

A successful clinical-academic partnership:
**Research about cancer treatment in
people with dementia**

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The study team



Common symptoms

- Communicating- e.g. word finding difficulty
- Memory- e.g. misplacing things
- Doing or saying things again and again
- Changes in mood- e.g. feeling low
- Getting disorientated- e.g. getting lost

Study purpose

To develop an understanding of the experience of cancer treatment for people with memory problems, to inform service improvement.

The study

Systematic Review



Medical Note Review



Fieldwork

Systematic review

Question:

What is known about the experience and outcomes of cancer treatment in adults with dementia?

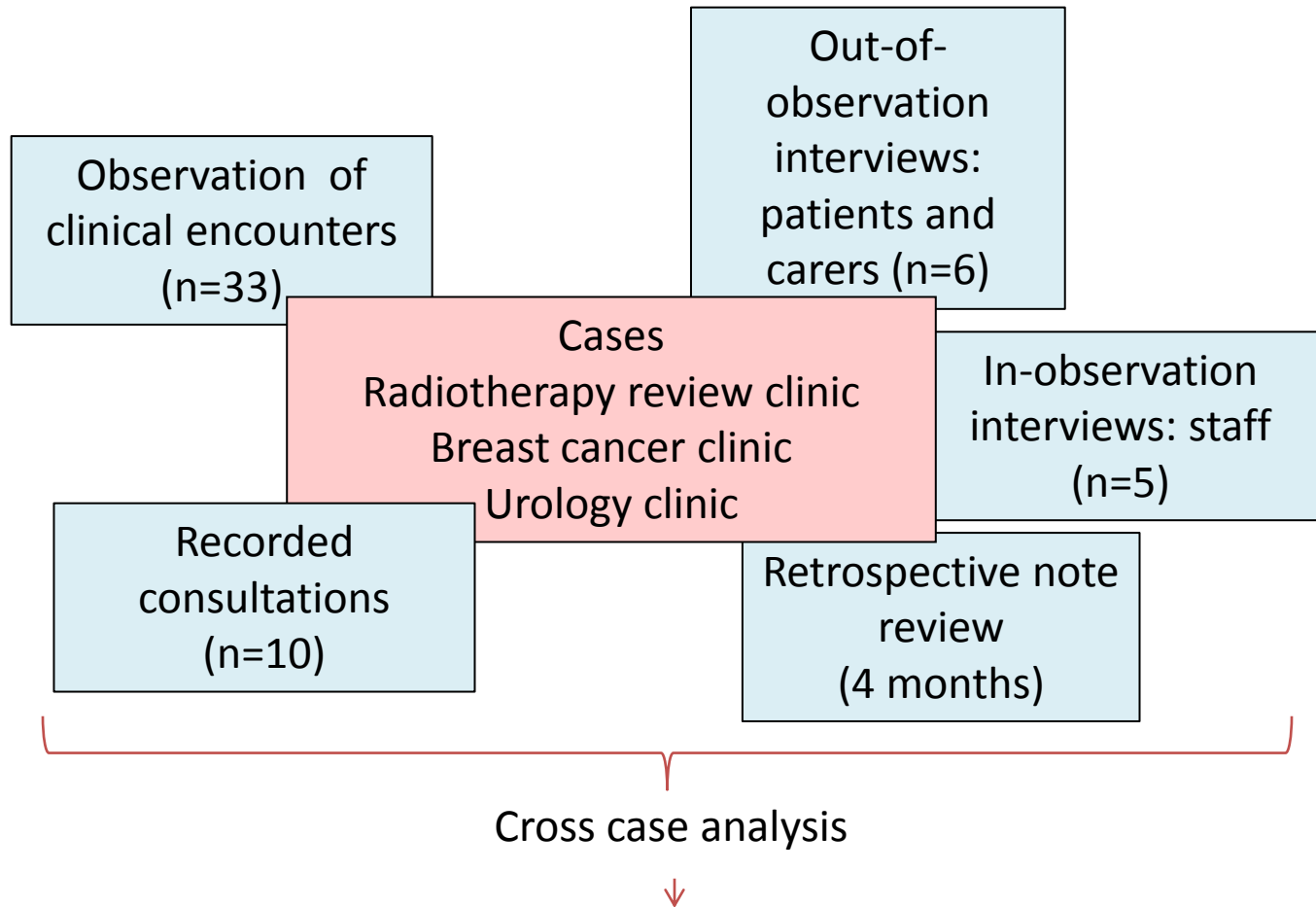
Results

People with dementia compared to people without dementia:

- Diagnosed at a later stage
- Receive less treatment
- Have poorer survival

Surprised?

Study design



Propositions relating to the supportive care of people with cancer and dementia

Note review

Patients attending

1st Dec 2013 to 31st Mar 2014 = 338

- A breast out-patient clinic
- A urology out-patient clinic
- A radiotherapy review clinic

Patients attending with a recorded diagnosis
of dementia = **One**

Observational and interview data

Themes identified:

- Role of memory in clinical encounters
- Staff attitude towards memory problems
- Management approach
- Role of the carer

Future research

'To improve cancer care we need to know more about....'

