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Experiences of men with prostate cancer regarding information related to radiotherapy in the UK

Summary of findings of a DHRes study

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(nb photographs appear with the kind permission of support group members and the NHS study site)

Acknowledgements

St Neots Acorn cancer support group

UH PIRg

My DHRes supervisors:

- Dr Angela Dickinson
- Professor Wendy Wills

And of course, my participants.

Session overview

- Some background about radiotherapy and prostate cancer
- Research objectives & justification for the study
- Impact of PPI
- Study design and data analysis
- Some theoretical perspectives
- Some participant insights
- Proposing an explanatory model
- Original contributions to knowledge
- Recommendations for practice

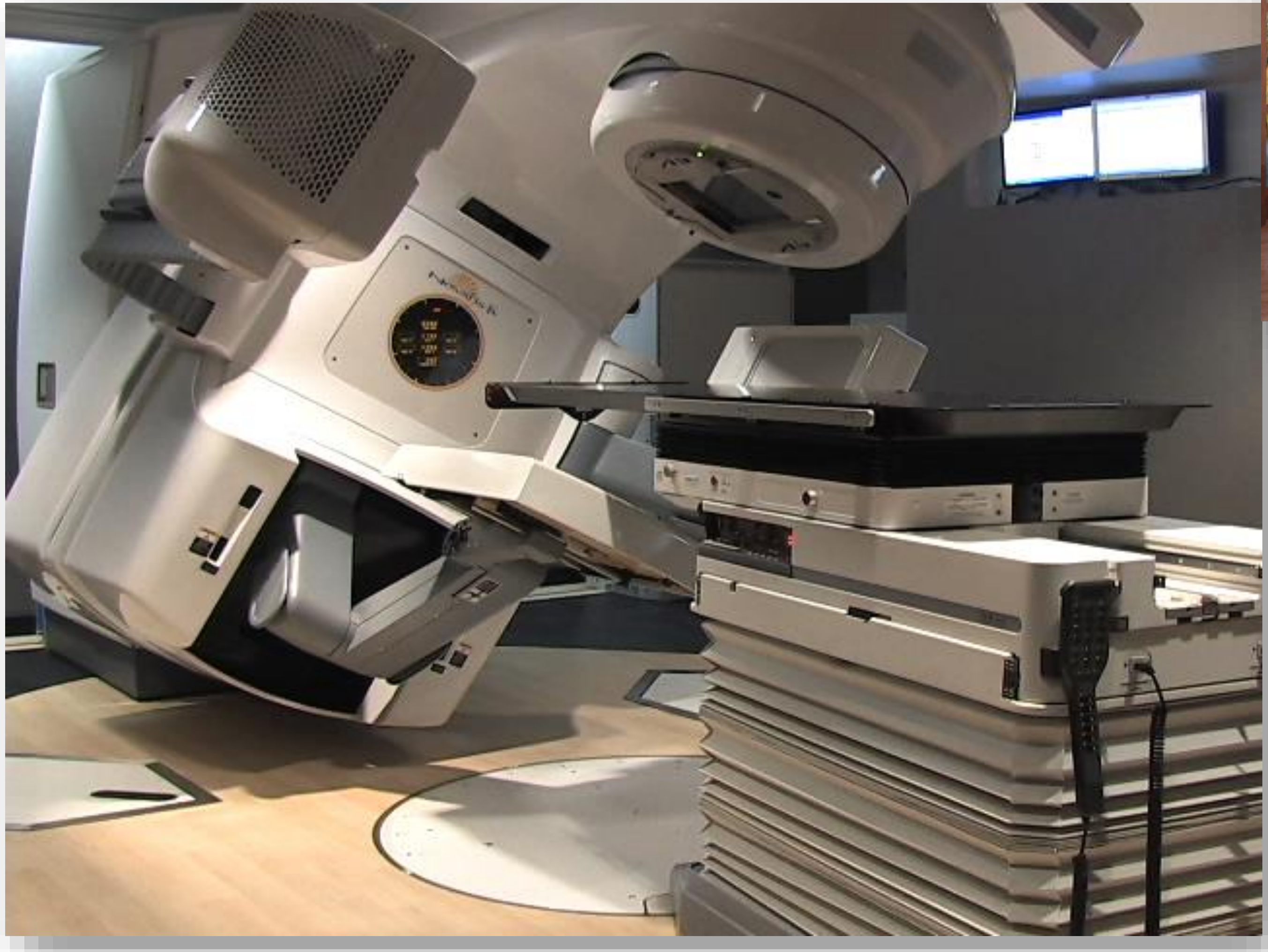
A few facts about prostate cancer

- the second most common cancer among men worldwide
- rates have been increasing in the developing world
  - In the UK, about 1 in 8 men will develop prostate cancer at some point in their lives
