

**Title:** Cancer and dementia: an exploratory study of the experience of cancer treatment in people with dementia

**Short title:** The experience of cancer treatment in people with dementia

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## **Abstract**

### *Objective*

Patients with comorbid cancer and dementia have poorer outcomes than those without dementia. We observe oncology teams managing patients with dementia and memory loss and explore these patients' needs and experiences of out-patient cancer services.

### *Methods*

A single site investigation of case study design to examine practices in four clinics using multi-methods of data collection; retrospective note review, observation, interviews and recorded consultations. A framework analytic approach identifies themes within and across cases.

### *Results*

Thirty-three clinical encounters with patients with memory loss were observed. Ten consultations were audio-recorded and 16 individuals interviewed (n=6 patients-carer dyads, n=1 lone patient, n=5 staff). Medical records were reviewed for 338 cases. Cancer referrals did not document memory health, so clinicians rely on patient/carers disclosure to identify patients with memory problems. In practice the problem often remains hidden. Treating teams who do become aware of memory difficulties are unsure how to support patients, but marked memory loss can limit treatment options and preclude radical intent. Carers are key facilitators of successful cancer consultations and management. Their support needs are largely unrecognised.

### *Conclusions*

Training that educates cancer teams on how to identify and support individuals with memory problems before and during treatment and recognise the carer role may facilitate complex cancer care and help reduce inequalities of outcomes.

## **Key words**

Dementia; Memory loss; Carers; Care needs; Cancer; Oncology.

## Background

Both cancer and dementia are primarily diseases of older people. Almost two thirds of cancers are diagnosed in those aged 65 and over [1] and one in 14 of this population are affected by dementia [2]. An ageing population means oncology teams are treating an increasing number of patients who present with comorbid cancer and dementia (CCD) [3,4].

Data from US cancer registries suggest that the prevalence of CCD for patients aged 68 and over is between 5 and 10% for the most common cancers: equivalent UK data is sparse. Cancer patients with dementia have an increased all-cause and cancer-specific mortality rate compared to those without dementia, and significantly poorer survival rates [4,5]. Inequity of outcomes is likely to be a function of later diagnosis [5–7], less aggressive treatments [6,8,9], a higher rate of complications related to treatment [6,9] and other confounding health factors. The reasons underlying these epidemiological observations are speculative.

Recent health and social policy aims to improve the care of patients with dementia and reduce inequalities in their health outcomes [10–13]. These documents broadly recommend assessment of dementia, staff awareness and training and individualised care plans that encompass carer involvement and dementia-friendly environments. The extent to which dementia guidelines are relevant to in the delivery of cancer treatment is unknown.

One challenge to excellent cancer care is the inherent complexity of dementia. The term encompasses a range of conditions that progressively impair cognitive function; typically presenting as memory difficulties and problematic behavioural and emotional change. Little is known about the complex care needs of people with CCD and their family carers [14]. There is also a population with mild cognitive impairment (MCI) [15] who, though not diagnosed with dementia, have memory loss and additional supportive care needs.

The study aims to explore the experiences of patients with dementia and MCI in accessing out-patient cancer treatment services and observe their management by oncology teams, paying particular attention to factors that may underlie inequities in medical outcomes of these vulnerable people.

## **Methods**

An exploratory qualitative investigation of case study design. A case was the management of memory loss in a person with self-identified memory loss attending an out-patient clinic for cancer management. Case study was useful to examine this complex and sensitive topic, where the aim was to access the unspoken and tacitly understood [16]. This approach enabled the use of multi-methods of data collection to understand the complexities of the everyday work within a cancer centre from the perspectives of patient, clinical and wider hospital staff [17,18].

Approval was granted by NHS ethics committee reference 14/WA/1030.

