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1 **Title**

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3 Potential for identification of memory problems in the cancer clinic to enable improved treatment
4 experience and outcomes: mixed methods case study research

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24

Abstract

Purpose

To inform improvement in cancer treatment experience and outcomes for people with dementia or milder cognitive impairment.

People with dementia, compared to those without, experience more side effects from cancer treatment and have poorer outcomes including poorer survival.

Methods

The research was a mixed methods exploratory case study. Each case was a cancer treatment in a person with memory loss, a common symptom of dementia. Observations were conducted in 30 clinic sessions at one cancer centre between September 2014 and February 2015. Thirty-three encounters between people with a memory problem and a staff member were observed and ten consultations recorded. Interviews were conducted with five staff members and six people receiving cancer treatment, five accompanied by their carer. Analysis, informed by hermeneutic phenomenology, enabled the treatment pathway to be mapped and modelled to reveal sites for intervention.

Findings

Five potential sites of intervention were identified in the treatment pathway. Five actions at the sites of intervention that may improve patient experience and outcomes include, raising awareness of common problems for people with cognitive impairment receiving cancer treatment, encouraging disclosure of memory problems, staff training to identify memory problems and to know what to do, offering tools and techniques to aid self-management of memory problems, and addressing carer support needs.

Conclusion

Embedding biomedical treatment of cancer within a dementia-friendly psychosocial system may enable safe cancer treatment for a greater number of people with dementia or milder cognitive impairment.

Keywords

Cancer, dementia, cognitive impairment, memory, case study research, patient experience, supportive care, chemotherapy, radiotherapy, psychosocial intervention

Background

Cancer specialists are treating an increasing number of cancer patients with comorbid dementia or its precursor mild cognitive impairment (Bartlett and Clarke, 2012; Robb et al. 2010). Thus, dementia is an important consideration in the treatment of cancer. The prevalence of a precancer diagnosis of dementia varies by cancer site and is estimated to be between 5% in breast cancer and 17% in colorectal cancer (Ornstein et al. 2020; Tarazona et al. 2019; Raji et al. 2008). The prevalence of comorbid cancer and dementia, when including post cancer diagnosis of dementia is included, has been reported to be as high as 45.6% in nursing home hospice patients (McWilliams et al. 2018a). A systematic review found limited literature about people with dementia who then receive a cancer diagnosis. The available evidence shows that people with dementia receive less treatment, experience more treatment complications and have poorer survival as compared to cancer patients without dementia (Hopkinson et al. 2016, updated April 2020). The overarching purpose of this research was to inform improvement in cancer treatment experience and outcomes for people with dementia or its precursor milder cognitive impairment.

Memory loss is a common symptom of dementia and milder cognitive impairment. In 2014, our exploratory research found memory to be important for cancer treatment adherence and the management of side effects (Courtier et al. 2016). Typically, patients and carers did not disclose memory problems or a diagnosis of dementia, and the cancer team were unable to identify these people from cancer records. Problems with memory and other cognitive abilities related to dementia thus were hidden in the cancer clinic with associated patient needs not being addressed. A research problem was revealed - to identify ways to meet the needs of people with memory problems for improved cancer treatment adherence and management of side effects. Similarly, unrecognised and thus unmet need has been found in carers of people with dementia receiving cancer treatment, in part because they do not disclose problems (Witham et al. 2018). Cancer clinicians may need advice from dementia care experts to help them address communication problems and meet information needs (McWilliams et al. 2018b)

Psychosocial support and education can help people to manage memory problems (Matovan et al. 2010). There is potential for exploiting this knowledge in cancer care to realise the likely positive effect on treatment adherence, side-effects management and clinical outcomes. To do this, it is first necessary to identify sites for intervention where supportive care may prove to be effective. A site for intervention is a time point along the cancer treatment pathway where a patient, carer or healthcare professional makes a decision.

Aim

The primary aim of the study was to identify sites of intervention and to propose supportive care actions with potential benefit for people with memory problems receiving cancer treatment.

