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Optimising care and the patient experience for people living with dementia: The perceptions of radiography practitioners

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To: The Editor-in-Chief
Radiography

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This cover letter is to confirm submission of the article entitled '**Optimising care and the patient experience for people living with dementia: The perceptions of radiography practitioners**' for your consideration for publication in the special edition of Radiography 'Patient voice'. On behalf of all the authors I certify that:

- The contents of this manuscript are not currently under consideration for publication elsewhere;
- The contents of this manuscript will not be copyrighted, submitted, or published elsewhere, while acceptance by this Journal is under consideration;
- The authors declare no conflict of interest;
- Each author has participated sufficiently in the submission of this manuscript and takes responsibility for appropriate portions of its content;
- Publication is approved by all authors;
- No parts of the manuscript have been sent by post to the Editorial Office.

Yours sincerely,

Dr Robert Higgins PhD
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Optimising care and the patient experience for people living with dementia: The perceptions of radiography practitioners

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Optimising care and the patient experience for people living with dementia: The perceptions of radiography practitioners

Abstract

Introduction: There is growing awareness of the importance of providing optimal care for people living with dementia (PLWD) as seen in professional guidance documents by the Society of Radiographers. However, there is limited research exploring the perceptions of radiography practitioners delivering care to PLWD. The aim of this research study was to explore the experiences and perspectives of both diagnostic and therapeutic radiography practitioners when providing care for PLWD.

Methods: A qualitative multi-method two phase approach was undertaken using online focus groups and interviews.

Results: Participants identified both positive and negative experiences when caring for PLWD. Findings were (1) Challenges in delivering person centred care to PLWD, (2) The need for role specific education and training, and (3) Partnership working with carers. Challenges in delivering care included dominant workplace practices where heavy workloads and 'rushing' were key challenges to achieve the care radiographers wished to deliver. The lack of dementia specific education compounded these difficulties. Care partners were seen as an asset in providing a positive patient experience.

Conclusion: Ensuring practitioners can devote the time required to individual patient needs is necessary but challenging within the workplace culture where time and resources are limited. Although radiographers are aware of the need to deliver high quality care, their practice doesn't always reflect this. Achieving high quality care for any vulnerable patient group is a challenge and raising awareness of the needs of the PLWD and their carers through education and training is one way of achieving this aim.

Implications for practice: Further work is needed to identify how best to support radiography practitioners when delivering care to PLWD.

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2 **Optimising care and the patient experience for people living with dementia: The**
3 **perceptions of radiography practitioners**
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56 **Keywords**
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58 Person centred care; Education and training; Diagnostic radiography; Therapeutic
59 radiography; Carers
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Introduction

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2 More than 55 million people live with dementia worldwide, and there are nearly 10 million
3 new cases every year [1,2]. In the UK it is estimated that approximately 850,000 people are
4 currently living with dementia with this number projected to increase [3]. Dementia is an
5 umbrella term that describes a collection of symptoms which cause the progressive loss of
6 brain function and cognitive abilities [2] and can affect people of all ages, although a
7 person's risk of developing dementia rises from 1 in 14 over the age of 65 to 1 in 6 over the
8 age of 80 [3]. People living with dementia (PLWD) often experience a range of complex
9 symptoms depending on the form and progress of the condition, as well as the individuals'
10 personality and life experiences [4]. The different forms of dementia include Alzheimer's
11 disease which contributes to 60-70% of cases of dementia. Other major forms include
12 vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to
13 frontotemporal dementia [1].
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28 PLWD are frequent users of health care services, with an estimated 25% of acute hospital
29 beds in the UK occupied by patients with AD [5]. Diagnostic and interventional treatment,
30 including medical imaging services, are increasingly used with PLWD with referrals to a
31 variety of imaging modalities for differential diagnosis as well as for injuries and pathologic
32 conditions [6]. The increasing prevalence of dementia will put further strain on radiography
33 services across the UK [7]. Clinical protocols used to treat and care for patients with
34 dementia vary, resulting in inconsistent training and guidelines for health professionals
35 which may potentially compromise quality of care provided [6].
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47 Implications for radiographic practice and patient centred care (PCC) are immediately
48 apparent when caring for PLWD. For example, when arriving in a radiographic department,
49 PLWD may feel disorientated and overwhelmed [6]. Frustration, along with an inability to
50 comply with or understand instructions when undertaking procedures, can raise difficulties,
51 making it difficult for the radiographer to provide adequate care or establish and sustain
52 rapport with PLWD, especially as some procedures can last 30 minutes or longer [6-7].
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59 Although policy and research in this area is growing there is still a gap in practice.
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1 Literature abounds on the radiographic diagnosis of dementia [8-15], however, there is little
2 research on how to best to care for PLWD during imaging or therapeutic procedures [9-10].
3 Perceptions of performance and quality of healthcare organizations have begun to move
4 beyond just examining the provision of excellent clinical care, alone, and now consider and
5 embrace the patient experience as an important indicator of quality and PCC [10]. Despite
6 current clinical practice guidance produced by the Society of Radiographers (SoR) [7] and
7 the recognition of the importance of patient experience of PLWD and their carers when
8 undergoing imaging and/or radiotherapy procedures little research has explored the lived
9 experiences and perceptions by radiography practitioners when caring for PLWD in the
10 department and their interactions with carers.
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22 The aim of this research study was to explore the perceptions and lived experiences of
23 radiography practitioners when caring for PLWD in clinical imaging and radiotherapy
24 departments. It also sought to investigate the compatibility of current professional guidance
25 when delivering care to PLWD by key stakeholders involved in developing professional
26 guidance to support the care of PLWD in the department.
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36 **Method**