  - Men aged 50 or over, men with a family history of prostate cancer and black men are more at risk of getting prostate cancer.
- Prostate cancer becomes more common as men age
  - As life expectancy increases we are likely to see more cases of the disease

- 52,000 new cases per year in the UK
- 30% of patients with prostate cancer in the UK receive radiotherapy.
  - Over 50% of people with stage 3 disease receive radiotherapy
- 78% of people survive for 10 or more years following diagnosis

(CRUK 2022)

Radiotherapy equipment



The therapeutic radiographer (TR)

- The UK state registered health care practitioner responsible for delivering accurate and reproducible radiotherapy
- Information and communication are core components of the TR role and set out in the HCPC standards of proficiency which state that they should:
  - "be able to formulate and provide information to service users about the treatment … with regular reappraisal of their information needs"

(HCPC 2013)

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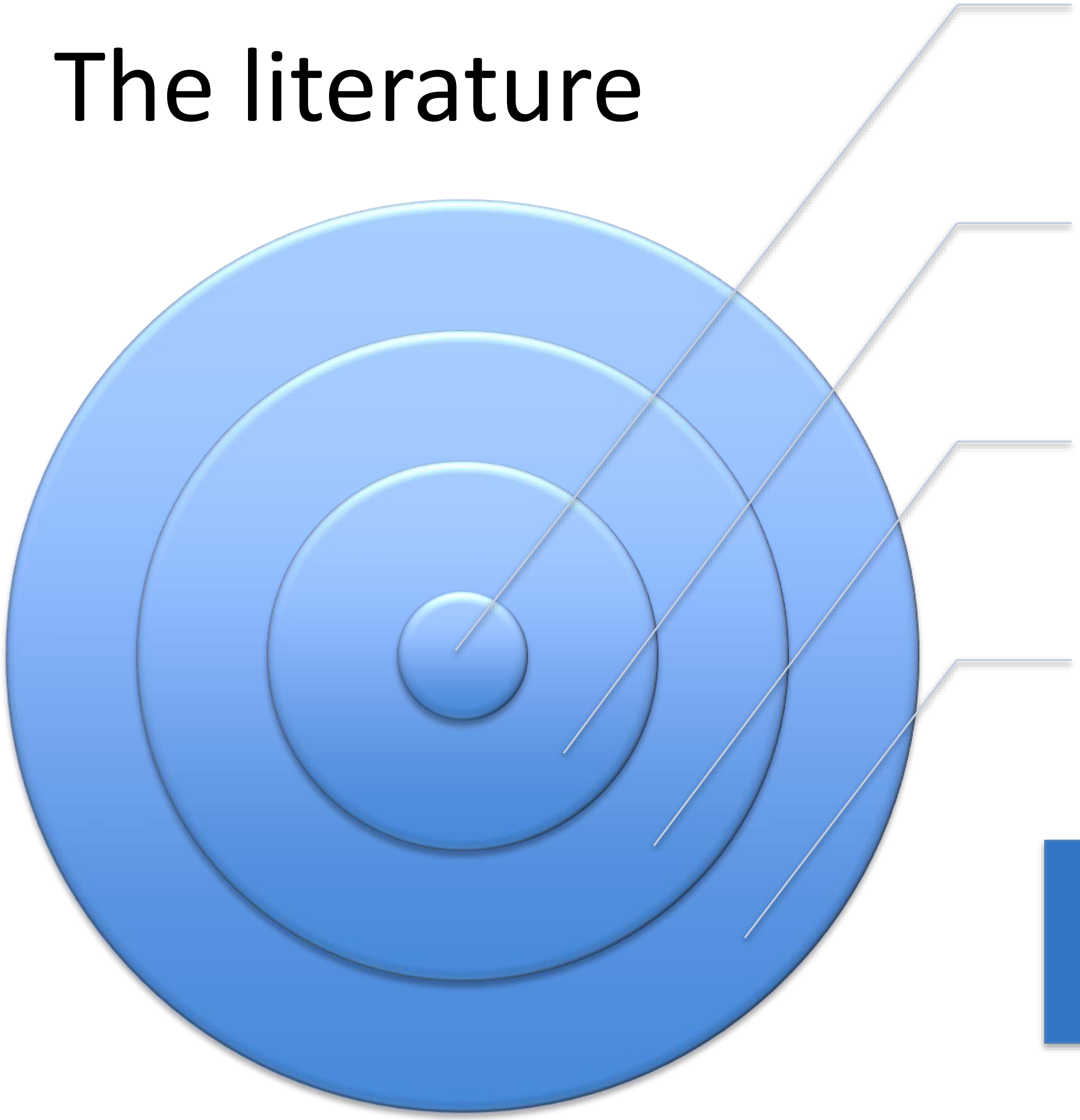
Justification for my doctoral topic (back in 2012)