Purpose

~~The overarching purpose of the research was to inform improvement in cancer treatment experience and outcomes for people with dementia or milder cognitive impairment.~~

Research design and paradigm

The research was of case study design, as case studies capture information about the how and why of a complex situation (Yin, 2009). The management of cancer treatment in people with memory problems was assumed to be complex and case study a way of examining events and decisions whilst minimising burden on study participants. ~~Each case was the cancer treatment experience of a person with a self-reported memory problem.~~

Context (setting/site)

Each case was ~~the cancer treatment experience of a person with a self-reported memory problem a cancer treatment in a person with memory problems~~ who was attending a cancer centre as an out-patient in Wales, UK. They were attending clinics for treatment of breast cancer, urology cancer or people with mixed cancers undergoing radiotherapy.

Sampling strategy

Clinic staff identified patients 18 years or older, already receiving cancer treatment who they had witnessed to experience a memory problem in clinic, for example, someone with difficulty recalling treatment side effects. The clinician screened the potential participant by asking if they had memory difficulties and, if so, whether the problem began prior to the initiation of cancer treatment. If the patient was found eligible to take part in the study, with agreement, they were introduced to a researcher who gave verbal and written information about the research. They were asked to consider talking with their family about the study and to meet with the researcher again at their next clinic visit to give their decision on participation.

Consent

~~Patients with and without capacity to consent were able to take part. When sharing information about the study, if the researcher judged the person may lack capacity to give consent for participation, then capacity was assessed. If the person was found to lack capacity then a carer, family member or friend was approached to act as a Personal Consultee, as required by the Mental Health Act (2005). Verbal consent was taken on the day of the clinic observation and formal written consent obtained following the consultation, when the researcher could then give time to use a person-centred approach to explaining the research using verbal and non-verbal methods to facilitate interaction without inducing stress. This might involve a family member able to help the person with dementia feel more relaxed and able to explain the study in a familiar way, thereby overcoming communication difficulties. If informed consent was not obtained, for example, the Personal Consultee did not support participation, then observational data was destroyed. Carers who accompanied the patient, and staff members providing cancer care who agreed to take part, gave written informed consent for observation and interview.~~

Data collection methods

Within the case study design mixed methods were used to collect data, but the dominant methods were qualitative. Qualitative dominant mixed methods research relies non-numerical methods and interpretation to develop understanding whilst recognising quantitative data is also likely to be of benefit in answering the research question (Johnson, 2007). The analysis was informed by van Manen's (2016) hermeneutic phenomenological approach to gaining insight into and understanding of lived experience. An underpinning assumption was of a reality independent of subjective perception. The perceptions of each study participant and researcher (recorded as field notes) were assumed to be unique but based on this shared reality. The analysis sought insight into and understanding of the shared reality of the cancer treatment pathway for someone with a memory problem caused by cognitive impairment. A measure of cognitive impairment was used to confirm eligibility and to inform assessment of the transferability of study findings.

Observations

Field notes were recorded during non-participant observation of clinic sessions and clinical consultations over a five-month period commencing in September 2014. The purpose was to capture the everyday work, practices and interactions relating to the care of people with memory problems. The selected clinical areas were served by a Clinical Nurse Specialist or Radiographer who was willing to work with the project researcher to identify patients with dementia or mild cognitive impairment. The researcher shadowed consenting team members in their everyday work. Data relating to any staff member who did not consent to study participation was not recorded or used in the analysis. The researchers received training in observational methods from an experienced ethnographer.

Interviews

All semi-structured patient interviews were conducted in the person's home following observation of a clinic consultation and audio-recorded with the participants' consent. The patient interview schedule was developed from findings of an updated systematic a literature review (Hopkinson et al. 2016) and the expert opinion of the project steering group members (see Appendix 1: Interview schedule). Each interview began by the researcher stating her interest in memory problems, then inviting the participant to complete the Addenbrooke's Cognitive Examination (ACEIII, 2012), an assessment of cognitive function. The person was then asked to talk about their cancer treatment experience and what they considered to help with treatment adherence and self-management of side effects. The

pattern of the interview followed the aspects of the illness experience that were of importance to the patient. The interview schedule was used flexibly to adjust to the needs of the participant and ensure the approach was consistent with best practice in dementia care, which is to respect personhood (NICE, 2018). The staff interviews explored opinion of scenarios observed in the clinics and the cancer care of people with cognitive impairment and memory problems, to gain insights into decision making and management.

Data collection instrument - Assessment of cognitive function

The Addenbrooke's Cognitive Examination (ACE III) is a screening test of five cognitive domains, attention, orientation, memory, language, visual perception and visuospatial skills. It takes approximately 20 minutes to complete and is based on a maximum score of 100, with higher scores indicating better cognitive function. It is a reliable and valid tool for differentiating people with and without cognitive impairment, with sensitivity to early stages of dementia.