37 A qualitative multi-method approach using online focus groups (OFG) and semi-structured
38 interviews was used to collect data. This two-phase study recruited participants via
39 purposive sampling. Phase 1 used an OFG to explore the perceptions of both diagnostic and
40 therapeutic radiography practitioners when caring for PLWD and what they felt were
41 effective care strategies. Phase 2 followed using semi-structured interviews with
42 stakeholders involved with the development of the SoR dementia and carer guidelines to
43 further explore the findings from Phase 1.
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52 Data collection

53 *Phase 1*

54 Health and Care Professions Council (HCPC) registered diagnostic and therapeutic
55 radiography practitioners of any professional background/role based on the College of
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1 Radiographers (CoR) Career Framework from across the UK were asked to participate in the
2 OFGs. OFGs offered a solution to the challenge of arranging face to face focus groups with
3 the geographical spread of participants and COVID-19 pandemic issues. A dedicated online
4 focus group platform (<https://www.focusgroupit.com/>) was used to collect qualitative data
5 and participants typed in a response to each question using free-text boxes in a discussion
6 board format. Ground rules were also provided at the start of each OFG. Participants were
7 recruited to a closed online asynchronous semi-structured OFG that allowed participants to
8 contribute at a time that suited them. Two homogenous OFGs were used, one for diagnostic
9 radiographers and one for therapeutic radiographers. This was to reflect the contextual
10 differences between therapeutic and diagnostic radiographers and to allow common
11 experiences to be shared and built upon by participants in each OFG. Questions for the
12 OFGs were derived following a synthesis from published literature or research from a similar
13 context and agreed by all authors (Table 1). RH acted as moderator and monitored each
14 OFG as well prompting further discussions around key areas. Each OFG ran for 4 weeks and
15 closed at the point of data saturation [17].
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37 *Phase 2*

38 Participants from the core group of the SoR who were involved with the development of the
39 current SoR guidance '*Caring for people with dementia and their carers*' [7] were invited to
40 participate with a 60-minute audio-recorded individual interview via Microsoft Teams. The
41 interview questions were inductively derived from the themes identified from phase 1 data
42 analysis and agreed by all authors (Table 2).
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Ethical considerations

Ethical approval for the study was granted by the University Ethics Committee (23/11/2020).

A Participant Information Sheet (PIS) was provided at the beginning of both phases to participants that explained the background and purpose of the respective phase of the study. Only on actively consenting to participate were they able to access the OFGs or take part with the semi-structured interview.

Participants

Fifteen participants were included in phase 1 diagnostic radiography OFG. Despite interest by 6 therapeutic radiographers, only 2 took part with the therapeutic radiography OFG. However, the data gained from this OFG was found to be in-depth and sufficient for the objectives of this study. Phase 2 study participants included 1 core member of the stakeholder group and 3 members from the individual stakeholder group that included representation by two diagnostic radiographers and one therapeutic radiographer.