The literature



patient experience of radiotherapy

experiences of patients with cancer

patient satisfaction with information

health policy increasingly focussed on needs of patient

Integrative review: see Gordon et al. (2019)

Evidence gap:

No in-depth exploration of patient experience specifically related to radiotherapy information for men with prostate cancer(MPC)*.

* Refers to biological sex at birth

Research objectives

- To explore:
  - the factors affecting the understanding of information received/exchanged by men undergoing radiotherapy for prostate cancer
  - whether information received was exchanged in a timely manner, appropriate to, and sufficient for their needs
  - what information for MPC was given/exchanged before, during and after radiotherapy
  - whether MPC had unmet informational needs
  - the perspectives of therapeutic radiographers related to information they give men undergoing radiotherapy for prostate cancer
  - the role of patients’ wives related to information given during the course of radiotherapy.

Patient and public involvement – a crucial component*

- **Engagement with members of a cancer support group**
  - Suggested involvement of spouses
  - Reviewed PIS and interview topic guides
  - Confirmed I needed to present to participants as therapeutic radiographer and educator
  - Members felt valued by being asked to contribute their knowledge and experiences.
- **UH PIRg**
  - Suggested participants be given the choice of a telephone interview
  - Confirmed the requirement for robust risk assessment related to interviewing in participant homes as a lone researcher

*see Gordon et al (2017) for more detail on the PPI aspect

Research design

- qualitative design within a social constructivist paradigm.
  - Semi-structured focus group interviews with therapeutic radiographers (n=14)
  - One to one semi-structured interviews with patients (n=20) and spouses (n=13)
  - Recruitment initially at one medium-sized radiotherapy department, then nationally
- Epistemological perspectives that might influence the research design were considered:
  - being female, my age, social and political contexts, my career as a therapeutic radiographer and educator, and my family experiences of cancer
- Ontological considerations:
  - subjectivity and an individual’s construction of their own reality were acknowledged:
    - the whole cancer journey from diagnosis to beyond completion of treatment affects experiences related to information.

Data analysis

- Thematic analysis approach adapted from the Braun and Clarke (2006) process

Step 1
- familiarising myself with the data, including transcription of interviews and focus groups
  - *repeated active reading and identification of possible patterns*

Step 2
- generation of initial codes
  - *data driven, contextual approach taken, using NVIVO12™ for management of data*