Data processing

Hand-written field notes were typed into Microsoft Word and stored with audio recorded clinic consultations and interviews in password protected files. Audio-recordings were transcribed verbatim and anonymized by a professional transcription company. Transcripts were checked against audio-recordings for accuracy (RM). Post data collection, familiarity with the data set was achieved through reading of the transcriptions (RM, AK, NC, JH) and through independent coding of all transcribed data by two members of the research team using electronic or hard copy as preferred by the individual (RM, NC). Coding was inductive and driven by the core study question:

What is the experience of people with memory problems receiving outpatient cancer treatment?

Data analysis

The analytic process had two-stages (see Figure 1.). The first stage was the coding and categorizing of transcripts and field note data, with RM and NC working independently. The team RM NC, AK and JH discussed the categories and agreed cross-cutting themes. The second stage mapped the multiple data sources for each case to the themes using method that conforms to Huberman and Miles (1994) 'mixed strategy for cross-case analysis.' Each map was an empirical based descriptive summary of a case (Miles and Huberman, 1994). Patterns and relationships crosscutting the summaries were identified and free imaginative variation (van Manen, 2016) used to derive an empirically based conceptual model. Hence, descriptive case summaries derived using a structured method provided the foundation for an exploration of cross-case patterns and relationships that were captured in a novel model of the experience of cancer treatment in people with memory problems. The model enabled identification of sites of intervention where action may improve patient experience and cancer treatment outcomes.

Researcher characteristics and reflexivity

Observational and interview data were collected by two research assistants. One, R1, had a non-clinical background but experience of research administration and recruitment in a different field of study and had received bespoke training in dementia care prior to the recruitment start date. The second, R2, was a dementia care expert and mental health nurse. Both received training in observational methods and research interview techniques (King et al. 2016). NC, Lecturer in Radiotherapy, contributed to data coding and thematic analysis and the model was devised by JH, a cancer and palliative care nurse with 20-years of experience conducting qualitative research. Each researcher brought a different historical personal perspective, which influenced the analytic process. For example, R2 sensitized the research team to the effect of clinic environment on the experience of cancer treatment for a person with memory problems.

Techniques to enhance trustworthiness

Descriptive data summaries triangulated all coding and categorisation of field notes, consultations and interviews within each case, which formed the basis of the interpretation. Identified patterns and

relationships were checked and refined through a search for disconfirming evidence (van Manen, 2016) by returning to the original interview transcripts and the field notes collected during more than 100 hours of contact with study participants. The final model (see Figure 2.) was presented as a flow diagram and tested for credibility through discussion with academics, clinicians and two members of the public affected by cancer during two face-to-face meetings and a workshop (van Manen, 2016).

Ethical issues

The research included a vulnerable group, people with dementia (all stages and types) and people with mild cognitive impairment (who may have similar needs to those with dementia.) This presented practical and legal issues. To ensure the research respected the dignity, integrity and personhood of the participants, a person-centred approach was interwoven throughout. Hellstrom et al. (2007) argues that the benefits of participation usually out weight the risks and that the exclusion of people with dementia is an affront to their dignity, irrespective of capacity to consent. Consent

Patients with and without capacity to consent were able to take part. When sharing information about the study, if the researcher judged the person may lack capacity to consent, then capacity was assessed. If the person was found to lack capacity then a carer, family member or friend was approached to act as a Personal Consultee, as required by the Mental Health Act (2005). Agreement from the person with dementia is required even when the Consultee supports involvement, therefore the researcher sought verbal permission for data collection at each contact. The intention was that no harm should result from participation in the study. Verbal consent was taken on the day of the clinic observation and formal written consent obtained following the consultation, when the researcher could then give time to use a person-centred approach to explaining the research using verbal and non-verbal methods to facilitate interaction without inducing stress. This might involve a family member able to help the person with dementia feel more relaxed and able to explain the study in a familiar way, thereby overcoming communication difficulties. If informed consent was not obtained, for example, the Personal Consultee did not support participation, then observational data was destroyed. Carers who accompanied the patient, and staff members providing cancer care who agreed to take part, gave written informed consent for observation and interview.

An NHS ethics committee, Wales Research Ethics Committee 1, approved the research, reference 14/WA/1030. To protect anonymity, patient participants are denoted by P and study number, carers by C and number, and staff by S and number.