Data analysis

All data were transcribed verbatim and analysed by 1 researcher (RH) who systematically coded the data across the entire dataset for both phases of the study. All OFG and interview data that related to the study aims was coded. All significant patterns in the data were noted and an initial table of second-order codes and quotes was created. Throughout this and subsequent stages, coding, analysis and thematic areas were reviewed by authors 2 and 3 allowing cross-checking of data and interpretations. These findings were then refined by repeatedly referring to data and codes, and by creating a detailed thematic map. Candidate themes were examined to establish whether they were coherent, externally heterogeneous, and had explanatory power according to the six steps outlined by Braun and Clarke [18].

Results

From our analysis we identified both barriers and facilitators to optimising care to PLWD.

Three groups of themes were identified relating to:

1. Challenges in delivering person centred care to PLWD,
2. Role specific education and training,
3. Partnership working with carers.

These themes were also identified in SoR guidance [7] and were seen across both data sets.

Within the presentation of findings below, the following codes have been used to denote different participant groups:

- P = Participant
- DROFG = Diagnostic Radiographers Online focus group
- TOFG = Therapeutic Radiographers Online focus group
- IP = Interview Participant

Challenges in delivering person centred care to PLWD

PCC and delivering good patient experiences to PLWD were time reliant. Health Trusts with more time and resources tended to adopt more pro-active approaches to care whilst participants identified that busy departments spent limited time with PLWD as there was no flexibility to react to their needs which impacted on PCC:

P6 DROFG1: *“Time pressures to get the mammogram done quickly and achieving a fine balance between not rushing the patient and achieving the best image quality possible. Mammograms require a lot of coordination and cooperation from the patient which can be difficult when the patient has dementia - this can be frustrating for both the radiographer and the patient.”*

Challenges to delivering PCC appeared to be linked to a culture of rushing within departments. It was apparent that radiographers felt that they had to rush examinations, which often lead them to exclude carers for PLWD to save time and get examinations completed faster:

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3 **IP1:** *“Radiographers though, because of the culture of time pressures, trying to get through an examination... it might be quicker for them to just get on and get that examination done”*
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7 Having strong leadership was seen as key in overcoming these issues and prioritising PCC
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9 not just for PLWD, but in general to help optimise experience for all patients:
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14 **P1 TOFG:** *“Radiotherapy management often doesn't understand the time commitment that is required with people who have dementia, as sometimes it appears they think about productivity more. Dementia often falls to the end of the list of priorities as maybe it isn't perceived to generate much income.”*
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23 **IP1:** *“We also need to have leaders who prioritise patient centred care, so the leadership and management and the organisation itself having some champions for person centred care and says that it's okay for us to take time, to spend time with these people.”*
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31 Having relevant information, particularly if a patient is attending for a non-dementia related
32 procedure, along with other key information such as like/dislikes on requesting systems was
33 thought to help improve interactions with PLWD:
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40 **P1 DROFG2:** *“Inclusion of the diagnosis in the clinical history on the X-ray request! Quite often, the only time we find out a patient has dementia is when they are in the room”*
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46 **P2 DROFDG1:** *“If each patient had their "this is me" ... before the scan. If CRIS [Clinical Record Interactive Search] had notes on for each patient as to what did and didn't work well previously... we just have "alarms" which rarely note that the patient has dementia, and to what degree and mostly you find out on the patient's arrival.”*
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55 Good communication with PLWD was seen as central to PCC but also to involve those caring
56 for PLWD. This was to ensure not only patient compliance with procedures but also to aid
57 patient understanding of the procedure leading to a positive patient outcome:
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P5 DROFG2: *“I always speak clearly and calmly. I make sure that I explain exactly what I am going to do before I do it. Plenty of reassurance throughout the examination is key, along with making sure that the patient feels safe and as comfortable as possible”.*

The adoption of a pre-visit was also seen as a way forward in helping to provide a positive PLWD and carer experience:

IP1: *“...pre visit might not be for the person with dementia; it might just be for the carer as a bit of/form of reassurance for them as well. Not everybody wants to do that, but for some people just having a trial run, finding where the car park is, where it is before that person is with them can help them as well.”*

Participants from both phases of the research recognised the importance of adapting and providing PCC to PLWD and their carers, but workforce pressures made putting this into practice difficult. Key in overcoming this challenge was the need for strong leadership by managers to recognise and support the need for radiography practitioners to deliver PCC.