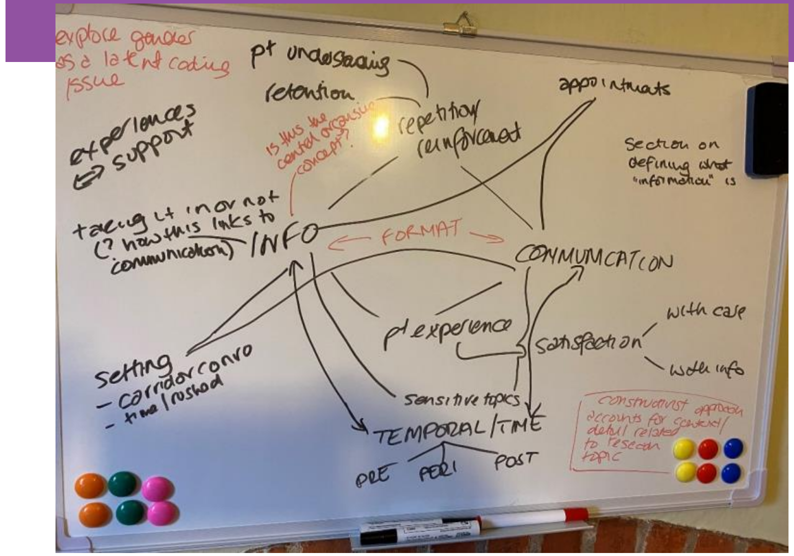
Step 3
- Searching for themes
  - *duplicate codes merged, sorted into potential themes; initial thematic map developed*

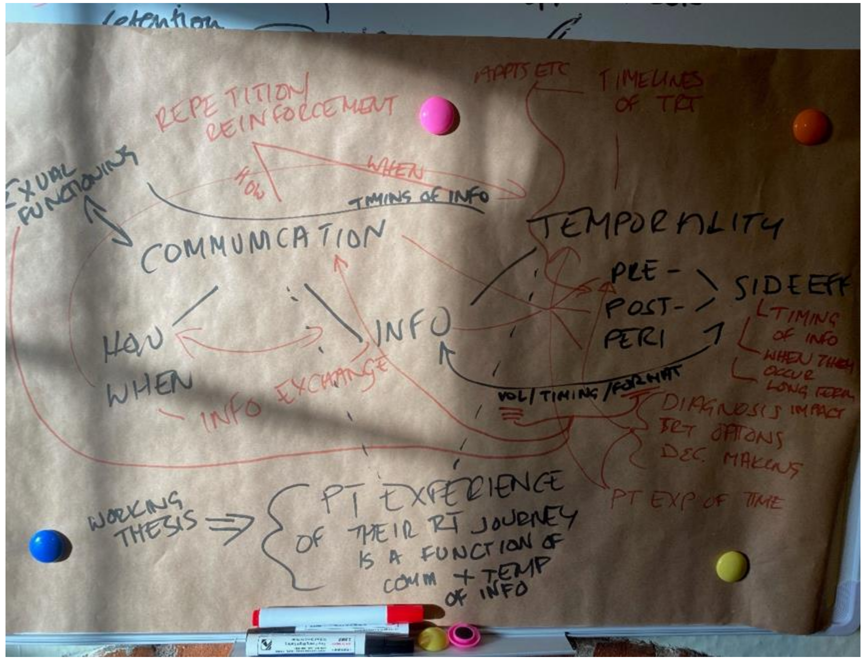
Step 4
- reviewing themes
  - *reviewing connections and disparities, revisiting coded extracts and initial themes for 'fit'*

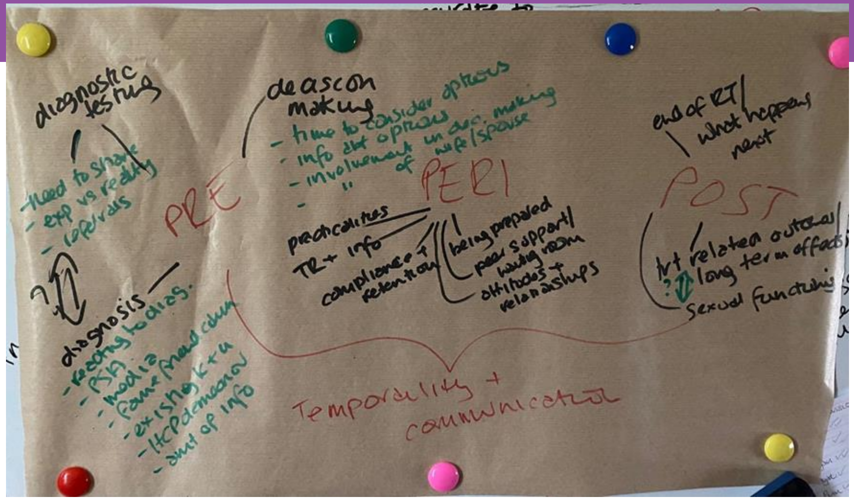
Step 5
- defining and naming themes
  - *identifying the 'essence of each theme', interpret and analyse each theme in detail*

