**“A real fine balancing act”: a secondary qualitative analysis of power imbalance in comorbid cancer and dementia in an outpatient treatment setting**

**Abstract**

**Aims:** Studies of health services reveal a focus on provision of scheduled care at the expense of patient need, placing the health service in a position of power and the patient as passive recipient. This secondary qualitative analysis of a focused ethnography draws on the Foucauldian concept of power as pervasive and relational, to examine how an imbalance of power is manifested in situations where people with both cancer and dementia are being treated for cancer.

**Design:** secondary qualitative analysis of a focused ethnographic study.

**Keywords:** cancer; dementia; power; agency; discourse; shared decision making

**Data sources:** In the original study, qualitative data were gathered from observation and interviews with people with cancer and dementia (n=2), caregivers (n=7) and staff (n=20). The study was conducted in the outpatient departments of two teaching hospitals in England between January 2019-July 2021. Data from all sources were analysed for this secondary analysis using constant comparison.

**Results:** The principal theme was *balance*, encapsulating the competing priorities involved in delivering cancer treatment. There was tension between maintaining safetyand ensuring an individual’s right to treatment, and difficulty reconciling the needs of the system with the needs of individuals.

**Conclusion:** The pervasive nature of power can be harnessed to enhance the agency of people with cancer and dementia by incorporating principles of shared decision making.

**Implications for the profession and/or patient care:** We recommend incorporating the principles of personalised care to achieve more equitable power relations, reduce health inequalities, and ensure that cancer treatment offered to people with dementia is safe and appropriate.

**Reporting method:** EQUATOR (COREQ) guidelines have been used for reporting.

**Patient or public contribution:** Patients and the public were involved in designing the original research questions and the study protocol including documentation such as interview topic guides and participant information sheets.

1. **Introduction**

There is a dearth of research regarding the experiences of people with coexisting cancer and dementia, although literature is beginning to emerge (e.g., Surr et al., 2020). Estimates of the number of people living with cancer alongside a dementia vary (McWilliams et al., 2018), although a recent UK study estimated that 1 in 13 (7.5%) people aged over 75 years have both diagnoses (Collinson et al., 2019). Evidence shows people with dementia have poorer cancer outcomes than people without dementia. People with dementia are diagnosed with cancer at a later stage (Solomons et al., 2013), more likely to experience treatment complications (McWilliams et al., 2018) and have poorer overall survival (Robb et al., 2010). People with dementia experience inequalities in access to, and quality of, care (Care Quality Commission 2014), and frequently feel denied, ignored, or experience discrimination in healthcare (Alzheimer’s Disease International 2019) either as a direct result of the stigma associated with the diagnosis, or through indirect mechanisms such as failure to provide inclusive services.

1. **Background**

Power can be described as the ability to act in a certain way (Solar and Irwin 2010). Along with income and wealth, power is one of the fundamental determinants of health, and a key cause of health inequalities (Dickie et al., 2015). An imbalance of power, where there is a difference in the ability or capacity to act, is a health issue. That a power imbalance exists in the lives of people with dementia has long been recognised. Health and social care professionals usually hold the most power and the person with dementia the least in a hierarchical power structure (Bartlett and O’Connor 2010). The WHO (Solar and Irwin 2010) suggests that the right to health requires a redistribution of power, and that understanding power differentials is key to tacking health inequalities.

We argue that a Foucauldian perspective of power as relational and productive, rather than solely controlling and coercive (Foucault 1980), is central to developing strategies to mitigate the power imbalance. We argue that this can be done by redistributing power; specifically, by enhancing the ability and capacity of people with cancer and dementia and caregivers to act.

1. **The Study**

**3.1 Aims and objectives**

A qualitative study (Farrington et al., 2022) was conducted to understand the provision of treatment and support, and the experience of care for people with dementia undergoing cancer treatment in an outpatient setting. That study (and others such as Featherstone et al., 2019) revealed a focus on the organisation and delivery of scheduled care at the expense of patient need. This paper builds on the evidence of power imbalance in the original study, and using secondary qualitative analysis, answers the research question: ‘*how is an imbalance of power manifested in situations where people with both a cancer and dementia diagnosis are being treated for cancer?*’.

1. **Methods**

Using a focused ethnographic approach, data used in the original study and in this secondary qualitative analysis were collected through observation, interviewing and document analysis to scrutinise the cultural environment of outpatient oncology departments. Data were collected January 2019 to July 2021 and detailed field notes recorded. The study took place in the outpatient oncology departments of two large teaching hospitals in England, which provided systemic anti-cancer treatment (SACT: chemotherapy or immunotherapy) or radiotherapy. Interview participants included patients (people with dementia having cancer treatment), informal caregivers, and healthcare staff.

**4.1 Population**

Patient participants were purposively sampled to participate in interviews and observation. The study included participants who had a confirmed diagnosis of dementia, and were either currently receiving radiotherapy or SACT, or who had completed treatment in the last six months. Patient participants were identified via their clinical teams, and their agreement gained for the researchers to approach. Participants were approached face-to-face where possible, although during the COVID-19 pandemic, this moved to telephone calls. Participation in each of the three formal data sources was not mutually exclusive, nor was it mandatory; patients could be interviewed, observed, and consent to document analysis, alternatively they could only be observed, or only interviewed.

