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Cancer treatment decision-making in dementia

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Overview

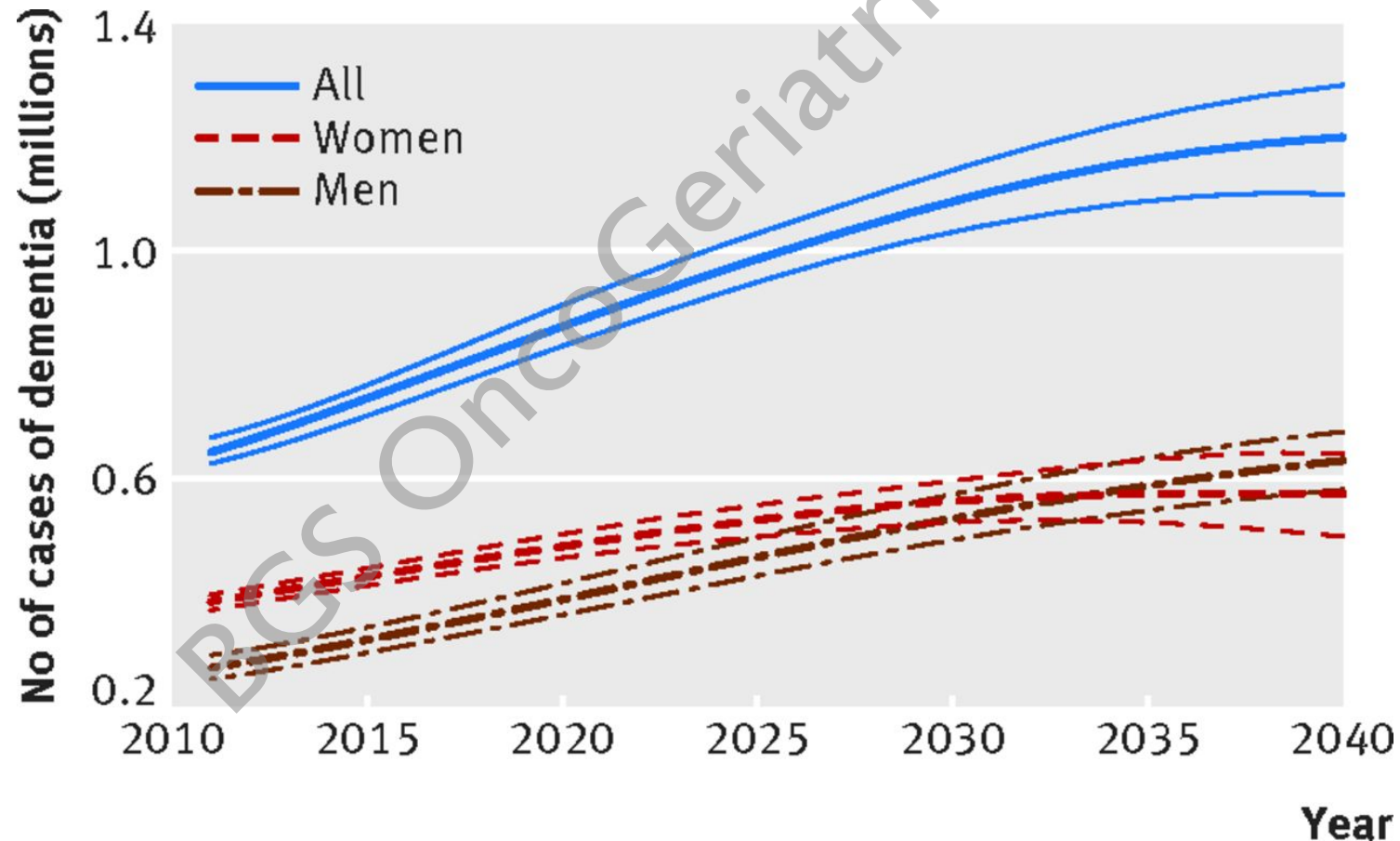
- Background (person/people with dementia = PwD)
- Findings from a systematic review
- Findings from an interview study
- Implications and considerations in practice

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Projected number of people with dementia in England and Wales 2011-40.

Sara Ahmadi-Abhari et al. BMJ 2017;358:bmj.j2856





Symptoms experienced in dementia & cancer discussions

- Short-term memory – *memory of diagnosis*
- Concentration/planning – *able to consider benefits/risks of treatment?*
- Daily tasks – *who is there supporting them? (before/during/after)*
- Communication – *can they express their treatment wishes (regardless of capacity)?*
- Mood/emotion/personality – *how are they right now within the consultation? Likelihood of change?*



Systematic review

Objectives:

1. Estimate prevalence of cancer-dementia
2. Describe cancer-related experiences of people with cancer-dementia, their informal caregivers and HCPs at any stage in cancer pathway
3. Describe cancer-related outcomes for people with cancer-dementia

(Review carried out in June 2016)

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Systematic review: findings

Included 47 studies (ONE UK; 14 had cancer-dementia specific aim)

