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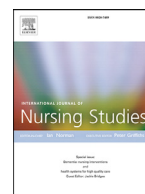
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# Balancing the needs of individuals and services in cancer treatment for people with dementia: A focused ethnographic study

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## ABSTRACT

**Background:** Managing multiple conditions is difficult for patients and their families, increasing complexity in care. Two of the most common long-term conditions, cancer and dementia, both disproportionately affect older adults. However, little is known about the needs and experiences of those living with both conditions, which could inform practice in the area.

**Objectives:** This focused ethnographic study sought to understand how oncology services balance the unique and complex needs of these patients with those of the service more widely.

**Design:** Focused ethnography.

**Setting:** Two National Health Service hospital trusts.

**Participants:** Seventeen people with dementia and cancer, 22 relatives and 19 staff members participated.

**Methods:** Participant observation, informal conversations, semi-structured interviews, and medical notes review.

**Results:** Improved satisfaction and outcomes of care were reported when staff were delivering person-centred care. Staff tried to balance the need for personalised and flexible support for individuals with dementia with managing targets and processes of cancer care and treatment. The importance of continuity of people, places, and processes was consistently highlighted.

**Conclusion:** Navigating and managing the delicate balance between the needs of the individual and the needs of services more widely was difficult for both staff and patients. Improved awareness, identification and documentation of dementia would help to ensure that staff are aware of any specific patient needs. Consistency in staffing and appointment locations should develop familiarity and routine for people with dementia.

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## What is already known

- Cancer and dementia both disproportionately affect older adults
- People with dementia are less likely to receive timely cancer screening, curative treatment and adequate pain management than patients without dementia

## What this paper adds

- Staff and patients face a range of challenges in navigating and managing the tensions between meeting the needs of the individual with cancer and dementia through delivering person-centred care, and adhering to the processes and targets that drive oncology services.
- Personalised support is required for people with dementia to successfully navigate the cancer care pathway.
- Oncology staff do not always have the time, training or resources to allow them to support patients with dementia appropriately.

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## 1. Introduction

The self-management of long-term conditions places demands on patients and their families (McCorkle et al., 2011; Howell et al., 2017). Individuals living with multiple conditions, known as multimorbidity, frequently require complex care and support from a range of health and social care services over extended time periods (Albrecht et al., 2016). With increasing complexity and cost in caring for those with multimorbidity, healthcare systems are challenged to find innovative and appropriate approaches to meet their needs (Newbould et al., 2012).

Two of the most common long-term conditions, cancer and dementia, disproportionately affect older adults (Smith et al., 2009; Prince et al., 2015) and providing cancer care and treatment for ageing populations with complicating comorbidities including dementia is a growing global challenge. Within the UK, oncology diagnosis and treatment are mainly provided in secondary care in hospitals that provide acute medical care, through outpatient 'clinics', following a GP referral to these services. Although, this process can vary by cancer location (Brown et al., 2014) and many people receive their diagnosis after an emergency hospital attendance or admission. Dementia diagnosis and post-diagnostic support are primarily undertaken by clinicians working in secondary mental health services, although there are some primary care led diagnostic services in some regions of the UK. In many cases people are discharged back to care of their GP following a dementia diagnosis (Wells and Smith, 2017). Dementia services have referral and diagnosis targets, and within oncology services the focus is on waiting times for, and between, diagnosis and treatment (NHS England, 2021). While cancer specialists report providing care to increasing numbers of people living with dementia (Bartlett and Clarke, 2012), estimates of the numbers of people affected by comorbid cancer and dementia vary widely (McWilliams et al., 2018). Our large UK dataset study recently estimated that at least one in thirteen (7.5%) people aged 75+ have both diagnoses (redacted). However, to date, very little research has considered the needs and experiences of those living with both conditions. Studies of treatment outcomes for this patient group suggest they are less likely to receive timely cancer screening, curative treatment and adequate pain management than patients without dementia (Baillargeon et al., 2011; Hopkinson et al., 2016; McWilliams et al., 2018), experience later diagnosis and lower survival rates (McWilliams et al., 2018), and have more comorbid conditions than people with cancer or dementia alone (Collinson et al., 2019). Additionally, sometimes people with dementia and their families do not disclose memory problems to oncology clinicians, and clinicians do not always ask about dementia (Ashley et al., 2020; Courtier et al., 2016). In summary, current evidence does not provide a thorough understanding of the implications of dementia on cancer treatment and care experiences.