Findings

Observations were conducted in 30 out-patient breast, urology and radiotherapy review clinics, between September 2014 and February 2015. Thirty-three scenarios were observed of a person with a memory problem engaged in dialogue with one of 20 participating staff members. In addition, ten clinical consultations and interviews with five staff members and six patient participants, five of whom were accompanied by their carer, were audio-recorded (see Table 1.) The six patients interviewed were asked to complete the Addenbrooke's Cognitive Examination (ACE III). An ACEIII score below 88 indicates likely dementia. The scores for participants able to complete the assessment (table 1) indicates our interview sample comprised people with mild to more severe cognitive impairment.

Participant code	Gender	Cancer	Data source	ACE III score	Treatment in progress	Carer code
P1	Female	Breast	Interview/Consultation	85	Chemotherapy	
P2	Female	Breast	Interview/Consultation	91	Chemotherapy	C1
P3	Female	Breast	Interview/Consultation	74	Chemotherapy	C2
P4	Male	Prostate	Consultation		Chemotherapy	C3
P5	Male	Prostate	Interview/Consultation	66	Hormone therapy	C4
P6	Male	Prostate	Consultation		Hormone therapy & radiotherapy	C5
P7	Male	Bladder	Interview/Consultation	Declined completion	Radiotherapy	C6

P8	Male	Head & neck	Interview/Consultation	40	Radiotherapy	C7
P9	Male	Colorectal	Consultation		Radiotherapy	C8
P10	Male	Head & neck	Consultation		Radiotherapy	C9

Table 1. Characteristics of interview and recorded consultation patient participants

Setting the scene - Clinic environment and practices

Organisation of the breast and urology clinics facilitated a pattern of information gathering and decision-making preceding each treatment cycle. Patients first reported to a reception desk, typically proceeded to have blood taken and be weighed, then waited for a clinical consultation at which blood results, clinical examination and self-report of symptoms and side effects and other problems, were considered prior to treatment. R1 describes the urology clinic as follows;

Location and layout is the same as for the breast clinic (...). The clinic is in effect three clinics merged, the lists are long. There are approximately 8 pages of patients for the day (...). This clinic is well organised, there are a lot of staff and it is obvious they are all aware of the running of the clinic and it runs like clockwork. The atmosphere is calm yet busy, people are busy but not frantic. Communication between nurses, consultants and other colleagues are good. There doesn't appear to be a hierarchy. Nurses and Health Care Assistants help consultants, consultants share workloads, if one has a lot of patients the other will take some of the patients to ease their workload and the same with the nursing team. (R1, field note, 16th October 2014)

Radiotherapy treatment was on consecutive weekdays with a review clinic appointment to assess and manage any problems scheduled periodically over the treatment course. The radiotherapy staff had an improvement project in progress to consider the needs of people with memory problems and how to improve their experience of cancer treatment. R2 reports;

Dementia awareness group set up a new 'dementia pathway to help these patients through treatment. Dementia link for the radiotherapy department who sits on a working group looking at the introduction of the 'This is me' biographical tool to help staff be person-centred in their approach and work more closely with family or friend. Information boards, information tables and Wi-Fi access help orientate people with memory problems. (R2, field note, 25th November 2014)

In all clinics the researchers observed patients who were given a lot of complex information. Staff were aware that during a single clinic visit the amount of information given might be confusing or overwhelming;

We do have patients that just got so many things going on that they forget about appointments. (...). It could be that they've got a review that day, they have got a treatment, they have got a chemo, they have got a complimentary therapy appointment, an appointment to see somebody from finance or palliative care team....they might give me the card and say 'I don't know what I'm doing. (S20, interview, 21st January 2015)

The staff in the three clinic areas spoke about memory problems differently. There was little expectation that the people attending the clinic for breast cancer treatment might have cognitive impairment or dementia;

S8 said this is a chemo clinic and we're unlikely to have patients with dementia here. She scrolled through her patient list and finished with a triumphant 'nope' once she got to the bottom of the list. (R1, field note, 2nd September 2014)

In the urology clinic, by contrast, it was known that people with memory problems presented for cancer treatment. However, there was uncertainty about what might be done;

S15 talked about a patient with dementia referred to a dementia care nurse. He wasn't sure what the outcome of this referral would be because he wasn't sure if there was anything available to help him. He asked what (staff) could do. (R1, field notes, 6th November 2014)