Role of the carer in cancer treatment for people with dementia



Implications for education

'Cancer care is person-centred. But...'

The cancer team had difficulty identifying people with memory problems

A need was identified for dementia friendly education

The future:

Person-centred cancer care for the person with dementia

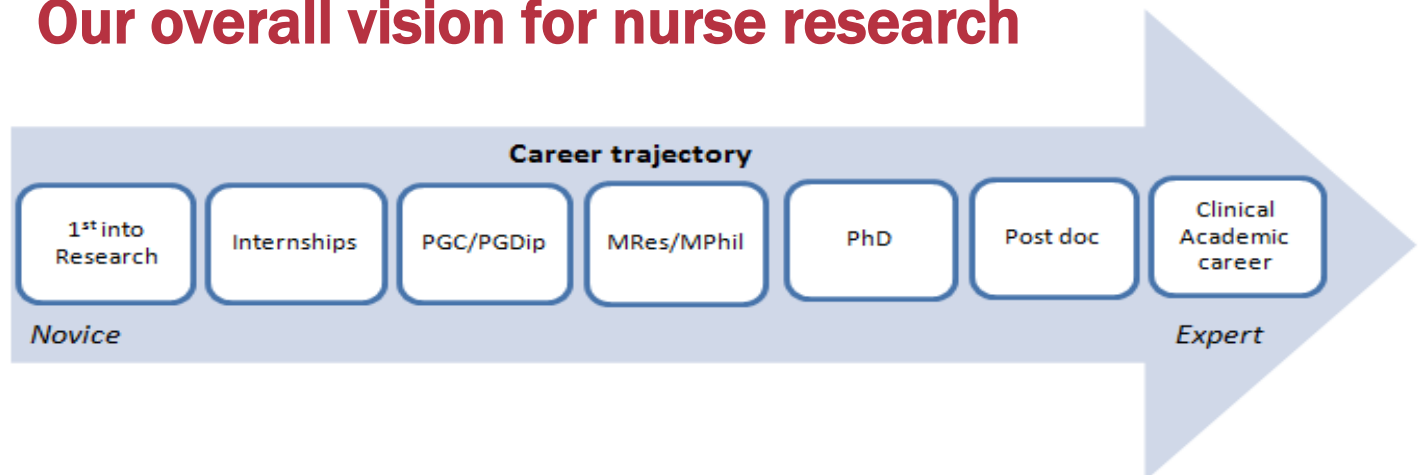


Context: Why the service got involved

Building nurse research capacity & capability

- Service has an established reputation for medical research & has clinical trials nurses
- Anecdotal feedback from nurses in clinical roles indicated they were interested in undertaking nursing research but experience constraints; time, skills, confidence
- Long standing Masters & recently introduced PhD opportunities for nurses in the service; taking part enabled nurses to be part of a nurse research team as an alternative to an individual research focus linked to an academic programme

Our overall vision for nurse research



Reflection: Challenges and Learning

Culture Change

- Tested a different way for nurses in clinical roles in the organization to become involved in nursing research

Planning & Implementation

- Staff change meant the nurse researcher was not involved in developing the research proposal; the nurse was identified as a collaborator rather than co-applicant
- Underestimated the complexity of the retrospective note review:
 - Time - 338 sets electronic/paper,
 - Clinical judgment required,
 - Capacity; clinical workload took priority resulting in slippage
- Underestimated the level of supervision & support for a novice nurse researcher

What would we do differently next time?

'Next time, we will....'



- Frame as equal partnership between the service and university; co-applicants rather than collaborators
- Seek expressions of interest from nurses in the service and select involvement through a competitive process
- Resource on the basis of dedicated time out of clinical duties
- Build in development objectives where appropriate
- Formalize supervision & support if a novice nurse researcher

'Small study but provides important insights for practice'



Key Findings:

- Lack of formal transfer of information about dementia diagnosis:
 - On referral to the service
 - Perpetuated in clinical encounters where patients/carers do not disclose

Opportunities for Change:

- Specific & targeted education & training at MDT members
- Recognition of the role of the family carer
- Enhancement of existing roles and development of new roles

So what? What next?

Our next clinical-academic partnership project

Carer involvement in cancer treatment and care

Educating student nurses

Learning from people with cancer and people with dementia

Work with our funder Tenovus Cancer Care

Impacting policy and guidelines

Publications

- King M, Hopkinson J, Milton R (2016) Reflections of a team approach to involving people with dementia in research. *International Journal of Palliative Nursing*. 22(1): 372-377.
- Hopkinson J, Milton R, King M, Edwards D. (in press) People with dementia: what is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review. *Psycho-Oncology*.
- Courtier N, Milton R, King A, Tope R, Morgan S, Hopkinson J. (in press) Cancer and dementia: an exploratory study of the experience of cancer treatment in people with dementia. *Psycho-Oncology*.