Role specific education and training

There was a strong theme around education and training for radiographers when interacting with PLWD. This was identified as a key gap and influencer in terms of the content and mode of delivery of care and PCC at both at pre and post qualification levels of education/training. More education and training were seen as an essential way to enable radiographers to deliver better quality dementia care:

P5 DROFG2: *“Having dedicated dementia training or at least an appointed member of staff with further knowledge for support.”*

Participants from both data sets spoke about gaps in dementia education and training for radiographers:

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IP1: *"...despite the fact that it's a requirement that all health and care staff are trained in dementia care, understanding, I, as a practitioner, had had half a day's training in 24 years. That is not enough."*

P2 TOFG: *"There should definitely be more training at both undergraduate and qualified level - knowledge needs to have a base and for this then to be built on and updated regularly. There needs to be more of recognition for this group of service users from undergraduate upwards."*

An absence of sufficient training was perceived to lead to a lack of awareness about dementia and what was described as a 'missing piece' in the education and training of radiographers that then led to difficulties for practitioners when working with PLWD and their carers:

IP 2: *"I think there needs to be an ongoing educational piece, because I think there's often an assumption... as soon as you see dementia, you assume the worst. Whereas actually if they are on early stages, they are still functioning"*

Different learning resources were mentioned, such as:

IP1: *"...there is a video that's used, is it from King's College that is used an awful lot, and I know they use that a lot in the training but it's not specific to radiotherapy or diagnostic imaging"*

But this was not seen as satisfactory due to the lack of direct relevance to radiography practice. Other resources were also problematic:

IP2: *"We obviously can't use NHS E-learning for health. Not all of our staff can use that, because obviously we're outside of the NHS, so we can't access readily dementia modules for training."*

1 Focus group participants reported awareness and access to training, but they were in the
2 minority:
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7 **P2 DROFG2:** *"We have Dementia Friends Champions within our departments and all*
8 *professionals can access dementia awareness training (online and face to face). As a*
9 *radiographer I have been aware of access to dementia training for many years."*
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14 Participants felt that having direct exposure to someone with dementia or carer to talk to
15 radiographers as part of their development was an effective approach:
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20 **IP1:** *"Getting somebody who is a carer coming in and speaking to them, or somebody*
21 *with dementia, so that they are real people to you and that experience of people."*
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25 **P1 TOFG:** *"During training a dementia carer came in to speak. It was really powerful,*
26 *some of the participants got quite upset, but it really drove the person centred care*
27 *home."*
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32 In addition, the importance of lived experiences of radiographers who had personal
33 exposure to dementia when interacting with PLWD was acknowledged:
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39 **IP1:** *"I suppose it's life experience really isn't it with some people. And that's nothing*
40 *to do with age because you can have a younger person who has got a grandparent*
41 *with dementia. And they are usually really good with other carers because they've*
42 *had that experience and they've been there, so they can empathise more I think*
43 *really"*
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48 However, not all practitioners had life experience of dementia:
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53 **P1 OFG2:** *"Life experience gives some training. Some people have this, some not. It*
54 *would make perfect sense to train everyone."*
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Trying to develop teams with dementia expertise was an approach described by participants in their work settings, and our analysis revealed examples of positive approaches to training and development, for example:

P2 TOFG: *“We have a team of dementia champions that have completed level 1 and 2 dementia training, the majority of staff have level 1 dementia awareness training (Trust e-learning package) and some have level 2 training - we are in the progress of ensuring staff have updated this training.”*

This approach to developing a team was reported by another focus group participant:

P1 TOFG: *“We have a dementia team who have received specialist training who are familiar faces for patients with dementia and their families.”*

This participant also reported being part of the development of this team:

P1 TOFG: *“I have undertaken advanced dementia training through my trust, giving me additional knowledge and skills in the area of dementia. This enables me to train others in my department to have enhanced skills in this area.”*

Training in advance of encountering PLWD was perceived as important, whilst acknowledging that there was a lack of education around PLWD available to both undergraduate student radiographers and qualified radiography practitioners:

P5 DROFG2: *“I had a very small amount of undergraduate training on dementia specifically. A lot of my experience was gained through life experience and working in other fields of work. I have also sought dementia training and awareness outside of work.”*