### *Setting*

Practices were observed across four outpatient clinics at a single UK cancer centre. Clinics were identified as those most likely to be treating people with memory loss by a cancer service manager and a dementia care nurse: a urology follow-up clinic; a clinic for patients receiving chemotherapy for breast cancer; two treatment review clinics supporting patients undergoing radiotherapy. Clinicians, clinic nurses and nurse specialists were typically present at the breast and urology clinics. The review clinics were radiographer-led with specialist input for complex treatment sites.

### *Participants*

All patients were approached for participation who were 18 years or older, receiving cancer treatment and identified as having memory problem (as judged by clinic staff and agreed by the patient).

The recruitment process followed ethical principles for conducting research involving people with dementia and cognitively impaired [19,20] (flow diagram in Appendix 1.) In brief, a clinician gave patients written and verbal information about the study and introduced those interested to the researcher. If the researcher had reasonable doubts that the patient lacked the capacity to give informed consent, at this point or any other, then study activity stopped and a Mental Capacity Assessment was arranged. If a patient was deemed to lack capacity, a family member/carer or close friend was approached to become a personal consultee. The Mental Capacity Act (2005), defines the consultee as a person who knows the patient well, someone who is interested in the individual's welfare and who can be consulted about the prospective participant's wishes and feelings about participation, if the person had capacity.

The clinic team gave consent to take part in study observations. The audio-recording of clinic consultations required both the patient and clinicians' consent.

All carers accompanying participants were invited to accompany the patient throughout the study.

Key staff members and all patient participants were invited to subsequent interview at a convenient place and time.

#### *Data collection methods*

- A retrospective review of all available electronic and paper-based medical records to estimate the prevalence of dementia during a four month period;
- Non-participant observation of patient consultations over a four month period. Extensive field notes captured practice within the clinics and interactions between individuals;
- During observation interviews with staff members after the consultations to understand management decisions and social actions.
- After-observation interviews with patients and their carers to explore what is experienced as facilitative of cancer treatment, care compliance and self-care. A cognitive screening test that is sensitive to early dementia, the Addenbrooke's Cognitive Examination (ACE-III) [21], was administered by the trained researcher prior to interview. Given reported deficiencies in clinical assessment of memory health, this tool was used to provide a standardised indication of cognitive function.

#### *Data analysis*

The analytic process was inductive and informed by Wolcott's framework for qualitative data analysis. Verbatim interviews, clinical consultations and field notes were coded and categorised for each case independently by RM and NC. Themes were then identified within each case and members of the research team (RB, NC, MK, JH) agreed those cross-cutting all cases and developed a thematic framework [22]. NC then used the framework to structure data summaries within case then across case [23]. Because of the small numbers of patients and staff who took part from each clinic, analysis is reported here at the level of the themes cross-cutting the cases, to protect the anonymity of individuals.

### **Results**

Of the 338 clinic attendees between 01 December 2013 and 01 April 2014 (head and neck cancer n=84, colorectal n=55, breast n=75, prostate n=124), one patient had a diagnosis of dementia documented in their records.

Thirty clinics were observed between October 2014 to February 2015 (breast n=10, urology n=13, radiotherapy review n=7). The twenty staff who agreed to take part in observations identified four patients with a diagnosis of dementia and 23 patients

with MCI. In total, we observed 33 clinical encounters between staff and patients with memory loss. Four patients were not due to return to clinic within the study timeframe and one patient died before their appointment. Of the remaining 22 potential participants, consent was gained to audio-record 10 clinical consultations (n=8 with patient and carer, n=2 with patient).

Our sample comprised three women with breast cancer and seven men – four diagnosed with prostate cancer, two with head and neck cancers and one with a pelvic malignancy. Three of these patients had a diagnosis of dementia.

Five of the patient carer dyads and one lone patient agreed to be interviewed. Total ACE-III scores for the patients were 91, 85, 74, 66 and 40, with one participant failing to complete the assessment. Scores below 88 are suspicious of dementia [18]: normative data have been reported as a score of 95.4 [24]. Interviews were conducted with five staff members.