 Caregiver participants were family or friends involved in supporting a person with dementia through radiotherapy or SACT. They could participate alongside the person they were supporting, or alone. As with the patient participants, they were identified by the clinical teams, and gave their agreement for the researchers to contact them about the study.

Healthcare staff participants involved in the delivery of treatment and support to patients undergoing radiotherapy or SACT were recruited using purposive sampling.They included: oncologists, nurses, allied health professionals, and other members of the healthcare team including support workers, and management and administrative staff.

**4.2 Data sources**

A topic guide was developed with Public and Patient Involvement (PPI) contributors using UK National Institute for Health and Care Research guidance (NIHR 2023), providing discussion prompts for semi-structured interviews. Interviews began by inviting the participant to describe their experience of cancer treatment. Subsequent questions covered the treatment environment, the different healthcare professionals involved, and what other factors people found challenging or helpful during their experience of treatment. Interviews were digitally recorded and transcribed verbatim. They were most commonly conducted face to face in the clinic environment, but were also conducted via telephone after the onset of the COVID-19 pandemic.

General and focused observations were conducted to gain both generalised and specific views of the departments. During general observations, a specific person was not being observed, but attention was paid to the environment, behaviour and interactions amongst patients and staff, to allow the researchers to focus on the delivery and experience of care with the aims and objectives of the study in mind. Focused observations entailed a detailed study of a discrete experience, such as a pre-treatment consultation, or a treatment appointment. Attention was paid to interactions between people with dementia, caregivers and staff, how the treatment journey was organised, and factors that challenged or assisted all involved to navigate the treatment process. Comprehensive field notes were kept during observational periods. The field researcher occupied a position of ‘privileged observer’ (Wolcott 1988), as they held clinical roles within one of the departments studied. This meant they occupied a position of trust as both researchers and nurses, and were granted access that may not have been available to a non-clinical researcher. While this made the practical aspects of research easier, having this dual role was itself an element of the power dynamics of the department; the researcher occupied a position of knowledge and authority within the treatment environment. An awareness of this dynamic meant that the researcher endeavoured to identify themselves clearly as conducting research rather than working in a clinical capacity when interacting with participants.

Document analysis was relevant only for patient participants. On seeking consent for an interview, patient participants were asked if they consented for the researchers to access their case notes. These were analysed to elicit information about the patient journey within and beyond cancer care, and focused on the organizational, clinical and interactional processes involved in care delivery.

**4.3 Ethical considerations**

Formal written consent was sought for all who participated in a semi-structured interview. If patient participants preferred not to sign, they were able to provide verbal consent instead. Written consent was not sought for those who were involved in the study in other ways, including observation and informal conversations, due to the fluid nature of the clinical environment and the many personnel involved. Ethical approval was obtained from the South Central – Berkshire Research Ethics Committee (REC number 18/SC/0590).

**4.4 Data analysis**

 Primary qualitative analysis is reported in Farrington et al. (2022). For the secondary analysis reported in this paper, data were analysed using the constant comparative method (Charmaz 2007). Data from all sources including field notes from observations and case notes were collated using NVivo software and coded. Themes were developed and then refined and reviewed to include those which captured the story being told by the data in relation to power dynamics. This secondary qualitative analysis used the constant comparative method to understand power and power imbalance, with a view to further understanding (and eventually to mitigating) the standardisation of care at the expense of patient need.

1. **Findings**

This section reports data gathered from multiple sources. **Table 1** provides details of participants recruited for interviews. 15 hours of observation were carried out. Pseudonyms are used throughout this paper to ensure anonymity.

Aspects of data relating to power in this study coalesced into the theme of *balance*. Being balanced relates to steadiness, stability, fairness, and equality (imbalance meaning a lack of proportion, or a lack of equality). The act of balancing requires that different elements are placed in equal proportions, and therefore involves comparison, evaluation or assessment of the different elements involved, assigning value based on certain priorities. The theme of balance represents the varied and competing priorities involved in delivery of cancer treatment*,* and the balancing act that is necessary to navigate them.Within this principal theme, two sub-themes were developed: ‘balancing safety with the right to treatment’, and ‘balancing the system with the person’.

**5.1 Balancing safety with the right to treatment**

The data show tension between maintaining *safety* and ensuring an individual’s *right to treatment.* There was concern amongst staff participants that treating people with dementia might increase the risk of adverse events, because of uncertainty around how the person will manage at home. One staff participant described how a woman receiving chemotherapy at home through an ambulatory infusion pump removed the pump while the treatment was running:

“*That’s when they investigated further and found the pump under her bed and a pool of chemotherapy on the floor*.” (Natalie, healthcare assistant)

This is a rare occurrence, but the safety consequences are potentially severe. Participants commonly experienced uncertainty over whether people with dementia would be able to take oral medications correctly:

“*I’ve seen patients come through the pharmacy with their prescriptions who really struggle to remember to take their medicines*.” (Evelyn, pharmacy staff).