The need to provide education on dementia at an early stage in the radiographers’ career was perceived as key:

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P4 DROFG2: *“Dementia awareness training to be available from undergraduate level, regularly updated. Preparing students for the potential challenges (and rewards) caring for patients with Dementia brings.”*

P3 DROFG2: *“Knowledge of dementia prior to attending the imaging department [for undergraduate students]. More training for all, especially when in training.”*

However, even when innovative approaches to education and training were adopted participants reported challenges such as:

P2 TOFG: *“...time pressure to attend staff education/training”*

A lack of consistency was evident with the participants exposure to training and development in dementia care practices. This overall lack of dementia awareness and education was perceived by participants to be problematic as were the resources available. The lived experiences, either hearing someone with dementia talk, or via personal experiences was reported as one of the best ways for awareness and implementation of more empathic approaches to practice.

Partnership working with carers

Partnership working with carers was commonly recognised by all participants as being central to PCC when imaging or treating PLWD. Most participants recognised and valued the role carers provided by highlighting how they involved the carer to support the examination or treatment:

P1 TOFG: *“They [the carers] are key, they give so much information and support. They are great at feeding back what does and doesn't work for the person living with dementia.”*

Participants felt it was important to recognise the PLWD as the main focus during imaging or radiotherapy procedures, whilst supporting the carer’s needs:

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P3 DROFG3: *“It is always important to recognise the person living with dementia as the main focus, but with support from the carers...they are the person that knows and understands them the best.”*

P2 TOFG: *“We also find that carers often need just as much support as the person receiving treatment... we have found sometimes as radiotherapy continues the person living with dementia due to the radiotherapy side-effects can worsen their dementia related symptoms which can greatly impact on the carer and their relationship.”*

Several benefits of carer inclusion were evident throughout the data analysis. For example, it was recognised that often carers have in depth knowledge of the PLWD and can therefore assist in the x-ray examination by supporting communication and key to facilitating PCC:

P6 DROFG1: - *“Utilising the carer's knowledge of how the patient can react in different situations and their ability to detect different triggers.”*

P6 DROFG1: *“The carer can offer valuable information to achieve better outcomes if they know the patient well. They are able to communicate with the patient in the best way for them and can reassure and calm patients.”*

Despite these benefits, several challenges to carer inclusion were identified, including the ability to recognise when to include a carer not in the PLWD procedure. Specifically, participants noted that carers can either be an asset or a hinderance depending on the relationship between the PLWD and the carer. A carer with a poor relationship can increase the PLWD feelings of anxiety and hinder the development of PCC:

P5 DROFG2: *“The carer can be the greatest asset or really hinder the process. A good carer will be able to provide information to assist you and will also help in a number of ways, to support, keep calm and know triggers. A carer who doesn't have a great rapport with the patient can cause anxiety to increase.”*

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Despite this our analysis suggests that including carers who have a good relationship with PLWD, can help radiographers in obtaining images or helping to provide reassurance during setting up for radiotherapy as well as delivering PCC to PLWD:

IP1: *“But actually involving the carer can be the thing that means that you are successful in obtaining your images with the person and the best experience for them as well. So, I think there's a whole lot of different factors.”*

Partnership working and being able to recognise and use the knowledge of carers during PLWD time in the imaging or therapy department was found to support a more personalised approach to care leading to better outcomes for all involved.

Discussion:

The findings identified three key themes linked to both facilitators and barriers to optimising care for PLWD. The first was that radiography practitioners recognised the importance of adapting and providing PCC to PLWD, but workforce pressures made putting this into practice difficult. For example, participants working in busy departments had limited time available with PLWD as there was no flexibility to react to their needs along with a culture of rushing to complete tasks and focus on technical skills [17]. However, our findings suggest a way to improve PCC for PLWD would be to have more forewarning in place to identify the need to allow more time, including time spent communicating with the PLWD and carer.