1 In the radiotherapy clinic, the staff were more alert to memory problems, (you) *keep your eyes peeled*
2 *and watch out* (S26, interview, 21st January 2015). *To facilitate identification of memory problems 'a*
3 *welcoming and personal atmosphere was created by the team that was strengthened by the seating*
4 *arrangements.'* (R2, field note, 3rd Feb 2015)

6 The team also knew what to do when a problem was identified;

8 *If a patient has memory problems, we'll help them out by, if they do come to their review clinic and we*
9 *have to give them a lot of medications, we'll help them out by giving them step-by-step approach*
10 *written on pieces of paper. We'll also ask them to, if they can, bring their carer or a family member*
11 *with them to help them, if they don't remember everything that's said.* (S18, interview, 21st January
12 2015)

14 **Patterns cross-cutting patient cases**

16 Commonalities were found across the cases. These were factors that were recurring, although not
17 present in all cases, they had important impact on the experience of cancer treatment.

19 **Carer support of patients**

21 Patients might bring a family member or friend to clinic to help them navigate the experience;

23 *(...) the lady has brought her friend with her because she is forgetful.* (R1, field note, 21st October
24 2014)

26 The support person was often essential for clinicians to accurately assess symptoms, treatment side
27 effects and other treatment related issues. Patients were noted to rely on a family member or friend
28 during the clinic visit;

30 *The patient is very reliant on her husband giving answers, he is extremely organised and has*
31 *completed the medication charts very neatly.* (R1, field note, 4th November 2014)

33 P6 explains to his doctor the reason his daughter accompanies him and writes things down;

35 *I will have forgotten what you said by the time I get to the car.....It is my memory gives me a problem*
36 *which, you know, I'm quite ashamed of.* (P6) [The doctor has given advice on, pain management,
37 prescribed new pain medication and laxative, explained regular pain killers can cause constipation
38 and suggested some possible adverse outcomes of not taking laxatives with pain killers, booked a
39 scan and given an appointment time and date, given information about the oral treatment to be
40 continued for 12 months, given results of blood tests, explained how radiotherapy is used for pain
41 management, given information about Marie Curie Nurses and promised a referral, and finally given
42 an opinion on using an exercise bike. (P6, observation of consultation, 22nd January 2015)

44 Treatment or cancer management decision making might be impossible in the absence of someone
45 with sufficient knowledge of the patient;

47 *Patient has come with a paid carer and his wife will not be coming.....S9 asks him how he is feeling*
48 *and if he has any pains. He says he can't remember how he feels. The only information the carer has*
49 *on this patient is that 'he is a wanderer'. She says he seems fine....S9 said the appointment was*
50 *fruitless, he couldn't work out how the patient was feeling, he was asymptomatic and no notes had*
51 *been sent from the referring hospital.* (R1, field note, 8th January 2015)

53 **Hidden memory problems**

55 Staff in the clinics spent a relatively short period of time with any one patient. In this situation, it was
56 difficult to identify those with memory problems or dementia, particularly if the patient lacked insight or
57 decided not to disclose;

1 *S13 said he was a complicated patient, they had argued about treatment options. It wasn't for a while*
2 *that he realised the patient wasn't being awkward but had memory problems (R1, field note, 6th*
3 *November 2014).*

4
5 Sometimes the person accompanying the patient also chose not to disclose a memory problem;

6
7 *Do they usually tell you? (R2) A lot of them do, but some of them you have to get to know first....Quite*
8 *often the relatives will say....The rest of the time we have to work it out for ourselves. (S24, interview,*
9 *21st January 2015)*

10
11 The non-disclosure may be unintentional, as described by S12;

12
13 *S12 talks about how she has noticed that those with dementia are often compensated by their partner*
14 *and the partner often isn't aware they are covering up for the dementia, it's just a natural progression*
15 *(an adaptation as the dementia progresses). (R2, field note, 16th October 2014)*

16
17 However, staff also suggested that patients may ask the person accompanying them not to disclose.
18 This behaviour was witnessed by the researcher in a clinic consultation;

19
20 *So how are you in yourself, in other respects? (S13) Just carry on taking the tablets, but I'm er, I'm*
21 *good I think. (P5) Just his memory is going a bit that's all. (C4) Oi! (P5) He told me not to say nothing.*
22 *(C4) (P5, observation of consultation, 22nd January 2015)*