Caregivers agreed that this was a concern:

“*I must admit I do struggle with the tablets*.” (Dennis, husband of person with cancer and dementia)

Staff members expressed doubt about what information people with dementia could retain, which caused them anxiety over safety:

“*You’d walk away feeling a little bit uneasy because you were never quite sure what he may have retained or what he may not have retained*.” (Tracy, nurse specialist)

This is of concern to staff supporting people receiving treatment in an outpatient setting, as they are highly reliant on them reporting adverse effects when they return home after treatment. One doctor stated:

“*So we say it’s not safe and it’s not ethical to put people through chemo if they really can’t follow what they’re supposed to be doing and coming to appointments and phoning in about dangerous side effects, so we usually say on those grounds it’s not the right thing to do*.” (Diana, doctor)

 Staff members with expert knowledge of potential toxicities talked more explicitly about safety than patient participants or caregivers. However, participants from all groups had concerns around the rights of people with dementia to receive anti-cancer treatment safely. One staff participant summarised the dilemma:

“*Do you deny people this treatment because they’ve got dementia and how will they cope with it and how will we manage to, for example, get chemotherapy into what might be an agitated confused person?*” (Evelyn, pharmacy staff)

Another staff participant described how the behaviour of a person with dementia became a safety concern on the treatment unit:

“*We have had people who have been stopped, their treatment has, because we’ve become aware that they’re not safe to others. We had one man who would walk around touching everyone else’s drips and then they realised and you can’t just stop it*.” (Natalie, healthcare assistant)

 The most important factor for staff when balancing safety and right to treatment was whether the person with dementia had a support network. This was seen by staff as being crucial to safety both in the outpatient department and at home, and to enabling the person to proceed with treatment:

“*And whether they’ve got a good support network, whether with their dementia they are going to be able to be safe in compliance with maybe supportive medication taking them at home, and have they got a good care set up package to support them with that, because they might not be able to go ahead with the treatment otherwise*.” (Leila, nurse).

This was reiterated by caregivers, who stated that their family member would not be able to go ahead with the treatment without their practical support. David, supporting his brother-in-law with cancer and dementia, stated that there would be “no possibility at all” that he would be able to have the treatment otherwise.

Doctors described how the nature or type of treatment may also depend on the level of support:

“*I think it’s a safety thing from our point of view if we know that we’ve got a family that’s going to remind that patient what the diagnosis is, what the plan is, what the treatment is, then we would feel much safer perhaps prescribing a more intensive treatment that suits them physically than for a patient that has nobody at home that’s not going to remind them to take their tablets….to come in when they’re unwell*.” (Teresa, doctor)

Teresa’s comments show that she assesses and balances the risks that accompany an intensive treatment regime that requires more self-care. It was not clear from the data whether Teresa and her colleagues routinely have this risk conversation with people with dementia and caregivers when weighing up treatment protocols.

The data show that family support plays a considerable role in treatment decision-making. However, the presence of a supportive family does not mean that treatment will go ahead irrespective of other concerns. One participant, a doctor, described having conversations with family members of people who have dementia as “difficult”, and in some circumstances, “quite painful” and “horrible”:

“*Then there are the ones that are clearly very demented but the family will say they’ll support them and will get them through their chemo, and you have to have even more delicate conversations about why do you want to get them through the chemotherapy, they have no idea what day it is, and have they got a quality of life that is worth preserving? Will they understand that actually they’re going to feel terrible on chemotherapy and understand what the point of it is? So sometimes you think it’s a bit cruel to put your mum through nausea, vomiting, constipation, hair loss, and actually she has no idea why*”. (Diana, doctor)

It is unclear to what extent Diana’s concerns relating to balancing the assessment of quality of life with treatment effects are shared with patients and caregivers. It is not possible to determine whether the assessment of ‘quality of life’ made by clinicians would be agreed by all parties involved in decision making, and therefore unclear whether clinicians, patients and caregivers can engage in decision making that is based on accurate information and mutual understanding.

In addition to concerns about whether to commence treatment in the first place, staff talked about the difficulty of stopping treatment as the dementia advanced:

“…*where do you draw the line as in to say, and I can see it’s a real fine balancing act as to whether that person is, you know you are actually in a way sort of not ending someone’s life but you’re taking away active treatment and that’s quite scary to do*.” (Natalie, healthcare assistant)

Caregivers felt a responsibility to accurately represent the situation of the person with dementia to the healthcare professional if the person themselves did not do so, whether this was due to memory difficulties or a desire to present themselves in a certain way:

*“There’s no resemblance to truth. Him with [doctor] he was saying how he lived on his own and did all his own shopping and cooking and washing and mowed the lawn. He does live on his own but the rest of it is not true*.” (David, brother-in-law of person with cancer and dementia).

This is a challenging situation to navigate for the person with dementia, family, and healthcare professional. Staff members also sometimes felt people with dementia or their family members chose not to accurately represent the situation, to ensure the person with dementia would receive treatment:

*“There are definitely the patients who mask their dementia because they want treatment or their families want them to have treatment….”* (Diana, doctor).

*“I think there’s a real fear that if they admit how bad the dementia is getting their relative won’t get any treatment.”* (Natalie, healthcare assistant)

 Statements made by health professionals interviewed showed that they saw their role as primarily maintaining the safety of people receiving treatment. Data suggested that they also recognised the power disparity when offering or stopping treatment, and they found this uncomfortable. People have the right to decline treatment, but are not able to demand treatment; the ultimate decision lies with the clinician (McCrossan and Siegmeth 2017). This can be challenging as the clinician is by default in a position of power; they are the gatekeepers and feel this keenly.