1. Prevalence of cancer-dementia:

- 34 studies
- 0.2% (ovarian) Danish population study to 45.6% (any) US nursing home hospice data (Tetsche et al. 2008; Miller et al. 2002)
- Similar rates of dementia in cancer v non-cancer comparison groups (in 7 studies)



Systematic review: findings

2. Cancer-related experiences

10 studies reported impact of dementia on cancer diagnosis:

- Less information on tumour staging and more likely to be diagnosed at later stage

7 studies reported on treatment decisions in PwD:

- Some evidence of < likelihood to receive colon or breast cancer treatment
- Plus 1 (hypothetical) carers study
- Plus 2 studies with HCPs (palliative care and GP referral)



Systematic review: findings

3. Describe cancer-related outcomes

7 studies reported on symptom management:

- dementia severity $>$, reported pain + opioids $<$
- $<$ likely to be enrolled in hospice care
- $>$ likely to use emergency services/be admitted
- $>$ likely to have longer stay in hospital

13 studies reported on cancer outcomes:

- $>$ risk of death compared to cancer only
- poorer survival rate (in 5 studies)



Interview study

Study Aims

- To identify cancer-related experiences of PwD (and their carers)
- To identify cancer HCPs' perceptions of information provision and decision making processes when caring for a patient with cancer and dementia

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Study Recruitment

- Single centre (tertiary cancer hospital), cross-sectional
- PwD, informal caregivers, oncology HCPs
 - Any dementia type (confirmed diagnosis)
 - Any cancer type
 - Any treatment decision
- Sampling via Psycho-Oncology



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Results: Sample

- 10 patients with cancer and dementia
 - 5 females; Age range 39-93 years
 - Two had capacity to consent
 - Cancer: urological, head & neck, gynaecological, skin, colorectal, haematology
 - Dementia: Alzheimer's disease, vascular dementia, Pick's & HIV-related dementia
 - Cancer treatment: surgery, palliative chemotherapy, radiotherapy, stem cell transplant, no treatment, oral chemotherapy and radiotherapy

Results: Sample and analysis

- 9 carers: son (2), daughter (2), husband (3), wife (2)
- 12 cancer HCPs: consultant (3), consultant radiographer (1), surgeon (4), clinical nurse specialist; CNS (2), registrar/clinical fellow (2)

Data analysed using thematic analysis: four main themes focussing on before-during-after cancer treatment decisions

1. Leading up to the initial consultation

- Support from family for investigations/diagnosis
- Lack of awareness on impact of dementia for cancer investigations
- Lack of information on impact of dementia

‘if I hadn’t been there it certainly would have been weeks’ (Joe)

‘...they're often labelled with dementia without actually acknowledging that’ (Joan’s consultant F)

‘...asking her very complicated instructions which she just wouldn’t be able to interpret and do for them...they weren’t adapting the care and the responses’ (Brenda’s husband)

2. Treatment decision-making processes

- Timeliness of consultations
- Navigating information

‘it may take longer to get the full information...you need to identify what they know, what they don't know, how much they understand of the situation’
(Joan's consultant radiographer F)

‘I can forget a few things and not ask the correct questions...it's good for somebody here to go with me’
(Joseph)

‘all that was spoken about I took in. But they [had] given us these leaflets; they had to be read for me cause I just can't do it’ (Ben)

‘That treatment consultation was really fast for me 'cause they talk really, really fast [laughing]. It's just fast and it's quick. This is a busy place for somebody with dementia. It all needs to be slowed down so much more’
(Ben's daughter)



2. Treatment decision-making processes

- Dementia diagnosis considerations

'I think they were thinking because she's got dementia, the 25 [radiotherapy fractions] might have been too much for her'
(Joan's daughter)

'It wouldn't be fair to deny her radical treatment based on the fact that she would find it difficult [due to dementia] but ultimately we were aiming to cure her of her cancer' (Brenda's registrar F)

'That [treatment decision] might take a little bit longer again because you've got to consider everybody else's opinions in the treatment of that patient' (Joan's consultant radiographer F)

'The pre-warning [about behaviour] from the daughter was helpful for us to get planning properly' (Alan's surgeon M)



2. Treatment decision-making processes

- Decision-making agency

‘Again you know with the dementia, she was more interested about talking to the registrar, whether he was married or not. You know did he have any children?’ (Brenda’s husband)

‘Yeah, they didn’t give you any option’ (Ben)

‘You can get bombarded with irrelevant information...I think to some extent I pushed all the negative things out-of-reach because the alternative is...worst’ (Victor)

‘I don’t think she understood what was going on really. She’s not understood the full implications but did have a chance to comment if she wanted to...but I think she was messing with someone’s hair’ (Agatha’s son)

3. Adjustments to cancer care

- Adapting communication for continuity of care
- Proxy healthcare professionals

'I tend to educate the relatives on signs to look out for, what they need to do...we need you to be active in looking for signs and symptoms of sepsis etc.' (Victor's CNS F)