The problem of memory loss and dementia in the cancer clinic was captured by four core themes: memory and the cancer consultation; staff attitudes; management approach; carer role. Findings from each theme are summarised (Table 1). Within each theme there was evidence of the veiling of memory loss, which will be the focus of the findings reported here [S denotes staff member, P patient, C carer and F field note.]

### ***Memory and the cancer clinic consultation: setting the scene***

The subject of memory was often notable by its absence from clinical encounters. The basic problem was stated as:

S22 (doctor): If they have got memory issues and they don't tell us, we don't know. I guess that dementia patients have it the whole time, so a lot of them will hide it and know how to hide it ...

Identification of a memory problem in a consultation was dependent upon patient disclosure or evidence of a memory difficulty:

P3: ... I said my memory's – you'll have to excuse me 'cos (nurse) said something and I couldn't remember - and she said oh, you know, we can help you there, you know, we've got a (specialist dementia nurse)...

But, memory is important in patient-cancer clinician consultations. Clinicians need patients to give details of their medical history, cancer symptoms, previous therapies and treatment side effects:

S13 (doctor) Just run it past me again where the, where the worst bits are where pain is concerned you say the  
P6: at the bottom of the spine  
S13: right down at the bottom?  
P6: yes and down this leg  
S13: down that leg, [pause] now this scan is a year old or more so whether it is going to help us  
P6: because I, I went a couple of weeks ago  
C5: what?  
P6: didn't I  
C5: no darling  
P6: are you sure?  
C5: no  
S13: this scan is two years old.

Veracity was actively sought from the carer. However, this rarely prompted discussion of the underlying memory issue. At interview, two patients mentioned the first enquiry about their memory in the cancer clinic related to participation in this study. If the carer did not know the patient well, then marked memory loss acted as a barrier to successful consultation:

S9 (doctor) asks him how he is feeling, and if he has any pains, he says he can't remember how he feels. The only information the carer has on this patient is that he is a wanderer .... S9 said the appointment was fruitless, he couldn't work out how the patient was feeling, he was asymptomatic and no notes had been sent over. (F 8.1.2015)

Patients were found to underplay the importance and extent of memory problems in their cancer consultations. For example, S9 (doctor) offers to write things down for a patient who was 'confused with all his appointments', but he 'refused and assured the doctor he understood and was happy with things' (F 20.11.2014)

At interview, patients expressed satisfaction with their cancer treatment and care and none suggested a need for improvement of the management of memory loss in clinic:

P2: If you need anything they have been really helpful. They have put me, put me right on what needs to be done.

### ***Staff attitude to memory problems***

Similar numbers of people with memory problems were identified in each of the clinics. However, staff associated memory problems with older age. S8 (doctor)

explained recruitment would be difficult because 'this is a chemotherapy clinic, the patient's aren't going to be old.' (F 2.9.2014)

Identifying memory loss was difficult. 'At 12.40, S22 (doctor) comes out and says he is ok, meaning that he doesn't have memory problems. I decide to wait until the consultation is over to discuss further. At 13.10 he comes back out of the consultation and says the patient does have memory problems.' (F 11.12.2014)

The focus in the clinics was on cancer treatment to the extent that staff did not actively seek to identify memory problems. This was particularly so when they were unsure there was any benefit to doing so and were aware memory was a sensitive topic. 'S13 (doctor) asked me what is the benefit of referring patients to the memory clinic, what is the memory clinic going to do? Confirm they have a memory problem? Can they help them? No, they can't cure them. He thinks the memory clinic must be inundated with people going to them for help.' (F 11.12.2014)

### ***Management approach to cancer in people with dementia***

Staff in the clinics were witnessed using different techniques to aid recall in people with memory problems. For example, offering practice in important self-care activities:

S17: Shall I show you this mouthwash then? So there's a blue box and a white box

P8: yep

S17: and then you've got lots of these little, um, little tubes. So you need to take one of the white ones and one of the blue ones

P8: yep.