Although evidence around the prevalence and clinical outcomes of co-morbid cancer and dementia has been examined in various countries (e.g. USA: Baillargeon et al., 2011; Japan: Iritani et al., 2011), the direct experiences of people living with both conditions have rarely been explored. This limited research has mainly been conducted within small UK based studies. Previous papers have highlighted that dementia is poorly identified or recognised within oncology services and can limit the treatment options offered (Courtier et al., 2016) and that existing cancer treatment pathways are inflexible and unresponsive to the needs of people with dementia (Witham et al., 2018). Dementia brings many complexities to decision-making and treatment (e.g. Cook and McCarthy, 2018; Griffiths et al., 2020), which can lead to patients experiences straying from the optimal cancer treatment pathway (Hopkinson et al., 2020). Families are integral in the management of cancer care for those with dementia, facilitating patient-clinician communica-

tion, supporting treatment adherence and monitoring side-effects (Kelley et al., 2020; Martin et al., 2019; McWilliams et al., 2018). However, we currently lack a triangulated understanding of how these many factors are considered and balanced, or how this affect patients, relatives, and staff, which is explored in the current paper.

As the evidence base is currently so limited, it is not known how staff working in oncology services in different countries balance the unique and complex needs of these patients with those of the service more widely. This paper aims to describe these issues in practice within one country, as one theme of a larger UK study exploring the cancer care experiences of people living with dementia (redacted, 2020).

## 2. Methods

Data were collected by two authors (redacted) using a focused ethnographic approach, involving short-term ethnographic data collection and examination of a distinct problem or phenomenon in a specific context (Rashid et al., 2019). This comprised observations, informal conversations, semi-structured interviews and reviews of medical notes, between September 2018 and May 2019. Both researchers were female with dementia and healthcare service research backgrounds. Non-participant observations, whereby researchers did not interact with anyone within the environment (exploring routine use of oncology and radiotherapy departments) were conducted, followed by participant observations, during which informal conversations were held with participants to explore their 'in the moment' experiences (Hammersley, 2015). These observations took place within oncology and radiotherapy departments, including reception, waiting areas, and treatment rooms. This approach facilitated the involvement of people with dementia who may have found formal interviews difficult to participate in. Observational fieldnotes were handwritten and typed up into fuller fieldnotes. Relevant information was extracted from participants' medical records. Interviews were conducted in private spaces (e.g. participants' homes, hospital quiet rooms) and explored experiences of cancer treatment and care. People with cancer and dementia and their relatives were interviewed individually, or as a dyad/group, depending on preference. Interviews were audio recorded and transcribed verbatim. Participants chose to participate in observations (if receiving cancer treatment at a participating site), semi-structured interviews, or both.

### 2.1. Participants and sampling

People with confirmed or suspected dementia (indicated by a FAST score (Reisberg, 1988) of 4 or above), were eligible to participate if they were currently or had recently (within 2 years and alongside memory problems) received cancer treatment or care (see Table 1 for demographics). Participants were recruited from two National Health Service (NHS) Trusts in Northern England providing local cancer services (e.g. surgery, chemotherapy), with one also providing specialist regional provision (e.g. radiotherapy). Staff members identified and approached participants at post-diagnostic clinic appointments to establish interest in speaking to a researcher about the study. We also recruited people who had completed cancer treatment via local community groups and social media. We used purposive sampling (Palinkas et al., 2015) to recruit participants with a range of cancer diagnoses, treatment experiences and demographics, and staff members working in different oncology roles. Where possible, we recruited staff who had provided care to participants in the study.

**Table 1**  
Participant demographics (N = 58).

	n (%)
Participants with cancer and dementia (n = 17)	
Female	10 (59)
Cancer type	
Lung	8 (47)
Prostate	4 (24)
Breast	1 (6)
Gastrointestinal	1 (6)
Other	3 (18)
Dementia diagnosis	
Alzheimer's disease	6 (35)
Vascular dementia	3 (18)
Fronto-temporal dementia	2 (12)
Posterior cortical atrophy	1 (6)
No confirmed diagnosis	5 (29)
FAST score (for those without diagnosis, n = 5)	
4	5 (100)
Ethnicity	
White British	16 (94)
Hispanic	1 (6)
Age (M,range) (n = 13)	75 (45–88)
<b>Relatives (n = 22)</b>	
Female	14 (64)
Relationship to participant	
Child	12 (55)
Spouse	7 (32)
Sibling	2 (9)
Grandchild	1 (5)
<b>Staff (n = 19)</b>	
Female	14 (74)
Role	
Clinical Nurse Specialist	8 (42)
Radiographer	7 (37)
Consultant	2 (11)
Social worker	1 (5)
Patient transport officer	1 (5)

## 2.2. Lay advisory group (LAG)

A LAG contributed to all aspects of research delivery, including piloting interview topic guides, conducting data analysis, and dissemination. This comprised one person living with comorbid cancer and dementia and three people with experience of supporting a family member with both conditions. They were recruited via the research team's existing networks.

