professionals to have a greater

awareness of visual processing impairments and also sensory impairments such as sight loss in people concurrent with (or without) dementia is an important aspect of professional education with our ageing population. However the dilemma for current pre-registration programmes is not a lack of awareness of such issues but an already crowded curriculum and changing educational priorities (Campion, Awang, & Ward, 2010; Deacy, Yuen, Barstow, Warren, & Vogtle, 2012; Wittich, Jarry, Barstow, Jarry, & Thomas, 2017) and post-qualification, an understanding of the differences between concurrent co-morbidities such as dementia and sight loss (College of Optometrists, 2016) and visual processing problems as part of some dementias.

In the (current) absence of an adequate evidence base for their practice, most practitioners who work with clients with dementia-related visual impairment seemingly use critical analysis and reflection of new and existing knowledge. This synergy of available and novel knowledge (i.e. based upon an understanding and identification of visual processing problems), expertise, critical reflection, experience and relationship with the client can inform health and social care practitioners' clinical reasoning and working with clients with dementia-related visual impairment until the evidence base grows. However, this is currently reliant upon practitioners being open to new or unfamiliar experiences in their professional reasoning rather than being reliant upon their existing knowledge and understanding.

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#### ETHICAL APPROVAL

The study received ethical approval from NHS Health Research Authority and Brunel University, London.

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