Different participant groups were involved in balancing priorities in some way. For staff, this was represented by an explicit discussion of weighing up the benefits of treatment against patient safety concerns. For caregivers, there was evidence of having to reconcile the needs of their relative with the practical requirements of having cancer treatment. For patients, it was usually a case of being caught up in the balancing act, without necessarily being able to engage as an active agent.

**5.2 Balancing the system with the person**

 Health systems are complex organisations, where the needs of the individual must be balanced with the requirements of the system:

*“I think a lot of the time, I think there’s too much in the NHS that’s a one size fits all.”* (Tracy, specialist nurse)

The data showed that people with dementia and caregivers sometimes struggled to fit in with the system, for example with the procedures involved in outpatient appointments:

“*Getting up, breakfasted and all ready and then getting up here and finding a parking space, it’s a bit of a panic if you’ve got to be here for 9.20am*.” (Annabel, wife of person with cancer and dementia)

Sometimes people did not want to fit in with the systems and processes on offer:

“*We had a lady recently who said, ‘I don’t want a biopsy dear it clashes with my day at Waitrose.*” (Diana, doctor)

The complexity of the outpatient clinic was also acknowledged by staff members as a challenge for people with dementia:

“*You come in, you check in here, if you are having treatment you see people go to the desk to check in so you are never quite sure where you’re going. You have a blood test here unless it’s on a Friday when there are no bloods then you have to go upstairs. When the patients then get bombarded with the information in clinic and then they get given a piece of paper which they have to hand to the desk which throws them a lot of the time especially the new patients*.” (Tracy, specialist nurse)

“*The sheer number of appointments, I mean the amount of patients that have no confusion whatsoever that can’t work out all their appointments and will have four appointments in one week, but they’ll all be at different times and in different places. You’ll have a blood transfusion on [ward A] but you’ll see the doctor in [clinic B] but then you’ll have your intrathecal on [ward C] and then you’ll be admitted to [service D] but then you’ll go to [ward E] and then in the middle of the night you’ll be transferred to [ward F]. It must be terribly confusing*.” (Teresa, doctor)

Conversely, one participant described how a familiar routine, while complex, allowed a person with dementia to navigate his own cancer treatment journey. In this example, a man having oral treatment for prostate cancer was managing well including attending clinic independently, until the point where things began to change, and the specialist nurse needed to step in to help navigate these changes, for example ensuring he attended for additional appointments:

*“Things like his PSA* [Prostate-specific antigen] *level were starting to go up, he was having to come up for scans, and we were asking him to have extra blood tests. And so that’s when I first started to get to know him actually*” (Tracy, specialist nurse)

 The onus is on the person with dementia to fit in with the standardised organisation of the clinic and treatment regimens. People with dementia and caregivers could demonstrate autonomy by choosing not to fit in with the system, or finding ways in which the system would adapt to meet their needs, such as adjusting appointment times. A third strategy was demonstrated by the man having tablet treatment for prostate cancer described above; he used the predictable structure of the system to function independently, until this was no longer possible, and the specialist nurse as care co-ordinator stepped in to provide support when his needs intensified.

 The data show that the outpatient cancer departments studied are not often able to take account of individual circumstances. In the cancer treatment area, cancer is the focus for the health professionals. However, it may not be the focus for people with dementia and caregivers:

“*In a clinic setting when you are working as a prescriber you do see patients who come through and it’s always very difficult because we get really focused on cancer and just seeing the cancer. But actually these patients have multiple co-morbidities normally. We know for things like obesity, heart disease, diabetes are all risk factors for cancers so these patients have lots of other conditions that go along with them*.” (Evelyn, pharmacy staff)

“*Quite often they are the older people who have complex health needs and their cancer might not necessarily be the biggest problem in their life*.” (Tracy, specialist nurse).

 Health professionals and administrative staff were usually unaware that a person with dementia would be coming into the unit, and therefore were unable to put any supportive processes in place.

“…*because the problem is quite often we’re just chasing our tails. We don’t know any issues until we’ve already booked the patient and they walk in the door and suddenly we find that it’s not suitable anymore*.” (Louise, administrative team).

It was accepted that preparation would be helpful:

“*People knowing of their issues prior to their attending would be the main challenge so that they can accept or alter their practice or alter their approach or whatever it is they need to do...*” (Orla, therapeutic radiographer)

 Staff interviewed were clear that their interactions with people with dementia would be varied based on the needs of the individual.

“*That actually I think our understanding of how a patient is going to be when they are in our footprint, and I know that’s going to be very different to each individual patient as to how they are suffering with their dementia*”. (Maisie, management team)

There was a sense that staff wanted to be fair and not discriminate:

“*Then as well as we know in our unit even though they have dementia we treat them as equal, as equal to anyone else who needs treatment*”. (Natalie, healthcare assistant)

“*And make sure that people speak to the patient not the family members…and that’s a big thing because make eye contact, smile, and even if it’s not going in they realise that they’re not just a blob in the corner that everyone is talking around them*”. (Olivia, administrative team)

 Distress was expressed when staff felt they weren’t getting it right, particularly with decision-making around treatments:

“*It feels like we’re withholding life from people sometimes. It feels like we’re saying no* [to chemotherapy] *for nasty reasons*”. (Diana, doctor)

The same participant also expressed a sense of relief that people with dementia were often seen by surgeons prior to coming to oncology, and therefore they were ‘filtered out’ by the surgical teams (not deemed fit for treatment). The responsibility of refusing treatment was taken on by another healthcare professional.