## 2.3. Data analysis

Concurrent data collection and analysis was conducted using ethnographically informed thematic analysis (Fetterman, 2010), informing subsequent data collection. Analysis explored content and patterns in the data via triangulation across participant groups and sources, through a coding framework. This was discussed and refined with the wider research team, including LAG, and developed as data analysis progressed. The staff and person with dementia/relative interviews, plus a sample of observational field notes, were initially analysed separately, then combined into an overall thematic framework. After completion of coding, definitive themes were finalised through further review and discussion.

## 2.4. Ethical issues

Ethical approval was gained from the [redacted] Research Ethics Committee. Written informed consent was obtained for interviews and in-depth observations. Those with dementia who were deemed to have capacity to consent provided this, with advice provided by a consultee for people lacking capacity (Mental Capacity Act, 2005). Verbal consent was gained from staff members in-

involved in less in-depth observations. Ongoing consent was established prior to each observation.

## 2.5. Reflexivity

The influence of the researchers on data collection was explored via a reflective diary and discussions with the research team. This included acknowledging the researchers' backgrounds in dementia research and clinical practice. Conscious attempts were made to recognise such biases throughout data collection and analysis. This was helped by a wider group, with varied backgrounds, conducting data analysis.

## 3. Results

Observations and informal conversations (totalling 46 h) were conducted with 12 people with cancer and dementia, 8 of whom also participated in interviews, and their families (see Table 1 for demographics). A total of 37 interviews were conducted (13 people with cancer and dementia, 18 relatives and 19 staff), lasting between 9 and 122 min due to varying communication abilities and participant preference. Medical notes were reviewed for 12 participants.

Three key themes were developed, each with sub-themes (see Table 2 for overview);

- 1 Delivering person-centred care
- 2 Managing targets and processes
- 3 Continuity of people, places, and processes

### 3.1. Delivering person-centred care

Although person-centred care should be standard practice, people with dementia particularly benefit from personalised care (where patients and their families have choice and control over the way their care is planned and delivered; NHS England, no date). Delivering person-centred care that met the needs of individuals with dementia and their families was imperative to oncology staff, particularly given the relatively regular contact they had with patients to deliver treatment and care over a period of time, which is unusual compared to other outpatient services. This involved 'knowing the person' and providing 'flexible support' tailored to individual needs, underpinned by 'good communication'.

#### 3.1.1. Knowing the person

Detailed understanding of the person's cognitive impairment, and how this might impact on them receiving cancer treatment and care, facilitated person-centred care. Challenges arose when limited information was available about the person's dementia-related needs, for example from their GP or care home. This impacted on oncology staff's abilities to provide care in a person-centred way, and was particularly pertinent for example when conducting invasive examinations or clinical tests required for cancer diagnosis and treatment, without knowledge of how to reduce someone's distress.

*"How do you examine somebody if they're not able to give consent to that? If they're verbally very agitated and distressed, then that can be really challenging." (B007, Breast Cancer Nurse Specialist [CNS])*

Staff delivering treatments asked questions to get to know patients with dementia better, for example, about what might help if they felt worried about treatment, and tried to discuss topics that interested them. Whilst this might be helpful for many older patients, it could be complicated, and potentially distressing, for some people with dementia, who may be unable to recall answers,

**Table 2**  
Themes and sub-themes.

Main Theme	Sub Theme
<b>Delivering person-centred care</b>	Knowing the person Flexible support benefitting patients and staff Communication approaches
<b>Managing targets and processes</b>	Reactive vs proactive recognition of needs Adaptation to processes
<b>Continuity of people, places, and processes</b>	"Conveyor belt care"

or answer consistently across multiple appointments. Whilst family members usually provided support in such cases, this was not always possible, for example in radiotherapy, where family members were not permitted in the same room. Here, understanding conversational preferences and abilities was particularly important to being able to deliver radiotherapy safely and effectively to people with dementia.

*"A lot of it is just asking. Then when they're forgetting stuff or you ask them something and they can't remember, it's that kind of awkward conversation as well. At the same time, you don't want to upset them just for the sake of you making idle chit chat whilst you're in the room trying to be friendly. Sometimes, you could cause more upset than good. It's difficult to gauge."* (L0022, Radiographer)

Information about how dementia might impact on appointments was sometimes noted within medical notes to support personalised care delivery and avoid potential distress. This was helpful for staff, who were able to quickly identify specific ways to support patients or prevent distress as was identified in the example below regarding the permanent pin-point tattoos that are often placed on a patient's body to enable alignment of the radiotherapy treatment. In this case the patient was not able to remember she had the tattoos between appointments.