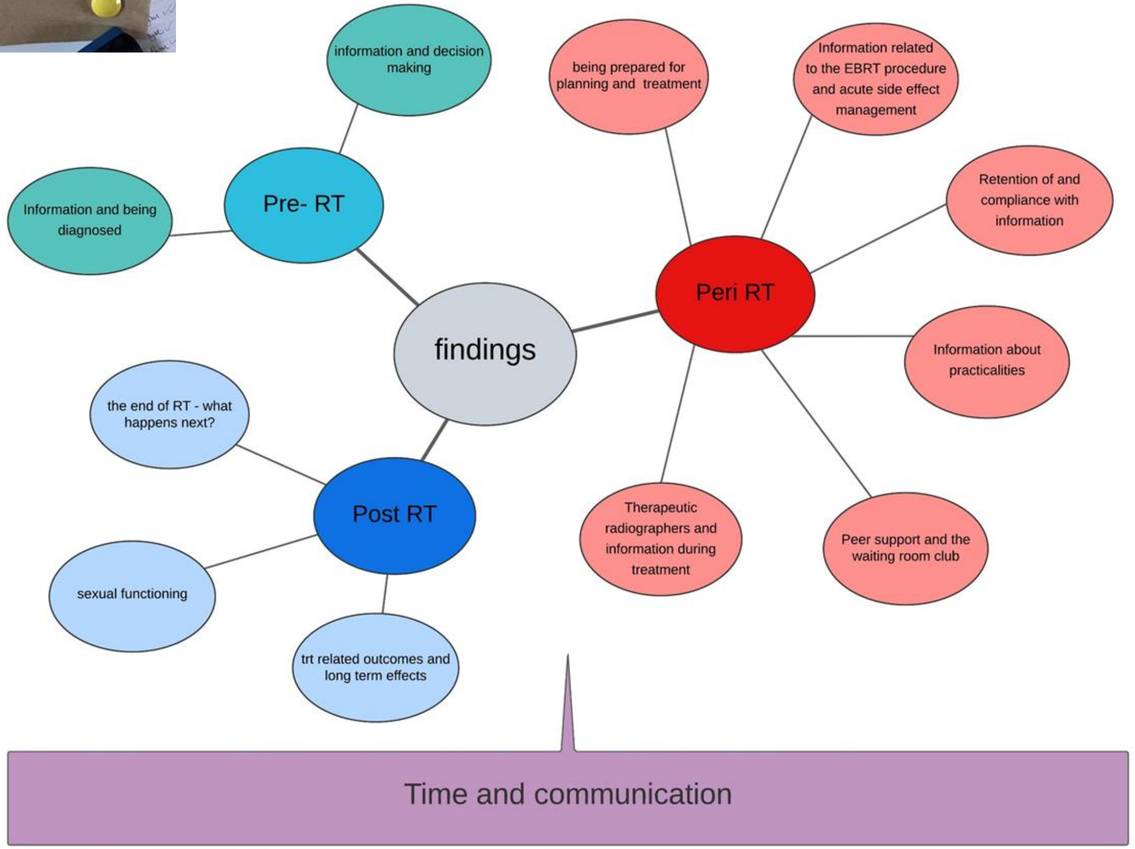
Step 6
- producing the report
  - *provision of a concise, coherent, logical and evidence/example-based report*

Data analysis









findings

Pre- RT

- information and decision making
- Information and being diagnosed

Peri RT

- being prepared for planning and treatment
- Information related to the EBRT procedure and acute side effect management
- Retention of and compliance with information
- Information about practicalities
- Peer support and the waiting room club
- Therapeutic radiographers and information during treatment

Post RT

- the end of RT - what happens next?
- sexual functioning
- trt related outcomes and long term effects

Time and communication

Theoretical perspectives 1

Models of and importance of communication

- Format, mechanisms of transmission, context, culture and societal processes all impact on the nature and success of communication

(Littlejohn & Foss, 2010; Stacks et al., 2019)

- information can exist as an entity, but only gains meaning for an individual when it has been communicated with intent

(Stacks et al., 2019)

- patient might not realise that communication with HCP is an information exchange. e.g. radiographers had "*a little chat*", "*they just went through what it would be like*".
- Assumptions are made regarding patient knowledge:

  "And you come in and you don't know anything and you're also concerned because of what's happening to you, and it's almost a little bit like it's assumed that, or I don't know whether it's assumed, but they do sometimes talk as if you should know what they're talking about, and actually you don't"

- Quality and timing of communication of information for cancer patients have consequences when considering long-term outcomes:

  "this was the light at the end of my tunnel and suddenly she switched it off." "could have been talking Dutch as far as I was concerned once you heard those words".