The data presented tension between meeting the needs of the system and the needs of the person, and giving equal weight to safety and the right to treatment. Healthcare professionals were aware of the power they held, and their responsibilities towards people with cancer and dementia, and this often weighed heavily on them. Conversely, people with dementia and caregivers tended to present their positions as reliant on the healthcare system and professionals within it to undertake tasks and manage care. Sometimes people with dementia ceded control of care to others because of memory loss:

“*I’m not concerned but I’m just curious to know how this new treatment is going to be because they are using a different drug apparently. I can’t remember the name of now. But they are going to try that apparently, so I don’t know yet, see what happens*.” (Katherine, person with cancer and dementia).

At other times, the participant was reliant on the hospital to provide information because of the way the system was organised:

“*It was just when he came home, for somebody that’s got dementia and not have any information I just thought oh my God. I didn’t know who I was supposed to speak to. I was ringing the ward, the ward clerk and everything*.” (Imogen, daughter of person with cancer and dementia).

These themes present the challenges involved in attempting to meet the organisational needs of the health system, while also meeting the individual needs of the person, and demonstrate that that the system is primarily designed to do the former, at the expense of the latter. The themes reveal how this weighting in favour of organisational requirements can lead to an imbalance of power, meaning that the individual finds themselves in a passive role while the healthcare service is the active agent, ultimately impeding the provision of personalised care.

The following discussion analyses where power rests in the environments and interactions under study, and how people with dementia and caregivers might be able to reclaim some of the power traditionally held elsewhere.

1. **Discussion**

Data from this study showed that a power imbalance exists in outpatient cancer services for people with dementia; inevitably, the needs of the person are subsumed to the needs of the system. However, the discomfort of the staff participants within the system found in this study shows that the classic view of power as domination, coercion and control does not fully serve to explain the power imbalance, and is not equipped to demonstrate how to mitigate the imbalance effectively. The WHO (Solar and Irwin 2010) describes four types of power: *power over*, where some people influence or control others; *power to*, where individuals organise and change existing hierarchies; *power with*being the collectivepower of communities and organisations; and *power within*, which describes an individual’s capacity to exercise power. A classic view of power focuses on power over, seeing power as negative from the perspective of those who do not hold it, and positive from the perspective of those who do. However, this study showed that staff participants recognised their position of power at the expense of patients, and often found this uncomfortable, for example in relation to treatment decision making. Power imbalance cannot be redressed if patients are passively gifted power by the healthcare system and those working within it, as a traditional view of power would advocate. Instead, the nature of power in healthcare environments needs to be understood and utilised.

 Power is not only rational and intentional, synonymous with control, allowing those at the top to exert power over those below. Power is relational; it does not belong to one person, but exists in interactions and relationships between people. Foucault (1980) argues it is not the case that individuals are oppressed by power relations, but rather people and practices are constituted by power relations. Power is productive as well as constraining, it is everywhere, and it comes from everywhere. Power is therefore both a barrier and an opportunity (Dickie et al., 2015). People (patients, caregivers, and staff) already hold power, as it is pervasive and dispersed. Redressing imbalances of power therefore relies on strategies to access and enable this. This requires a cultural shift at all levels within health services. To enable a redistribution of power, 2 key actions are necessary:

1. Enabling discourse navigation
2. Enhancing agency

These actions serve to support people with dementia and cancer and caregivers, to utilise the specific kind of systemic power available to them, which will mitigate the tensions evident in the themes found in this study. The actions help alleviate the need for such stark opposition between safety and the right to treatment, and between system and person, and by re-examining power dynamics, redress the balance which is currently detrimental to both patients and staff.

**6.1 Enabling discourse navigation**

Discourse is the social activity of making meaning with language (Lemke 1995) and is an arena for the negotiation of power. Discourses, such as those around cancer, treatment, patienthood, healthcare and so on are constructed not in isolation but in contrast to other discourses, and are therefore organised around practices of exclusion. Mills (2003) described how those who lack familiarity with information networks and capital are prevented from having access to discourses, and therefore may be unable to navigate the healthcare environment successfully. Data from this study illustrated a discourse on ‘safety’, for example, which was connected to (and held in opposition to) the discourse on ‘the right to treatment’. One needs to be equipped to negotiate the discourse, which forms, and is formed by, the highly complex health system. Exclusion from the relevant discourse is a manifestation of power imbalance, as it excludes people from understanding and therefore navigating the system effectively. This results in distress and frustration, as Imogen eloquently describes above; she is excluded from the discourse, excluded from understanding the system, and therefore is unable to gain what she needs. The hospital, as part of the healthcare system, holds the power at her expense. Staff interviewed acknowledged that the complexity embedded in the healthcare system, for example in terms of the appointment processes, and the number of different places and personnel involved, were confusing to navigate. The data suggest that people with dementia and caregivers are not currently fully equipped to navigate a discourse that is complex, confusing and jargon-filled, meaning that they are ultimately excluded. The complexity of the discourse suits the system, and not the individual.