They sought information from alternative sources when patients could not recall clinical facts:

P3: Something like that I think. I'm awful sorry, I thought I put (medicine bottle) in (my bag)

S1: that's alright, don't worry. I'll um, I can ring them, it's okay, don't worry.

They also sought support from other services, for example when changing medication regimes:

P4: Well one's bigger than the other two see (talking about steroid tablets)

S22 er, I-, I tell you what I'll organise it through your GP.

C3: Yeah.

S22 Safest thing to do.



However, to receive complex cancer treatment and services the patient had to be 'reliable' and have someone at home who could monitor for treatment side effects:

S22 (doctor): if they are not reliable and they miss treatments, the treatment (radiotherapy) becomes less effective and so the marginal benefit they get goes then anyway ... if you have got umm a person with reduced mental capacity living on their own then the safety of giving chemotherapy is a risk.

One of the clinics was actively working to improve the support people with memory problems undergo treatment. 'S18 explains to me that she is the designated dementia link for the department and that she sits on a working group that is looking into introducing a biographical tool such as the 'This is Me' [25]. This will help staff to be more person-centred in their approach and work more closely with the family or friend.' (F 25.11.2014).

### ***Role of carer in cancer treatment***

Away from the cancer centre, during interview, patients described being dependent on their carer for both cognitive support and practical help with cancer management:

P5: I used to go originally on my own – but the reason (daughter) comes with me is because I don't always remember what he says ... So somebody accompanying, somebody in there to remember in case I forget, which I do forget, as you know.

At the cancer centre, patients often allowed carers to speak and take decisions on their behalf:

S13 (doctor): so you have got your prescription, the (oral chemotherapy) is prescribed on the computer.

C5: right.

S13: and I shall just drop a note to your GP to ask them if they can arrange for you to have a Marie Curie nurse on call now and again if you need one.

C5: ok that is fine thank you I appreciate that.

When asked questions the patient might either check their response with the carer or look to the carer to answer:

S25: Are you taking any nutritional supplements at the moment as well?

P8: Um...

C7: He's taking Ensure, a few drinks.

S25: Are they the milky ones or juicy ones?

C7: Milky.

The carer's compensation for their partner's impairment seemed unconscious, but may have been influenced by known patient sensitivity to exposure of their memory loss. One patient was witnessed to become angry when his daughter disclosed his memory problems:

C4: Just his memory's going a bit that's all.

S13: Yes.

P5: Oi!

C4: [Laughs] He told me not to say nothing.

P5: I am having some memory loss, yes, I admit that.

S13: Has it, has it, has it changed much over the, the last few months do you think?

C4: I think so yeah. I think that it, the last...

P5: I told you I'd shut you outside (this consultation) if you don't shut your mouth.

Clinicians were content to conduct consultations with the carer in the decision making role. Some commented that they may not be aware when someone had a memory problem because of a carer taking a lead role:

S20 (support worker): I think (memory loss is) something we don't see lots and lots, or maybe it is there but obviously because they've got relatives and, you know, people with them, then, then that kind of disguises it... a little bit. ...So maybe we're not as aware as we probably should be sometimes.

Although carers played a central role in facilitating cancer treatment when the patient had a memory problem or dementia, they did not seek support for themselves and clinicians were not found to enquire about their needs. The potential for interaction between cancer treatments and patient's symptoms of dementia, and the accompanying additional demands on the carer, were not considered, with the exception of one recorded consultation where the adverse consequences of opioid medication for pain were outlined:

S9 (doctor): For some patients who are a little bit prone to it, they can worsen confusion as well. So just watch out for that kind of thing. And if you do notice that he's excessively drowsy or confused then bear in mind that it may be these that are the culprit. Of course you can take them off and then that will ease off...

**Table 1** Summary of theme findings

## **Discussion**

The problem of memory loss was found to be veiled in cancer clinic consultations. It was undisclosed or played down by patients, compensated for by carers and often unidentified by staff.