'her husband was so caring. I had no concerns about the safety of her getting the tablets [be]cause I knew he would give them to her' (Joan's consultant F)

'They did the various tests with us where they put little bits on her [mask fitting for radiotherapy]...then explained it, like a wet flannel, a warm flannel; so again that's...that has sunk into my Mum's head about a wet flannel. So all the treatment, when she had this mask on each day, the only one thing that she always remembers - if you ever ask her - she always remembers the wet flannel' (Sally's son)

4. Following completion of cancer treatment

- On-going decision-making process
- Lasting impact of treatment decisions

'I'm still recovering so I'm more aware of problems...I've come home and having to adapt and things in the house or re-learnt things which I'd forgotten about' (Victor)

'They didn't really go through what we need to know now... I don't really know what's happening, which isn't a great position to be in' (Agatha's son)

'They want me to go for it but do I want to go for it? Surely that's my choice? I know we're only really going to know if I go for the biopsy, the scan, but do I really want to know that?' (Joseph)

'I want to be nearer home'
(Brenda)



Summary of findings

- Complex interplay between cancer and dementia across a range of types of dementia, cancer and cancer treatment
- Dementia specific considerations come in to play during cancer treatment decision-making: impacts on patient involvement
- Importance of caregiver in supporting the person with cancer-dementia understand information about their treatment as well as help make decisions throughout the entire pathway

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Implications/Considerations in practice

Information needs and cancer treatment decision making:

- What information do you receive with a referral?
- What information would be more helpful at MDTs?
- How can you most easily get additional information about impact of dementia on the patient's life (that is easier for patient/carer too)?
- How do you record information about 'impact' of dementia?

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Implications/Considerations in practice

Decision-making support (should you need it):

- Is there a specific person/team to support in the context of dementia (for staff and person with dementia/family)?
- Is it possible to allocate more time in appointments?
- At what point should a best interest meeting be arranged (if one is required)? Who should be at it (e.g. surgeon / radiology)
- What tools could you use to communicate with the PwD?
- Is there any way you could try to have carer from nursing home who is informed (enough) about PwD to support communication?

Open Access

Research

BMJ Open Cancer-related information needs and treatment decision-making experiences of people with dementia in England: a multiple perspective qualitative study

To cite: McWilliams L, Farrell C, Keady J, *et al.* Cancer-related information needs and treatment decision-making experiences of people with dementia in England: a multiple perspective qualitative study. *BMJ Open* 2018;8:e020250. doi:10.1136/bmjopen-2017-020250

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Ageing & Society (2018), 1–22
doi:10.1017/S0144686X18001411

ARTICLE

Bridging the divide: the adjustment and decision-making experiences of people with dementia living with a recent diagnosis of cancer and its impact on family carers

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A systematic review of the prevalence of comorbid cancer and dementia and its implications for cancer-related care

L. McWilliams, C. Farrell, G. Grande, J. Keady, C. Swarbrick & J. Yorke

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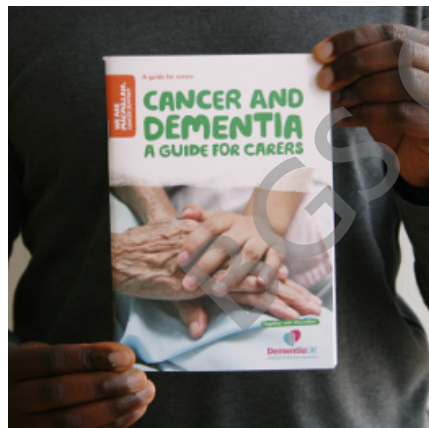
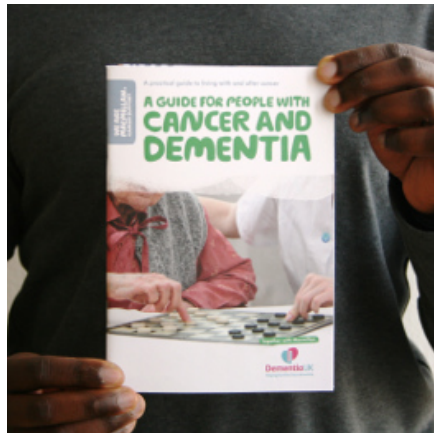
More (UK) progress!

FindAPhD

PHDS EVENTS FUNDING

The care and support needs of residential care home residents with dementia and comorbid cancer: a qualitative interview and ethnographic study

Leeds Beckett University | School of Social Sciences | Leeds | United Kingdom



PAPER

Psycho-Oncology 2016; 25: 1079–1084

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

Nick Courtier, Rebecca Milton, Amanda King, Rosie Tope, Susan Morgan, Jane Hopkinson

A team of researchers from Leeds Beckett University's [Centre for Dementia Research](#), led by Professor Claire Surr, Professor of Dementia Studies at Leeds Beckett University, working with colleagues from the University of Leeds, will be the first researchers to profile the size and demographics of the population of people with cancer and dementia from a large dataset of GP records.

Dr Naomi Farrington! (University of Southampton)

Thank you for listening

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