The discourse is a locus of power: “discourse transmits and produces power; it reinforces it but also undermines and exposes it, renders it fragile and makes it possible to thwart it” (Foucault (1978:101). Therefore, the language used in healthcare is important; the discourse helps to form what we consider to be true and determines the reality we perceive (Foucault 1972). Enabling people who have historically been excluded from discourses to enter, alter, and shape the discourse allows them to subvert traditional power structures, and enact individual agency.

Health professionals can ensure that people receiving treatment are better equipped to navigate the discourse. Bartlett and O’Connor (2010) suggest strategies for addressing power imbalances by influencing the prevailing discourse, which include:

* Allowing experiential knowledge to be equally important as medical knowledge; the clinician is the expert in diagnosis, care and treatment, and the person is the expert in their own experiences.
* Reducing social distance by using clear and jargon-free language.
* Providing information about diagnosis/prognosis, along with making clear the procedures for challenging a decision.
* Paying attention to how information is transferred during an encounter with a health professional – is there a reliance on conventional ways of communicating?

These strategies involve a) giving people with dementia and caregivers the tools to negotiate the discourse and b) altering the discourse itself to make it more accessible. If all the stakeholders can enter the sphere of discourse around cancer and cancer treatment, and act meaningfully, it is more likely that the needs of all involved will be met.

**6.2 Enhancing agency**

People have agency when they can act to influence their personal circumstances (Boyle 2014). Agency is often reduced for people encountering the healthcare system. In a study of people with cancer and dementia, Griffiths et al., (2021) noted that “Patients with dementia did not always feel a sense of agency to challenge staff or request changes, perceiving this as immoveable or “the appointment we’d been given”.” When interviewing people with chronic conditions as well as cancer, Corbett et al., (2022) found that individuals who normally displayed a sense of active agency in managing their health needs, reported ceding control to healthcare professionals when it came to undergoing treatment for cancer. It can be difficult for individuals to exercise agency within a highly-structured system upon which they are reliant.

Participants in this study reported difficulties fitting in with the needs of the system, such as attending for appointments at designated times. Sometimes, the rigidity of the system was supportive rather than restrictive. Tracy’s account of a man with prostate cancer suggested that the structure and schedule provided the framework which allowed him to come to appointments, take tablets and so on, as it was familiar and routine. Problems arise when this structure no longer fits, at which point the individual may need a mediator (family member, specialist nurse) to enable them to navigate the altered structure. The system can provide the structure for the person to navigate their healthcare effectively. However, when the structure does not meet the needs of the individual, it is challenging for people with dementia having treatment for cancer to exercise agency.

A longstanding assertion of dementia research is that recognising and enhancing the agency of people with dementia is crucial (Bosco et al., 2019). Dementia literature incorporates concepts such as personhood (Kitwood 1995) and citizenship (Bartlett and O’Connor 2007), which help to place people with dementia as people with power. One way of enhancing agency is to look in more detail at communication styles (suggested by Bartlett and O’Connor 2010 above). Going against staff expectations may constitute an expression of agency rather than a lack of ability. When David described how his brother-in-law tells the doctor that he does all his own shopping and cleaning, David is uncomfortable because this is a misrepresentation of the truth. Another way of seeing this encounter would be that David’s brother-in-law is communicating to the doctor what is important to him, and how he wants to be seen. Similarly, the person with dementia Diana describes as declining a biopsy as it clashes with her shopping day is communicating information beyond the words of her polite refusal. She is letting the doctor know what is important to her, and in doing so asserting her agency. This does not mean that the doctor accepts this with no further discussion; but they can recognise that an important communication has been made, which will influence the conversation around treatment. The needs of the person therefore have a chance to become more balanced with the operational requirements of the system.

Enhancing agency for people with dementia having treatment for cancer does not automatically compromise safety or quality of care. Data collected for this study revealed doctors’ concern when they declined to offer chemotherapy against the wishes of the person with dementia or caregivers. However, enhancing agency does not mean that patients or families could insist on care against the advice of the clinician. No person can insist upon receiving treatment. Enhancing agency may, however, make it easier for people to refuse treatment they do not want (Cook and McCarthy 2018). There are multiple strategies available to enhance agency whilst maintaining safety and quality of care, including pre-assessment and pre-treatment optimisation, to ensure that an individual’s needs, concerns, and expectations are identified, and aligned with what can be offered. This could involve a Holistic Needs Assessment (Doyle and Henry 2014), or form part of a Comprehensive Geriatric Assessment (Extermann and Hurria 2007) if clinical capacity allows.

Enabling discourse navigation and enhancing agency using some of the strategies described above works towards reducing the imbalance of power that leads to tension between safety and the right to treatment, and between the needs of the system and the needs of the person. These actions enhance the power of healthcare professionals, patients and caregivers to participate in a healthcare system that is better able to account for the needs and preferences of all involved. This approach is exemplified in the concept of shared decision making; a set of principles and practices which support patients and professionals to meet as partners.