*'Self-conscious when undressing so needs female radiographers. Was shocked, almost distressed when tattoos were mentioned – please do not mention tattoos.'* (L001, Medical Notes)

### 3.1.2. Flexible support benefitting patients and staff

Staff offered personalised support and flexibility to patients with dementia during cancer treatment, including practices not offered to other patients, for example flexibility around appointment times or lengths and sending consultation letters to relatives with agreement from all parties. For example, when individuals with dementia struggled with mood or agitation in the morning, appointments were scheduled for the afternoon. Many staff built on what patients with dementia and families said worked for them, through getting to know them, their routines, and their abilities.

*"I think looking at different ways that work for [people with dementia]. So, saying, what works for you already? What do you do? I'd always start with that, rather than try and come up with something, because people don't engage with it."* (B008, Lung CNS)

Flexible approaches for those with more advanced dementia helped support people who may struggle to understand the treatment experience. For example, a loudspeaker system, which allowed conversation with staff outside the radiotherapy treatment room, was used to maintain conversation with some participants with dementia during treatment.

*I: [Radiographer] used to speak to you over the tannoy [loudspeaker system]. Did that make you feel calm?*

*P: That's right, yes.*

*I: Would you have been less calm if you were just there on your own?*

*P: I think it's nice to have somebody... if they just have a word, you feel welcome then don't you? (L002, lady with cancer and dementia)*

These adaptations benefitted both staff and patients, as patients were more likely to attend and be relaxed during multiple appointments.

*"If we can treat them ... keep their routine as much as they can. If we can get time where they're well – that's benefitting everybody. That's benefitting patients, that's benefitting us, really, isn't it?"* (L0042, Patient Support Advanced Radiotherapy Practitioner)"

Sometimes, however, staff teams were unaware of the specific needs of patients with dementia and their families. Patients with dementia did not always feel a sense of agency to challenge staff or request changes, perceiving this as immovable or *"the appointment we'd been given"* (L0039, daughter of man with cancer and dementia).

In addition, not all staff understood how dementia might affect the person's behaviour or needs. In certain cases, staff labelled patients as 'difficult', or disregarded or misunderstood the impact that dementia could have on the person's cancer care. Staff sometimes focussed on supporting these patients to move on or back to other departments they perceived as better suited to meeting their needs.

*"If they've got UTI's, infections can make them more confused ... I think they should go back to where they originated from as soon as possible, because when they start to feel well, they absolutely kick off. While they're poorly, they're really easy to manage."* (L007, Urology CNS)

### 3.1.3. Communication approaches

A wide variety of communication approaches were seen. Good communication was at the heart of person-centred care delivery for patients with dementia, central to which was inclusion of the person with dementia.

*"What to me is the most important thing is treating every patient as a person and making sure that you speak to the person and not to their carer. That you're tolerant, that you have an understanding of how the dementia may be affecting the patient's ability to cope with their treatment."* (L0041, Consultant surgeon)

Ensuring that the person with dementia was central to the dialogue (i.e. spoken to directly, rather than just their family members) was key to developing relationships and is often a marker of good quality dementia care.

*"Whilst we [researcher, daughter and patient] wait for the lift, we chat and [daughter] tells me that she thought that went very well and that he [Consultant] was really good and very nice and that he spoke to her mum which is the main thing, that she [daughter] can listen and say things if she wants to, but it seems important to her to have doctors that talk to her mum first, as 'it's mum's body'."* (L0010–11, Field Notes)

Staff members highlighted that sometimes people with dementia were *'used to their relatives being asked how they are'* (L0042,

Patient information and support radiotherapy advanced practitioner), rather than them. In addition, some medical notes highlighted that professionals conversed primarily with relatives rather than the person with dementia themselves.

*"[Patient] has some memory issues and that's why most of the conversation was done with his daughter." (L0039, Medical Notes)*

People with dementia became upset or withdrawn when ignored, spoken over, or about, whilst they were present in consultations. One participant described feeling like 'a kid in the corner' (B009, man with cancer and dementia).

*"The doctor asks if [patient] is 'back to normal?' She replies 'Yeah' but her husband follows with 'No'. She shakes her head to signal disagreement with this in an exasperated manner. Her husband says she is not able to do things at home, which she again shakes her head in disagreement with, looking towards me [researcher] with an exasperated look. Her husband continues that she is still 'short of breath', 'slowed down' and is 'struggling to walk far'. I [researcher] look over to her again. Her arms fold defensively as the conversation about her continues between the doctor and her husband over her head." (Field notes, L0023–24)*

Using an appropriate approach and conversational tone was important, which happened to varying degrees within practice. Conversation styles which showed a developed and ongoing relationship, sharing knowledge and friendly exchanges, enabled people with dementia to gain a sense of familiarity and reassurance with otherwise unfamiliar environments and people.