Theoretical perspectives 2

Biographical disruption

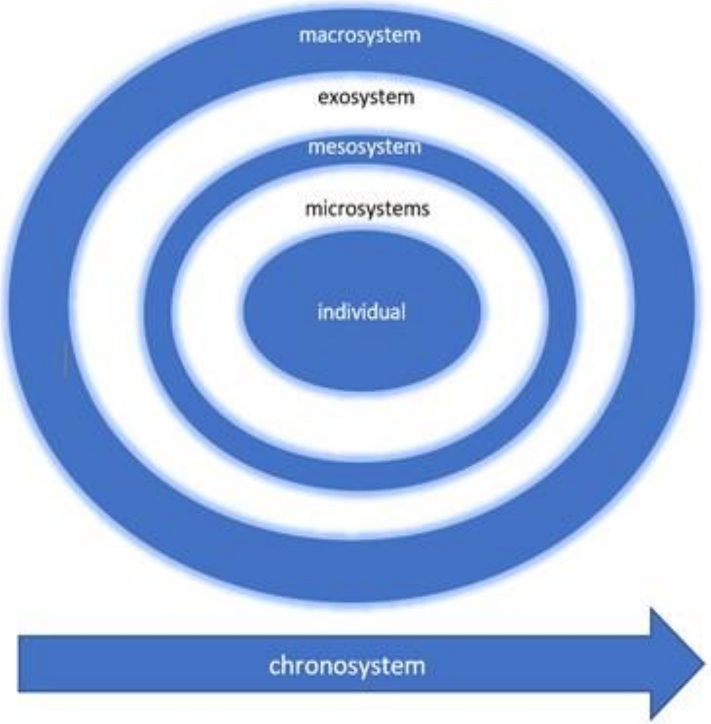
- refers to the way an individual experiences the change in their expected life course when faced with a serious illness and how it changes the way that they engage in daily life as a consequence

(Bury, 1982; Engman, 2019; Hudson et al., 2016)

- In my study participants reported: *"preparing for the worst but… hoping for the best"* and reflected on the impact of the cancer diagnosis and treatment on their relationships:
  - *"I don't want the relationship to suffer, but this is something that we both have to accept … I thought it would be a reduced libido, but I didn't read into the lack of lubrication that obviously I'd made, that I never even thought about, and I certainly didn't realise that as deeply as it has affected me that there would be no ejaculation… yes, that's properly hit me for six"*

Theoretical perspectives 3

- **Ecological systems theory (top) and bioecological model**
  - Conceptualise human development within the context of an individual's ecological environment
  - The later model (bottom) incorporates the importance of time and gives more focus to the individual



Macrosystem: overarching system of societal and cultural norms, belief systems socioeconomic and government factors; broad social context

Exosystem: settings in which events occur that influence the individual, but in which the individual would not normally have direct participation, e.g., health services and systems, community groups, media