**6.3 Shared Decision Making**

 To achieve enhanced agency and enable discourse navigation for people with dementia and caregivers, we recommend incorporating the principles of shared decision-making (SDM) into routine practice in cancer services. Shared decision-making is a key component of personalised care (NHS England 2019), the principles of which are recognised internationally to varying degrees (Bravo et al., 2022). It is a collaborative process where the healthcare professional and patient work together to reach a decision about care, with the healthcare professional providing expert information on the evidence for treatment options, and the patient providing expert information on their preferences, beliefs and values (Barry and Edgman-Levitan 2012, NICE 2021, Shepherd et al., 2022). If the default position is that the clinician is in a position of power because of their control of access to cancer treatments, the information that the clinician has about the patient’s needs, concerns, and expectations (what is important to them) is as crucial as the information the patient (and caregivers) have about the benefits, risks and alternatives of treatment options. SDM is more than information provision, however, and requires a cultural shift (Joseph-Williams et al., 2014). We recommend utilitising the principles of SDM in outpatient cancer services, because it heightens understanding between patient and clinician, and sees both parties as equal participants with expertise to bring to a discussion. It helps to avoid potentially troubling situations highlighted by the doctors in this study, who assess quality of life and weigh this against potential treatment effects, while not necessarily sharing assumptions with patients and caregivers. Shared decision making enables both responsibility and power to be redistributed; the agency of people with dementia and caregivers is enabled, and they are better able to navigate the discourse to achieve the best outcome for them at the time.

Many of the techniques used in shared decision making will already be used in consultations by skilled clinicians; however, there exists an evidence-based set of practices which increase the likelihood that health professionals and patients will meet as equal partners (**Box 1a** and **1b**). How these practices are used will vary on a case-by-case basis, and depend on the individual person with dementia, including cognitive and communication abilities. This is separate from discussions about mental capacity (Department of Health 2005). It may be important to involve family members or outside agencies in discussions to support the person with dementia to take an active part in SDM. Explicitly incorporating the principles of shared decision making into interactions in outpatient cancer environments would assist in redressing the imbalance of power that currently exists to the detriment of all involved.

**6.4 Strengths and Limitations**

The study was suspended for 6 months during the COVID-19 pandemic, and recruitment and observation were made more challenging by the pandemic. Only two people with cancer and dementia were recruited for a formal interview, which itself could represent an imbalance of power within the study. We had hoped to recruit more patient participants; however, the COVID-19 pandemic made this challenging. Opportunities for face-to-face interactions with potential participants were limited, and it was difficult for the researchers to build rapport over the telephone. However, the interviews represent only one aspect of investigation, and patient perspectives were gained via other routes, including observation and informal discussion.

The inclusion criteria chosen may have inhibited recruitment of patients; only patients with a confirmed diagnosis of dementia were eligible for invitation to participate. While we maintain that this criterion was ethically sound (reducing the likelihood of causing distress to people without a confirmed diagnosis), it limited the number of people available to approach. Despite this, we are satisfied that the findings represent the experience of people with dementia having treatment for cancer. Member checking with patient participants was challenging in this study due to advancing cognitive impairment. To access the experience and perspectives of patients and the public in relation to the study findings, a meeting was convened after the close of the study. People with lived experience of cancer and dementia were invited to attend, and the study findings were presented. Contributors were asked to comment on whether they felt the findings were representative of their own experiences, and whether there were any significant omissions. Contributors confirmed the findings matched their own experiences.

* 1. **Recommendations for further research**

Further research is required into how shared decision making should be integrated into existing cancer services, and subsequently into measuring the effect it has on experience of cancer care, and associated health outcomes.

1. **Conclusion**

 People with dementia having treatment for cancer often have complex needs, and outpatient cancer services are not routinely organised or designed to meet these needs. A power imbalance remains between those who provide treatment, and those who receive treatment, the latter having been historically excluded from the discourse. To redress the disparity, people with dementia and their families need to be equipped to navigate the discourse of cancer treatment, which can be achieved by enhancing the agency of those who receive treatment, by altering the discourse to be more inclusive, or both. We recommend incorporating the principles of personalised care and in particular, shared decision making, to achieve more equitable power relations, reduce health inequalities, and ensure that cancer treatment offered to people with dementia is safe and appropriate.

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**References**

Alzheimer's Disease International. (2019). *World Alzheimer report 2019: attitudes to dementia*. London: Alzheimer’s Disease International.

Alzheimer’s Society. (2022). *This is me*. <https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me>, accessed 25 May 2022.

Barry, M.J., & Edgman-Levitan, S. (2012). Shared Decision Making: the pinnacle of patient-centred care. *New England Journal of Medicine*, 366(9), 780-1.

Bartlett, R., & O’Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Ageing Studies*, 21, 107-118.

Bartlett, R., & and O’Connor, D. (2010). *Broadening the dementia debate: towards social citizenship*. Bristol: The Policy Press.

Bosco, A., Schneider, J., Coleston-Shields, D.M., Jawahar, J., Higgs, P., & Orrell, M. (2019). Agency in dementia care: systematic review and meta-ethnography. *International Psychogeriatrics,* 31(5), 627-642.

Boyle, G. (2014). Recognising the agency of people with dementia. *Disability and Society,* 29(7), 1130-1144.

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, 15(3), 304-314.

Bravo, P., Härter, M., McCaffery, K., Giguère, A., Hahlweg, P., & Elwyn, G. (2022). Editorial: 20 years after the start of international Shared Decision-Making activities: Is it time to celebrate? Probably…. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, advance online publication 31 May, doi: <https://doi.org/10.1016/j.zefq.2022.05.009>.

Care Quality Commission. (2014). Cracks in the Pathway: people’s experiences of dementia care as they move between care homes and hospitals. <https://www.cqc.org.uk/sites/default/files/20141009_cracks_in_the_pathway_final_0.pdf>, accessed 23 September 2021.