23 24 **Change in memory during treatment**

25
26 In all three clinics, there were patients who had experienced change in their memory during treatment.
27 P2 is receiving treatment for breast cancer. She explains;

28
29 *(....) how she has had memory problems prior to treatment and diagnosis, however, they are getting*
30 *worse. (R1, field note, 11th November 2014)*

31
32 The researcher in the urology clinic observed interactions with staff and consultations where carers of
33 patients reported behavioural change during treatment. For example;

34
35 *....he has been having very bad memory problems and his wife said he is a complete nightmare. He*
36 *has been suffering with UTIs and without the antibiotics he is unbearable. (R1, field note, 15th January*
37 *2015)*

38 39 **Implications of memory loss for treatment**

40
41 Known negative impacts of cancer treatment on people with cognitive impairment influenced
42 treatment decisions;

43
44 *S22 said that patients with dementia aren't often recommended for treatment because of the toxicity.*
45 *(R1, field notes, 6th November 2014)*

46
47 S22 was consistent in this view, on another occasion explaining to R1 the need to consider risk of
48 harm versus benefit;

49
50 *If it's a simple drug or treatment such as 'you're bleeding from cancer, this drug will help you' then*
51 *this is clearly explained to the patient and family then it will likely be administered, but as soon as*
52 *treatment gets complex they are unable to treat patients with memory problems/dementia. (R1, field*
53 *note, 11th December 2014)*

54
55 Treatments were changed or stopped because of treatment safety concerns, in response to emergent
56 side effects likely related to not only the treatment, but also cognitive impairment. P3 explains his
57 initial treatment proved 'dangerous';

58
59 *I'd already had the (chemotherapy), which they were going to offer me again and (doctor) said oh it's*
60 *a bit dangerous. I don't know why and she offered me this other one. (P3) Well she said it was less*

1 *problems with it. (C2) (...) I had to end up in hospital. So all in all, the last one, I wasn't well. (P3) (...)*
2 *Was there anything else? I can't remember. (P3, interview, 12th December 2014)*

3
4 C6 explains a change in P5's treatment, which included cessation of chemotherapy;

5
6 *Now he done three weeks and then he was ill. So we had to take him to hospital...and...then they*
7 *stopped his treatment....He was having chemotherapy tablets. Then they cut him down to six. And*
8 *then his third week, when he was so ill, they cut him off them altogether. He was just having*
9 *radiotherapy. (C6, interview, 5th March 2015)*

10
11 A safety concern was that the patient might put themselves at risk through non-adherence to
12 treatment. As a consultation with P4 proceeds, S22 changes his plan from giving the patient
13 instructions to take a reduced dose of medication, to asking the patient's GP to organise services in
14 the community to enable safe administration;

15
16 *I'll leave you a message, I'll say one of two things. To carry on the three tablets a day, or drop down*
17 *to two tablets a day. (S22)*

18
19 *Yea, but its two – there's three different tablets, two different. (P4)*

20
21 *Okay, umm...so maybe I shall write to your GP. Is he the one that does the blister packs? (S22)*

22
23 *Yeah. (C3)*

24
25 *Right. Okay. In that case I'll write to your doctor and organise it through him (...) Safest thing to do.*
26 *(P4, observation of consultation, 30th January 2015)*

27 28 **The challenge for the carer**

29
30 Supporting a patient with cognitive impairment or dementia during cancer treatment could prove
31 challenging. A carer might find themselves unable to manage the demands. The patient described in
32 the following field note was admitted to an acute hospital bed a few days later;

33
34 *(The patient's wife) has a huge handwritten file of all his medication and all their medical history*
35 *including allergies. She also has a calendar print out and there are hundreds of appointments*
36 *pencilled in. The amount of paperwork and notes she has is overwhelming and chaotic.....she is*
37 *worried that if she isn't with him when he needs to take his medication he won't take it.....She tells me*
38 *how he wakes in the night and goes downstairs or outside and gets cross with her if she asks him to*
39 *come upstairs. She hasn't slept properly for two weeks. Her concentration is lapsing due to extreme*
40 *fatigue. She says his anger towards her is completely out of character and he has never raised his*
41 *voice to her before. (R1, field note, 13th November 2014)*

42 43 **The challenge for the oncology staff**

44
45 As non-experts in dementia care, some oncology staff had difficulty in identifying memory problems
46 and/or recognising the risks of treatment for people with cognitive impairment.