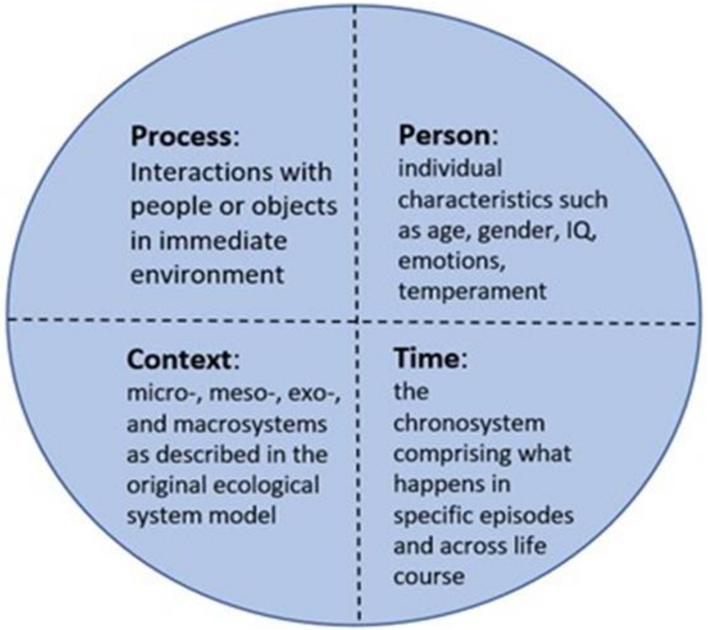
Microsystems: activities, roles and groups having direct participation or influence on the individual, e.g., family, friends, work colleagues, religious groups/beliefs

Mesosystem: a layer providing interconnectivity between the individual and/or some or all of the layers in the model

Individual: inherent factors such as age, sex, gender, culture, temperament, prior life experience

Chronosystem: the evolution and change of systems over time, e.g., as a person ages they move from school to work, therefore the influences within their microsystems change

Adapted from Bronfenbrenner, (1979); Bronfenbrenner & Morris, (2006); Härkönen, (2001)



Process: Interactions with people or objects in immediate environment

Person: individual characteristics such as age, gender, IQ, emotions, temperament

Context: micro-, meso-, exo-, and macrosystems as described in the original ecological system model

Time: the chronosystem comprising what happens in specific episodes and across life course

Adapted from Bronfenbrenner & Morris, (2006); Tudge et al., (2009)

Some insights from the participants

Lack of choice/incognizance:

"I wasn't given any choice on type of radiotherapy but they decided what was best and that's what I agreed to. I mean at that point I probably didn't realise there were different types. It was only as these came through [pointed to booklets] that I realised … I was quite happy the way it all went … They told me enough, then they sent me some more and I learnt a bit more. Jack

"I think a lot of it they have no frame of reference to, so when you are talking about what we are gonna do in the room … they've no idea what you are talking about. A lot of the information, they are trying to, kinda digest stuff that they have no inkling really of what's gonna happen, amongst all the other stuff with side effects" James (rad)

Radiographers and info about sexual functioning

"we don't cover the sexual side of it enough … that people tend to gloss over…You know it's very rare that they'd ask about something like that but some will. I don't think that really gets discussed when they have their pre-treatment or their treatment discussion … I don't think really we go through that at any stage per se unless they ask specifically about it." James (rad)

Impossible choices

"one of the leaflets … indicated that you could be incontinent or impotent. Impotent I wasn't bothered about anyway … incontinence because that was something… did I really want to live with that or would I rather put up with, if there was an option, with having prostate cancer? … I did consider not doing it. Because I didn't want to end up incontinent" Andy

Retention of information

"once someone informs you that you have prostate cancer, you don't want to listen to anything else, you just want to basically get some fresh air… I wanted to get out of the room I didn't want to listen to anything. I'm not in the frame of mind to disseminate any information that came towards me... and that sort of made me close down a bit. I suppose that's why they ask you to bring your wife, partner or a friend along" Angus

Male hegemony

"they're stubborn … they think asking questions is weak … you know that mind set of oh men are strong, they can't ask questions because … still that old-fashioned mind-set of man. Men are men, they're steel, they are hardy, they're… almost like they got a… outer armour that when you do break down that its almost… not too late in the treatment but it's quite a way through before they actually start to realise how important it really is" David (rad)