*"[Surgeon] cycles almost past [patient]'s house and knows the area she lives in. She comments jokily that he hasn't been past yet and says she has been 'standing on the corner in all bad weather' waiting for [surgeon] to come past so she can push him off his bike. They laugh about this." (L004–5, Field Notes)*

Staff perceived that extra attention to communication and a personalised approach allowed them to effectively communicate with patients with dementia. They highlighted the need to 'really check their understanding and write things down more' (B005, Lung CNS).

*"If they've got dementia, you will know by the end of the conversation. You clarify what you've said to people. You ask them to, can you just explain to me what you understand about what I've said, if you're concerned that they've not understood. I guess in medical terms, to some people, it's a foreign language." (L007, Urology CNS)*

However, clinicians sometimes used approaches that did not recognise the communication needs of people with dementia. For example, asking questions that were difficult to answer, required recall of past experiences, or were delivered in quick succession. Sometimes assumptions were made that patients with dementia could understand and process complex information quickly, including medical terminology or instructions for medication, which were noticeably difficult for the person to process.

*"During the conversation about pain management, the Doctor asked [patient] specific questions that she struggled to answer, looking to her daughter for support. A few times her daughter corrected her answers, which led to [patient] looking embarrassed and withdrawing eye contact from the Doctor, looking at her feet instead." (L0038, Field Notes)*

At times, communication approaches were infantilizing i.e. 'happy in his own little world' (L007, Urology CNS) or based on stereotypical views of people with dementia as incapable of understanding conversation.

*"Some will just do as they're told, and they're fantastic. They don't know where they are, but somebody just told them to do something, so they do." (L0042, Patient support worker)*

On some occasions, poor communication, for example providing too much information too quickly or giving unclear instructions, left people with dementia unaware of what was happening. This could also lead to issues around dignity for example, where removing clothing and subsequently putting on a gown was not clearly explained and so not undertaken correctly.

*"[Patient]'s chemo drugs were not working on the first machine, so [nurse] brought a second machine. [Patient] was confused about this and wanted to know what was happening. [Nurse] did not explain but just changed it over. [Patient] became visibly distressed, asking questions in quick succession. 'What's going on? Why is it beeping? Why are you getting another?'" (B0010–11, Field Notes)*

In summary, staff engaged with patients and their families to understand their specific needs, which improved their experiences. Communication approaches varied, and where communication was unclear, this sometimes led to inappropriate outcomes that lacked dignity.

### 3.2. Managing targets and processes

Balancing the need for personalised and flexible support for individuals with dementia often created tension with the target and process-driven nature of cancer treatment. These features of the oncology department environment made it difficult to implement personalised care, but patients were particularly negatively impacted by 'reactive versus proactive care' and benefitted where 'adaptions to processes' were possible. Staff experienced tensions trying to maintain this delicate balance.

#### 3.2.1. Reactive versus proactive recognition of needs

Where possible, delivering care in a proactive way benefitted people with dementia and their families. This included inviting people with dementia into treatment departments for familiarisation visits ahead of treatment and to discuss any support needs, allowing families to help their relative 'settle in' to treatment, and scheduling follow up appointments via telephone where possible. This reduced distress and the burden of coming into hospital for the person and their family. However, by doing this, increasing onus was placed on families or care homes to manage the person's care, monitor any changes in symptoms and notify the hospital accordingly.

*"We've tried to do a bit of education with the family. So, these are the things you would watch for and you can bring [patient] if there's something changing. But actually, if you're happy that things are fairly stable, then we will just continue to manage this conservatively, without bringing back routine appointments." (B007, Breast CNS)*

However, pressure to provide an efficient service could mean that adaptations for people with dementia, such as longer appointments or additional support, occurred reactively, if issues arose, rather than being proactively planned.

*"I feel like there's a bit of a focus on just getting them through treatment ... not dealing with the reasons behind why they're nervous or whatever, but things could be done. Sometimes, I feel like it gets to the point where they're on treatment and it's like right, we'll deal with it now... why wait to the point where they get to treatment? Let's try and put something in place earlier. (L0022, Radiographer)*



Proactive care was possible when personalised needs had been identified. Having team members responsible for patient support helped to ensure proactive care, although these teams often had multiple patients requiring support meaning waits for their attendance could delay treatment schedules. Additionally, patients reported benefitting from having a named Cancer Nurse Specialist (CNS) who they could contact if they had any questions in between appointments. Although this is standard practice, staff felt the familiarity and personal knowledge of a specific nurse was particularly beneficial for patients with dementia. Examples in medical notes highlighted times where, through communication with their CNS, patients had raised concerns and the CNS had sought alternative treatments on their behalf.