Charmaz, K. (2007*). Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage.

Collinson, M., Mason, E., Ashley, L., Farrin, A., Griffiths, A., Hennell, J., Kelley, R., & Surr, C. (2019) Effective clinical cancer treatment, care and management for people with comorbid cancer and dementia: understanding population demographics and intervention priorities and outcomes (CanDem-Int). *British Journal of Cancer,* 121, 30–1. National Cancer Research Institute conference abstract.

Cook, P.S., & McCarthy, A. (2018). Cancer treatment decision-making with/ for older adults with dementia: the intersections of autonomy, capital, and power. *Health Sociology Review*, 27(2), 184-198.

Corbett, T., Lee, K., Cummings, A., Calman, L., Farrington, N., Lewis, L., Young, A., Richardson, A., Foster, C., & Bridges, J. (2022). Self-management by older people living with cancer and multimorbidity: a qualitative study. *Supportive Care in Cancer,* 30(6), 4823-4833.

Department of Health. (2005). *Mental Capacity Act*. HMSO: London.

Dickie, E., Hearty, W., Fraser, A., McCartney, D., Doyle, E., & Myers, F. (2015). *Power – A Health and Social Justice Issue*. NHS Health Scotland.

Doyle, N., & Henry, R. (2014) Holistic Needs Assessment: Rationale and practical implementation. *Cancer Nursing Practice*, 13(5), 16-21.

Extermann, M., & Hurria, A. (2007), Comprehensive Geriatric Assessment for older patients with cancer. *Journal of Clinical Oncology*, 25(14), 1824-1831.

Farrington, N., Dantanus, K., Richardson, A., Bridges, J. (2022). Understanding the cultural environment of the outpatient care setting for patients with dementia receiving cancer treatment: a qualitative study. *Health Expectations* <https://doi.org/10.1111/hex.13523>.

Featherstone, K., Northcott, A., & Bridges, J. (2019) Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences. *International Journal of Nursing Studies*, 96, 53-60.

Foucault, M. (1972). *The Archaeology of Knowledge*. London: Tavistock.

Foucault, M. (1978). *The History of Sexuality: An Introduction, Volume 2*. Harmondsworth: Penguin.

Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings 1972-22.* Brighton: Harvester.

Griffiths, A.W., Ashley, L., Kelley, R., Cowdell, F., Collinson, M., Mason, E., Inman, H., Henry, A., Farrin, A., & Surr, C. (2021). Balancing the needs of individuals and services in cancer treatment for people with dementia: A focused ethnographic study. *International Journal of Nursing Studies*, 121, 104006.

Joseph-Williams, N., Edwards, E., & Elwyn, G. (2014) Power imbalance prevents shared decision making. *BMJ,* 357:g3178. doi:10.1136/bmj.g3178 pmid:25134115.

Kitwood, T. (1997). *Dementia Reconsidered: The person comes first*. Buckingham: Open University Press.

Lemke, J.L. (1995). *Textual Politics: Discourse and Social Dynamics*. London: Taylor & Francis.

McCrossan, L., & Seigmeth, R. (2017). Demands and requests for ‘inappropriate’ or ‘inadvisable’ treatments at the end of life: what do you do at 2 o’clock in the morning when ...? *British Journal of Anaesthesia,* 119 (S1), i90-i98.

McWillams, L., Farrell, C., Grande, G., Keady, J., Swarbrick, S., & Yorke, J. (2018). A systematic review of the prevalence of comorbid cancer and dementia and its implications for cancer-related care. *Aging and Mental Health*, 22(10), 1254-1271.

Mills, S. (2003). *Discourse*. London: Routledge.

NHS England. (2019). *Personalised Care: Shared Decision Making – Summary Guide.* <https://www.england.nhs.uk/wp-content/uploads/2019/01/shared-decision-making-summary-guide-v1.pdf>, accessed 26 April 2022.

NICE. (2021). *Shared decision making*. <https://www.nice.org.uk/guidance/ng197>, accessed 30 November 2021.

NIHR. (2023) *PPI (Patient and Public Involvement) resources for applicants to NIHR research programmes*. <https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437>, accessed 01 February 2023.

Robb, C., Boulware, D., Overcash, J., & Extermann, M. (2010) Patterns of care and survival in cancer patients with cognitive impairment. *Clinical Reviews in Oncology/Hematology*, 74, 218–224.

Shepherd, J., Gurney, S., & Patel, H.P. (2022). Shared decision making and personalised care support planning: pillars of integrated care for older people. *Clinics in Integrated Care,* 12, 100097.

Solar, O., & Irwin, A. (2010). *Conceptual Framework for Action on the Social Determinants of Health*. WHO: Geneva.

Solomons, L., Solomons, J., & Gosney, M. (2013). Dementia and cancer: a review of the literature and current practice. *Aging Health*, 9(3), 307.

Surr C, Griffiths AW, Kelley R, et al. Navigating cancer treatment and care when living with comorbid dementia: an ethnographic study. Supp Care Cancer. 2020;29:2571-2579.

Wolcott, H.F. (1988). Ethnographic research in education. In: R. M. Jaeger (ed.) *Complementary methods for research in education*. Washington, DC: American Educational Research Association, pp. 187-249.