



Cancer-related information needs and decision making preferences in people with dementia who have cancer, their carers and cancer clinicians

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Background to the research

- Ageing UK population
- Cancer is more likely in older people
- Approx. 7.1% of people aged 65 or older have dementia
- Chance of co-morbid cancer and dementia is increasing
- Systematic review: to investigate the impact of dementia on cancer pathways including prevention, detection, cancer treatments and outcomes



Cancer, Dementia and information needs (Can-DO) study

Aims

- To identify cancer-related experiences of people with dementia and their carers
- To identify cancer clinicians perceptions of information provision and decision making processes when caring for a patient with cancer and dementia



Methods

- Single centre, qualitative study
- Semi-structured interviews
- N = 30 participants (approx. 10 patients, 10 carers and 10 cancer clinicians linked to patient)
- Thematic analysis



Sample

- 10 patients with cancer and dementia
 - Age range 39-93 years
 - Cancer: urological, head and neck, gynaecological, skin, colorectal, lymphoma
 - Dementia: Alzheimer's disease, vascular dementia, Pick's disease and HIV-related dementia
 - Cancer treatment: surgery, palliative chemotherapy, radiotherapy, stem cell transplant, no treatment
- 9 carers
- 9 cancer clinicians



Early findings

Themes

1. Patient's perspective of cancer
2. Role of carers
3. Challenges in cancer treatment in the context of dementia



Patient's perspective of cancer

Impact of dementia on awareness and understanding of cancer

I think the dementia played a big part in that, in blunting the trauma and the, you know, possible embarrassment of having to be examined and things...again she just went with it and didn't seem at all worried.

Brenda's Husband



Patient's perspective of cancer

There was no issues because she knew she had a sore throat, and she's always just remembered it as a dirty throat...I don't think even now she knows that she's got cancer, or has had cancer. *Sally's son*

So to begin with, I thought...she wasn't really sure, she couldn't remember, but then with prompting she knew that she had cancer in the throat...at the time I felt she was aware of her [cancer] diagnosis, but in retrospect I'm not sure that she was that aware of it. *Sally's clinician*



Role of carers

Supporting cancer treatment decision making

Yeah, 'cause I can listen alright like what you're saying to me now I know that, but in a few minutes, I can't tell you what you've said to me...I wouldn't be able to manage at all without them. *Ben, patient*

...if their relatives have a clear understanding about why he's coming and what's involved, and are also kind of in agreement that it's in the patient's best interests and are supportive of that, then that's quite helpful because they can keep doing that, reiterating it at home and explaining it to the patients, it will make things go smoother. *Ben's clinician*



Role of carers

I've had a terrible week this week, haven't we? I've been falling out with her because everything I do is wrong, and it's only through me telling her about these two scans and her operation, I think it's playing on her mind. *Joan's husband*

...when people have got dementia it's the carer making sure that the right thing is being done for that patient...they may not be able to be as vocal about it because of the dementia; and so I suppose sometimes it's extra burden on the carer because they're the voice...to a degree they're the voice of that patient, when they can't make that decision themselves. *Joan's clinician*



Challenges in cancer treatment

Impact of dementia on cancer treatment

...if she hadn't have had the dementia then I think maybe we should have done something, but with the fact that it would make her dementia worse I just didn't really want her to go through it. So that's how it was all left. *Wendy's son*

I don't know, you know, you know, I don't know....Yeah, I think it will go better. *Wendy*



Summary

- Complex interplay between cancer and dementia
- Importance of caregiver in treatment decision-making and support
- Clinicians receptive to the development of more dementia-specific training



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