*"The hormone therapy has affected him quite dramatically. Not coping with catheter. [Daughter] states he has been sleeping for much of the day. His-catheter is making him inactive as he is unable to get out and swim now he has a catheter. Will speak to [Consultant] and try to arrange trial without catheter sooner. I have suggested he has one more monthly injection and we review the situation after that. I will arrange for him to be reviewed in the medical clinic before his next injection is due." (L0039, Medical Notes)*

### 3.2.2. Adaptation to processes

Whilst staff were often working within strict, time-limited processes, in some cases they adapted these to incorporate specific needs of people with dementia. For example, before each radiotherapy treatment, patients must provide their full name and date of birth. Where patients with dementia were unable to remember this, some staff suggested patients bring this with them on paper instead.

*"If we can manage to ID them once, we might get them to put a hospital wristband on so that we can check that every day. We've got the photo on the screen as well, which obviously isn't in our official guidelines for ID'ing people. But if they've been able to tell you their date of birth and then you can see from the picture that it's them..." (L0022, Radiographer)*

Where possible, staff scheduled longer or additional appointments to accommodate individual needs, for example when making decisions around treatment. Staff members acknowledged *"with the resources in the NHS at the moment, that gets harder and harder"* (B005, Lung CNS), describing it as a *"logistical nightmare"* (L0028, Therapeutic Radiographer). Additional appointments were made, often in 'breach' of targets, despite being considered essential to an informed choice being made.

*"We have to make time. It's very challenging, especially if you get somebody in a very busy clinic ... Sometimes we might bring them back to another assessment clinic. We might give them limited information on that day and say, 'we need to discuss in a lot more detail, so why don't we book in a bit more time to do that?' I think otherwise, you make poor judgements, don't you? They might do something that potentially has a big impact for them that they've not had enough time to consider, so we make time, but it's hard when there's cancer targets as well." (B007, Breast CNS)*

When working reactively, staff consistently demonstrated efforts to prioritise dementia-related needs, despite knock on effects of this for clinic timings.

*"I think it means perhaps making somebody else wait another five minutes, but everybody is an individual and if somebody needs extra time then they need that time." (L0025 Radiographer)*

In summary, staff were pressured to meet strict cancer-related targets and procedures within oncology services. Despite this,

many staff made specific efforts to ensure that the individual needs of people with dementia were considered and met.

### 3.3. Continuity of people, places, and processes

Staff recognised that people with dementia benefitted from familiarity and made efforts to provide continuity within care. Examples of staff adapting practices to achieve this included ensuring consistent staff or treatment rooms.

*"[Patient] was very confused. She didn't know why she was coming every day. We just took the time every day. We got her longer appointments and tried to make sure that at least one of the same people treated her everyday if possible, that there was somebody that she recognised." (L0025, Radiographer)*

Getting the balance right for each patient and their family involved sensitivity and consideration of their individual circumstances.

*"[Husband speaking over tannoy] worked really well for that patient because she would keep still because he kept telling her to stay still. She obviously remembered who he was as opposed to us that she'd never met before. How would you feel if you were laid down, strapped to a bed and some stranger was talking to you telling you to keep still but you had no idea why? You'd be really scared, wouldn't you?" (L0022, Radiographer)*

People with dementia found continuity important, regularly commenting on familiar corridors, treatment rooms or staff members.

*"[Patient] told me 'some things I find really easy to remember, but I really struggle with faces and names. I know [Nurse] in here but if I saw her outside of hospital I wouldn't know who she was.' I asked if the Nurse had introduced herself. [Patient] told me 'she did the first week but I don't know her name now, I just say hi. When she called me in she said 'oh we've met before' and I'm thinking 'have we?!'." (B009, Field Notes)*

Ensuring effective running of departments sometimes meant that continuity was not possible. Patients and their families developed trusting relationships that supported their confidence to ask questions and indicate any uncertainties. Patient support teams helped to ensure a familiar face was present. Where continuity of people was not possible, issues arose, such as disclosure of diagnoses that patients and their families were unaware of, in potentially insensitive ways.