### *Veiled memory issues*

Our review of medical records revealed why it is difficult for staff to identify people with a diagnosis of dementia – referrals to specialist cancer services do not provide this information. Clinicians therefore rely upon noticing the signs of memory loss or, more typically, upon patient/carer disclosure. Barriers to patient disclosure reported in the literature include resistance to acknowledge unpleasant effects of dementia, considering memory irrelevant to cancer and concern that disclosure may adversely affect treatment decisions [26,27].

Routine assessment of cognitive function before treatment is fundamental if cancer clinicians are to provide support that enables the best (complex) treatments safely. Some clinicians expressed uncertainty as to the benefits of identification of memory loss problems and, when aware of memory problems, were uncertain what to do to support the patient. In this context, dementia awareness training is relevant to all cancer clinicians [29]. This study did not include observation of the actual administration of treatments. Further research is now needed to examine the process of consent preceding and during treatment [30], which seeks to find out how staff can best identify the impacts of cognitive loss to create person-centred care plans that do not make assumptions about compliance with treatments [29].

### *The carer*

Carers were key to successful cancer treatment and side-effect management. They provided physical support, such as navigating patients to and through clinics, but also provided cognitive support that enabled productive consultations. They gathered information on behalf of the patient and acted as the reliable messenger between patient and clinician. This role was crucial as the volume of information that modern oncology entails was considerable.

Carers are individuals in their own right. Their role was largely unrecognised and their support needs hidden and unaddressed. This was partly a consequence of the (conscious or unconscious) compensating behaviours they adopted to veil memory loss.

Knowledge of the mental and physical health of cancer carers is an identified gap in the literature and constitutes an important area for further research [31]. More broadly, carer's perspective on cancer services should be actively sought in future

studies, given their key role identified by this study in cancer treatment of people with memory loss.

### *Limitations*

This study explored patient experience of four out-patient clinics at a single centre. Further work is needed to test the transferability of findings to other settings and cancer populations.

The study was designed to identify patients with memory loss irrespective of causation (as currently differentiating between memory loss due to underlying pathology versus cancer treatment is not possible), and we assumed benefit in examining practical management irrespective of cause. That these people were difficult for staff to identify, and participants had to agree they were experiencing memory loss to participate, suggest this is a sub-set of all those clinic attendees. As the recruitment process was initiated by clinicians, we do not know how many of the 22 potential participants identified were invited to take part in the study, or who was approached but declined.

The proportion of cancer patients attending the clinics with a diagnosis of dementia was smaller than might be expected from cohort studies [5,9]. This suggests that explanation of the inequality in outcomes in cancer treatment for those with dementia compared to those without lies beyond the cancer clinic and may, in part, be explained by referral decisions, which also need to be explored.

### **Conclusion**

It is known that patients with CCD receive less treatment and experience more complications from treatment than patients without dementia. Our study suggests three areas that could have a positive effect on these inequalities. Routine cognitive assessment to identify cancer patients with memory problems, dementia awareness training for the cancer team to help them support people with memory problems to undergo complex therapeutic regimes safely and strengthening support of carers who enable the treatment of cancer in someone with dementia.

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### *Conflict of interest*

The authors have no conflict of interest to disclose.

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**Table 1**

<i>Memory &amp; the cancer consultation</i>	Clinicians rely on carers and patient self-report of memory difficulties. Patients can underplay the importance of memory and resist support.
<i>Staff attitudes</i>	Staff expect people presenting with memory problems to be elderly. Identification of problems was difficult and the value in doing so was questioned.
<i>Management approach</i>	Clinicians who are aware of memory problems can adapt their practices to enable a person-centred approach. A 'reliable' patient and a supportive carer was suggested as a prerequisite for complex cancer treatment.
<i>Carer role</i>	Patients were aware of the key role carers play in consultations, allowing them to speak and decide on their behalf – sometimes obscuring memory problems. The cognitive support and physical work done by carers seemed to be taken for granted by clinicians.