47
48 R2, noted a situation where a patient was persistent in explaining non-adherence to morphine-based
49 analgesia prescribed by his GP. The clinician he talked with about pain management did not seem to
50 be aware of the increased risk of behavioural and psychological symptoms in people with cognitive
51 impairment taking a morphine-based medication;

52
53 *'You would be allowed to have these and have your treatment. They are painkillers we use very*
54 *frequently with people having the same treatment as you are.'* (Radiotherapy review team member)

55
56 *....when I had my second operation, um, they put me on morphine-based....when I come round, I was*
57 *all over the place*

58
59 *It can sometimes make you a bit woozy and a bit light-headed'* (Radiotherapy review team member)

1I couldn't move. I had a job talking.....I was having visions about things that wasn't actually there.
2 (P7, observation of consultation, 3rd February 2015)
3
4

5 There was also a challenge of teaching complex self-care to a patient who might forget instructions;
6

7if you can remember that exercise (a swallow exercise), I want you to do it ten times, three times a
8 day. (S25, observation of consultation, 24th February 2015)
9

10 Communicating information could be challenging, for example, never being 'quite sure how to
11 approach them' (S20). This challenge might be exacerbated if the person used techniques to disguise
12 memory problems, such as 'people with them, it kind of disguises it a little bit.' (S20) or reverting to
13 conversation about the past. (S20, interview, 21st January 2015). P8 changes the topic of
14 conversation during his consultation;
15

16 '....back in the seventies, early seventies, they won every single, Wales, won every single one. (P8,
17 observation of consultation, 13th March 2015)
18

19 Solutions proposed for communication difficulties included;
20

21 It helps by normalising that a little bit because by, you know, saying that a lot of people do go through
22 that (memory difficulty), and do have some problems. (S18, interview, 21st January 2015)
23

24 **The pathway through treatment** 25

26 The patterns of, carer support of patients, hidden memory problems, change in memory during
27 treatment, implications of memory loss for treatment, and challenges for both carers and oncology
28 staff were considered against the backdrop of observed clinic environment and practices. Although
29 any one data source or case could only reveal part of a journey through treatment, exploring
30 relationships between the patterns enabled the mapping of sequences of events. These were maps
31 that set out possible pathways through treatment for someone with a memory problem. Maps that
32 illustrated how the vulnerability of someone with a memory problem is, or is not, managed in a cancer
33 clinic. The analytic process concluded by combining maps in a model of the experience of cancer
34 treatment for a person with a memory problem (see Figure 2.).
35

36 The model revealed time points along the treatment pathway when decisions were made by the
37 patient, carer or a clinician that determine the course of the cancer treatment pathway. These points
38 are potential sites of intervention, when different decisions and actions might change patient
39 experience and the management of cancer treatment and its side effects.
40

41 What was learned from the analysis led to the proposition of five actions with the potential for
42 improving patient experience of cancer treatment and outcomes for people with memory problems.
43 The actions hypothesised to be of benefit were,
44

- 45 1. *Raising awareness of memory as a common problem* to be addressed for optimal cancer
46 treatment.
- 47 2. *An environment that supports disclosure.*
- 48 3. *Identifying and addressing the needs of carers* to enable maintenance of the relationships
49 and social networks needed to help the person with cognitive impairment through cancer
50 treatment.
- 51 4. *Upskilling multidisciplinary oncology staff* in knowledge and skill to help people with
52 cognitive impairment through their treatment thus creating a dementia-friendly context for
53 cancer care.
- 54 5. *Hints, tips, techniques and advice for management of memory difficulties* through cancer
55 treatment to address the needs of the individual, respect their personhood and promote the
56 supported independence needed for safe cancer treatment.
57

58 A coherent implementation of the five proposed actions would require intervention across the
59 psychosocial system that supports the person with a memory problem (see Figure 3.). The findings

indicate that a supported psychosocial system can enable safe biomedical cancer treatment in a person with cognitive impairment or dementia.

Discussion

This research found that mMemory problems caused by dementia and milder cognitive impairment can lead to variance from an optimal cancer treatment pathway.

What can be done to improve care of people with memory problems receiving cancer treatment?