*"Doctor: the pain you're describing is in keeping with cancer in the spine.*

*Patient: it's in the spine?*

*Daughter (visibly surprised): we thought it was in the lung.*

*Doctor: it started there, it's spread to the spine."*

*(L0038, field notes)*

#### 3.3.1. Conveyor belt care

Alongside the person-centred practices observed, there were instances where processes dominated and individual needs were not met. For example, in a single day, patients often saw multiple clinicians in different departments. This resulted in a more impersonal approach, particularly for tasks such as blood tests in between treatments, where individuals were asked to *'take a ticket'* and felt *'just a number in there'* (L0018, Daughter of woman with cancer and dementia). Treatment plans did not always consider the cumulative burden or consistency across multiple components of treatment and their associated waiting times and the impacts of these for people with dementia.

*"They don't appreciate why we get so agitated is because if she's going for bloods, it's adding an extra hour or two to an eight-hour day and for (mum) that's quite difficult." (L0018, daughter of lady with cancer and dementia)*

This was particularly the case for people who were younger, who had rarer forms of dementia or who were not formally diagnosed with dementia. These individuals were more at risk of staff failing to recognise they had dementia, particularly those with non-memory related symptoms. In contrast to this, one family highlighted that at a time where care could have become conveyor belt like, staff ensured that each patient was seen as an individual by greeting them in a friendly manner and using their name.

*"Because at that point it could be a production line, couldn't it? That's where it could shine through that you're just another number. But it wasn't." (L0017, sister of lady with cancer and dementia)*

However, within departments such as chemotherapy, where staff often worked under significant pressure, responsive to patients needs was a particular issue, impacting how patients and their families perceived the care process.

*"Husband: If you had a problem, like [chemotherapy IV] blocked and the alarm went off, nobody bothered.*

*Patient: No, they just left it while they tended to everybody else.*

*Husband: You could be ten, fifteen minutes waiting. If you went to find somebody "oh yeah we'll be there shortly". Nobody bothered.*

*Patient: it's not a case that they're not bothered, there's just not enough staff."*

*(B001–2, person with cancer and dementia and husband)*

In summary, offering continuity of people, places and procedures reassured people with dementia and their families. However, the adaptations required to support people with dementia were not always considered or possible.

#### 4. Discussion

Whilst dementia is known to lead to additional complexities in cancer care and treatment, we do not currently fully understand the reasons for dementia-related disparities in cancer care. This paper provides unique insights into how staff and patients navigate and manage the delicate balance between the needs of the individual and the needs of services more widely, as reported by these individuals or observed by researchers. This highlights specific factors that could improve adherence if implemented by oncology services.

In line with existing research (e.g. Witham et al., 2018), we found that the need to deliver person-centred care, considered best practice within dementia care (Brooker, 2004), was consistently highlighted by participants. Many staff demonstrated how this was possible within busy departments. This included staff adapting consultations to improve communication and understanding, such as providing personalised reminders of key information, offering appointment time and location flexibility (Ashley et al., 2020), and ensuring family involvement (Witham et al., 2018). However, oncology staff also report being unsure how to provide appropriate care for this population (Courtier et al., 2016), lack clarity on identifying the signs of dementia (Hopkinson et al., 2020), and recognise that they may not have appropriate training to understand the impact of dementia or risks associated with treatment for this population (Ashley et al., 2020; Hopkinson et al., 2020). As the number of people with dementia continues to rise, it is imperative that dementia education and training is provided to the oncology workforce, to improve understanding and ensure appropriate support is provided to people with dementia and their families.

This should reduce the reported challenges in communicating with people with dementia within oncology services (Hopkinson et al., 2020; Martin et al., 2019). Systematic reviews of dementia training programmes for acute hospital staff (Surr and Gates 2017; Scerri et al., 2017) do not identify any programmes specifically for staff working in oncology. In addition, research and practice improvement initiatives around dementia in acute hospital settings have focused on improving inpatient services (e.g. Royal College of Psychiatrists, 2019). Emergent research from oncology outpatient services indicates the importance of dementia education and practice development programmes, in order to improve care for people with dementia in general hospital outpatient departments (Ashley et al., 2020).

Managing targets and processes within cancer care, where there are strict and externally imposed waiting time targets, can lead to a sense of urgency to make decisions about and begin cancer treatment (McWilliams, 2020). Previous research has suggested cancer treatment pathways lack flexibility to meet the needs of those with dementia (Witham et al., 2018). In contrast, in the present study, we observed many staff trying to offer flexibility wherever possible to support individual needs and preferences. For example, where the impact of dementia on the understanding of treatment options was recognised by staff, patients were able to make well-informed decisions with their families (Griffiths et al., 2020). People with dementia frequently needed more support and time before treatment, which may impact on targets. Allocating time for people to familiarise themselves with the department before commencing treatment could help increase preparedness and reduce the impact of dementia on cancer-related targets. This may include offering opportunities to visit departments before treatment begins or explaining treatment processes using images and videos of treatment rooms (Ashley et al., 2020).