The second theme was the need for further role-specific dementia education and training, as previously identified in the literature [7, 9, 12, 13]. Participants unanimously supported the need for more education and training in dementia care in both imaging and radiotherapy departments, despite the array of resources available including SoR guidance [7]. Our findings would seem to indicate that these resources are not meeting the needs of practitioners in the clinical workplace to optimise care to PLWD, and specific training or education aimed at radiography practitioners is needed. It was also suggested that training should commence at undergraduate level and there was a need to develop foundational

1 knowledge via regular continuing professional development (CPD) activities. Nonetheless, it
2 was acknowledged that sustaining dementia training could be difficult in a busy department.
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4 Participants suggested that video resources sharing the experience of PLWD, or their carers
5 could be used, so they were seen as real people. However, challenges to training included
6 access to resources, such as e-Learning for Health for those not employed in the National
7 Health Service (NHS) or time to attend such training as it was not given priority.
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15 In the third theme carers were seen as important to providing a positive patient experience
16 and supporting PCC, but there was also a perception by some participants that there could
17 be issues based on their relationship to the patient. For example, a family member may
18 know the PLWD better and provide support, as opposed to a carer who may have met the
19 PLWD for the first time when attending the department. Challen et al., [9] have previously
20 highlighted issues around poor carer inclusion, but our findings would seem to indicate a
21 positive shift in radiographers' attitudes and understanding of carer inclusion since 2018.
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32 **Limitations**

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34 Despite this being a nationwide study, recruitment to the OFGs was perhaps lower than
35 expected (especially for therapeutic radiographers). However, the wide geographical area
36 participants support the findings representativeness of experience and practice. Phase 1
37 participants may have self-selected and therefore have had an interest in dementia;
38 however, the study did include perspectives from a range of professional experience and
39 backgrounds. Wide recruitment from members of the core stakeholder group was not
40 achieved, but the data provided can still be considered relevant in relation to the study
41 aims.
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53 **Conclusion and recommendations**

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55 This study has identified themes linked to optimising the patient care provided to PLWD when
56 attending imaging and radiotherapy departments. Participants reported that training needed
57 to be specifically aimed at radiographers rather than being generalised from other disciplines
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and should represent the lived experience of dementia. Despite policy and research growth in this area there is still a need for further research to explore how radiography practitioners can be supported in delivering optimised care to PLWD.

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Icebreaker/Introduction	Can you please introduce yourself by sharing a little bit about your professional background and years of experience
Question 1	Please describe in a few sentences what you do so that persons living with dementia and their carers get support when undergoing imaging/therapy in the department?
Question 2	Think about how you interact with people living with dementia and their carers when attending the imaging/therapy in the department. What are the challenges? What makes it easier?
Question 3	Please describe a situation (good or bad) that you have experienced when delivering care for those living with dementia or their carers when undergoing imaging/therapy
Question 4	What do you think people living with dementia and their carers expect from you when attending for imaging/therapy in the department?
Question 5	What do you think about the role of the carer in these situations?
Question 6	What protocols or guidelines for caring for people living with dementia have you come across in practice?
Question 7	Against the background of your experience what would help you to better support people living with dementia and their carers when undergoing imaging/therapy in the department?
Question 8	Are there any existing programmes in place in your place of work to help develop and improve your care for those living with dementia and their carers, e.g. training programmes?
Question 9	What do you think should be done (if anything) to improve the delivery of care for people living with dementia undergoing imaging/therapy in the department?
Question 10	Is there anything that should have been discussed, but not mentioned here?

Table 1. Phase 1 Online focus group questions

Question 1	What do you think people living with dementia and their carers expect from radiography practitioners when attending for imaging or radiotherapy?
Question 2	What do you think might be the barriers (if any) in how radiography practitioners provide patient centred care for PLWD?
Question 3	What do you think might be the barriers (if any) in how radiography practitioners and involve the carers for PLWD when attending imaging or therapy departments?
Question 4	What do you think might be enablers to help radiography practitioners provide a patient centred care for PLWD when attending imaging or radiotherapy departments?
Question 5	What do you think might be enablers help radiography practitioners involve carers for PLWD when attending imaging or therapy departments?
Question 6	What do you think about a carer policy to help provide advice and guidance for radiography practitioners when involving carers in the support of PLWD?
Question 7	What do you think about the idea of dementia leads in imaging and therapy departments?
Question 8	What would you consider to be a supportive environment for PLWD?
Question 9	What learning do you think radiography students need when preparing to care for PLWD?
Question 10	What do you think are the training and education needs for qualified radiography practitioners?
	Any further comments or items not discussed that you would like to raise?

Table 2. Phase 2 Individual interview semi-structured questions