The model derived from our analysis enables the identification of intervention sites along the treatment pathway and supports the proposition of actions that may enable people with cognitive impairment to continue a guideline recommended treatment. However, the interventions hypothesised to improve cancer treatment experience with likely associated improved cancer outcomes for people with mild cognitive impairment or dementia, do not fit within the scope of the medical model of disease and treatment. Putting the model into practice would be to adopt a biopsychosocial system of treatment and care (Engel, 1977).

Cook and McCarthy (2018) similarly argue that social networks comprising people who know the person through their personal involvement can empower and support people with dementia through cancer treatment. They make the case that to sustain the relationships that help maintain self, identity and agency, requires the focus of decisions to be widened from the individual's physical robustness (fitness to cope with treatment) and pathology. Pure biomedical focus on the individual is problematic when someone with dementia may need support to make decisions (Witham et al. 2018) or lack capacity, therefore require a decision to be made in their best interest. Our research shows that Patient experience, safety and effectiveness of cancer treatment for people with cognitive impairment and/or dementia may be improved if the model of cancer care further evolves to embed the medical model for treatment within a psychosocial systems approach to care.

A hidden problem

~~Their findings of this research mirror our own research conducted in Wales, are mirrored by the work of~~ Witham et al. (2018) who interviewed seven carers of people with dementia receiving cancer treatment in England. ~~Their findings mirror our own research conducted in Wales.~~ The carers reported increased burden that was unrecognised by the oncology team (Witham et al. 2018). The oncology team can accept what patients say without question and fail to work with carers, who can then feel marginalised (Witham et al. 2018) ~~and excluded from decisions (Martin et al. 2019).~~ Martin et al. (2019) also found carers can feel excluded from decisions and proposed a An explanation is that clinicians are aware carers can misjudge patient preference and become an obstacle to treatment (Martin et al. 2019). However, Witham et al. (2018) conclude that, if carers are to help the patient manage treatment and its side effects, then addressing their needs for information and training across the treatment pathway is important to help them with decision making and other involvement. Other researchers have found carers enable cancer treatment by facilitating patient-clinician communication, supporting treatment adherence, seeking help for the patient, and monitoring for side effects (Martin et al. 2019; McWilliams et al. 2018b). Our own findings add by revealing that i Including them in clinical discussions may also be important for identification of memory and other problems related to cognitive impairment during cancer treatment. Our research is the first to highlight the importance of identifying people with memory problems early in the cancer treatment pathway, to enable support for safe cancer treatment.

Oncology staff education and training in dementia care

The finding that oncology staff can find it challenging to identify memory problems and may not appreciate the risks of treatment for people with cognitive impairment, supports the argument that Dementia care should be included in the education and training of the oncology workforce, if it is to meet the needs of people with cognitive impairment receiving cancer treatment and their carers. Education and training may facilitate adjustment to the way information is given (McWilliams et al. 2018b) and help with the challenge of communicating with people who have dementia (Cook and McCarthy, 2018; Martin et al. 2019). Flood et al. (2019) audited nine of the 12 radiotherapy

departments across the Republic of Ireland in 2017. No centre had implemented the role of 'dementia champion,' as recommended in The Society and College of Radiographers guide (p817, 2015). The audit found many departments 'do not recognise the need to implement policies and protocols regarding the dementia care of patients or invest in specific training and education,' despite oncologists feeling unable to manage or diagnose cognitive impairment. Six departments had no awareness of the specific distress associated with the usual safety restraints, for people with dementia undergoing radiotherapy. This research and other studies show that there is potential to use knowledge of environmental adaptations, communication techniques and methods used in other contexts, to enable cancer treatment and reduce variability in cancer treatment outcomes.

Limitations

The research was conducted at a single specialist cancer centre. It does not explore the decision to treat, but what happens after treatment has commenced. The patients interviewed completed an assessment that confirmed all to have cognitive impairment, five with likely dementia, however other patients observed because they reported memory problems did not complete an objective measure of cognitive impairment. The model of the experience of cancer treatment for people with memory problems was tested for credibility through presentation to and discussion with a panel of nurses and allied health professional oncology staff, academics with an interest in dementia care, clinical experts in dementia care and members of the public. However, they were all living and working in South East Wales where cancer care contexts may differ to other parts of the UK and beyond.

Conclusion

A call to action – embedding treatment delivered according to a medical model within a dementia-friendly psychosocial system may improve patient experience and enable safe cancer treatment for a greater number of people with dementia or milder cognitive impairment.

Conflict of interest:

Declarations of interest: none.

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