The importance of continuity of people, places and processes within cancer treatment was clear. Whilst cognitive impairment is known to reduce treatment adherence (Puts et al., 2014), the present research identifies specific factors that could improve adherence and satisfaction. People with dementia should receive treatments in appropriate environments (Reilly and Houghton, 2019). Relatively small changes such as appropriate signage, colour schemes, and opportunities to engage in activities, can improve the dementia friendliness of outpatient units (The King's Fund, 2013) and help people to navigate through oncology departments (Surr et al., 2020). Additionally, reducing waiting times where possible (Surr et al., 2020), using the same treatment room (McWilliams, 2020) and the same clinicians, could help to improve patient experiences through familiarity and routine. In the present study, utilising patient support teams helped ensure familiarity in staff teams, and having a named CNS provided reassurance to patients and their families, although no CNSs had received dementia-specific training. As cancer care involves multiple lengthy appointments over a period of time, understanding these issues is an important avenue for future research.

There are several limitations associated with the present study. The study was conducted in one area of the UK, across two NHS Trusts, and the experiences of people with cancer and dementia may vary between hospitals and NHS Trusts, with further research in the UK and internationally required to validate our results. Within the NHS, healthcare is offered free at the point of use, which may influence patient likelihood to seek diagnosis and treatment. Additionally, as we only recruited participants who were receiving cancer treatment within hospital settings, we do not yet understand the experiences of those who opt not to receive any treatment. As is typical for many studies involving people with dementia, around a third of patient participants did not have a formal diagnosis of dementia and probable dementia was indicated through use of a widely used dementia severity assessment tool.



This further highlights the importance of routine assessment questions focused around cognitive impairment in services such as oncology where many older people are treated. Our sample was predominantly White British and, apart from one participant, all patient participants had at least one family member who regularly attended appointments with them. Therefore, our sample may not be representative of the population of people with comorbid cancer and dementia more widely. However, a very low proportion of study eligible patients from Black, Asian and Minority Ethnic groups are likely to be present in oncology services of a hospital at any given time. It is estimated that only around 25,000 (3%) of people with dementia in the UK are from these communities (Baghirathan et al., 2020), an issue confounded by low diagnosis rates (Pham et al., 2018). Of these individuals, only a small proportion would also be diagnosed with cancer. Therefore, future studies wishing to consider the needs of people from Black, Asian and Minority Ethnic communities will need to consider how such recruitment challenges could be addressed. Additionally, participants tended to be in the earlier stages of dementia, and were frequently able to participate in interviews and informal conversations. Less is known about the experiences of those in the later stages of dementia, who may have different needs and challenges related to cancer care. Therefore, our sample may not be representative of the population of people with comorbid cancer and dementia more widely. Triangulation of data sources was not possible for all participants and we sometimes relied on retrospective reflections of their experiences. Although subjectivity is inevitable within ethnographic research, we mitigated this where possible by acknowledging our preconceptions before data collection began, having two researchers collecting data, reflexive journal keeping, group data analysis, and synthesis of multiple data sources. Additionally, the data presented here were collected before the COVID-19 pandemic. The COVID-19 pandemic is likely to have further magnified the difficulties people living with dementia face when accessing cancer services, for example the increasing need to travel alone, attend appointments without family members, and the difficulties of communicating when wearing facemasks. This further highlights the importance of recognising comorbidities such as dementia within oncology services.

Although this research was conducted within the UK, the results and clinical implications are relevant for those working in oncology services in other countries where person-centred approaches are promoted, taking into consideration their local context. Practitioners are currently working with little evidence-based guidance to support their practice. Several clinical implications arose from this paper that can be implemented in oncology services. These include improved dementia awareness, identification and documentation, through asking about dementia at initial appointments and understanding the potential impact of dementia on treatment and ensuring this is documented appropriately, to ensure that all staff are aware of the specific needs of cancer patients with dementia. Support for people with dementia to attend oncology services, such as offering flexibility in timing and location of appointments, may also improve care experiences. Where possible, appointments should be arranged at a time that suits the person with dementia, longer appointments should be considered, and clinicians should consider offering follow-up appointments by telephone (Ashley et al., 2020).

## 5. Conclusion

In conclusion, supporting the delicate balance between the needs of the individuals and the needs of services is particularly difficult when patients are living with dementia. Personalised support allows people with dementia to successfully navigate the cancer care pathway. Due to the lack of research in this area, staff are

currently working within a limited evidence base and frequently with limited training. Further research is required to understand how the factors identified in the present study influence the decision of people with dementia and their families on whether they seek cancer diagnosis and treatment, including how staff influence this.

## Declaration of Competing Interest

None.

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