Decision regret

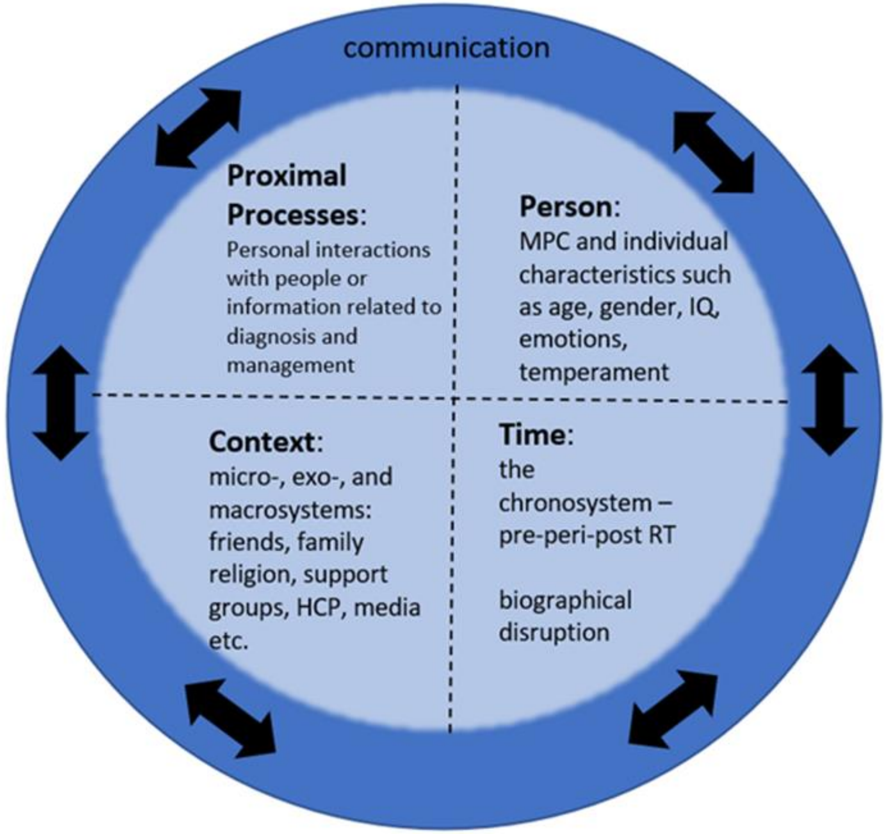
"maybe one of the problems with discussing these things, is it's right at the beginning when your mind is full of everything but if you leave it and so will talk to him later, then you will have had to have made a decision … some of those early meetings were a bit vague … if there were discussions it wasn't much of a discussion … when I found out that the ED could well be permanent, and they told me as if well everybody knows, and that was devastating to me. Because you know, they should have said at the beginning" Adrian

Expectation vs reality

"but it was the amount of weight I put on and my physical body changed, like my testicles and my penis had become extremely small, my breast, well I have boobs now and I've never had these before … I think that is all explained in the documents that you get … I've been through, looked at all of those things, but not enough I think, that should be more forefront to people rather than a bit of a shock, yeah" Donald

Proposing an explanatory model

- Communication of information is a core component at every stage of the patient's cancer journey and impacts on their experience of radiotherapy and its longer term consequences
- Information needs change over time and are mediated by complex, intertwined societal and personal factors
- Emphasises biographical disruption as a major temporal contextual influence



The ecology of information related to radiotherapy for men with prostate cancer

Original contribution to knowledge

This study demonstrates that:

- Information for MPC related to radiotherapy is mediated by communication and time
- Information for patients undergoing radiotherapy cannot be seen as a discrete entity
    - it must be contextualised within an individual’s experiences of diagnosis and treatment decision making, and factors impacting on daily living and a patient’s expected life course
- Biographical disruption caused by a prostate cancer diagnosis can impact on treatment decision making and subsequent use and processing of information related to radiotherapy
- Patients have unmet informational needs during the pre-radiotherapy period that can impact profoundly on their longer-term outcomes
- There was a dearth of detailed information about the reality and likelihood of the long-term adverse effects of treatments, in particular related to sexual functioning.

Recommendations for therapeutic radiography practice

- Ensure patients are given enough time to consider the different options by being offered the opportunity for further discussion of the long-term effects before their final treatment choices are made
- Where there is a choice to be made between several treatment options, the NICE guidelines should indicate that a period of time should be given to allow decision making
- Introduce service changes that allow advanced practice therapeutic radiographers to expand their practice to be more included as part of decision-making, perhaps by being available for supplementary consultations once the initial diagnosis has been conveyed
- Development of specialist services that give patients access to focussed support in the weeks between end of treatment and first follow up to help improve long term QOL
- Further education of all HCP who care for MPC regarding long-term sexual dysfunction is required

Thank you!

Any Questions?

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