

# Impact of prostate cancer on younger men's sense of masculinity and daily lives

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# Overview of presentation

- o Background/rationale for study
- o Aims and objectives of study
- o Methodology
- o Ethical approval & recruitment
- o Data analysis
- o Summary of Super-ordinate themes
- o Key findings and contribution to knowledge

# Background

- Prostate cancer (PC) is the most common male cancer in Ireland.
- 1 in 7 Irish men will be diagnosed with PC and one third are <65 years of age at time of diagnosis (Irish Cancer Society, 1999-2017).
- An increased up-take in PSA Screening has led to an increased detection of PC in younger men in Ireland.
- Majority of literature reports on issues relating to the experience of PC of all men, irrespective of age group.
- Limited research is available on the impact of PC on younger men's identity, masculinity, information and support needs, and influence on daily lives during treatment and survivorship.

# Younger men

- Younger men represent a group of men who are socially active, self-aware and have a longer life expectancy at time of diagnosis. They possess unique concerns relating to potency, social activity, employment and sexuality.
- The category 'younger men' with PC is poorly defined in the literature and ranges from <50 to <60 years' of age (Kotsis *et al.*, 2002, Khan *et al.*, 2003, Rosser *et al.*, 2002, Smith *et al.*, 2000).
- Frequently definitions that are applied refer to life span or developmental stage and researchers apply chronological cut-offs. Chambers *et al.* (2015:104) identify that *'chronological age alone is insufficient to explain life experiences and individual responses in situations of adversity'*.
- In this study a life course approach was adopted which requires consideration of participant's social context, for example, employment and family responsibilities.

## Aim of study

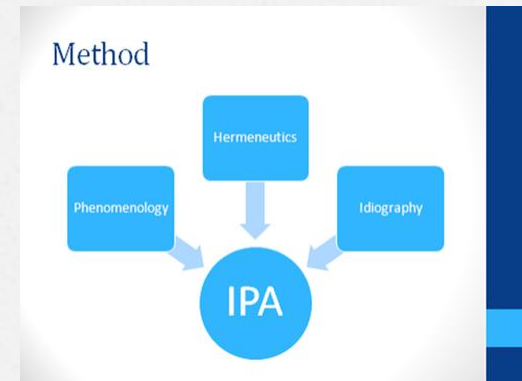
- o The overall aim of this study was to examine younger men's experience of prostate cancer diagnosis, treatment and survival. In particular, this inquiry aimed to understand how this experience influenced their sense of masculinity and daily lives.

# Meaning through the lens of masculinity & PCA

- When examining men's health it is necessary to understand the meaning of what it is to be a man and how masculinity is defined.
- Masculinity is a collection of qualities or characteristics considered typical of or appropriate to a man (Oxford Dictionary, 2002).
- The study of men's experience of ill-health informs understanding of how men construct their identities while coping with illness.
- An increasing body of empirical evidence has described an association between masculinity and prostate cancer across the illness trajectory (Bokhour *et al.*, 2001, Broom, 2004, Chapple and Ziebland, 2002, Clark *et al.*, 2003, Fergus *et al.*, 2002b, Hedestig *et al.*, 2003, Kelly, 2009, Oliffe, 2005b).
- In particular, studies relating to information seeking (Broom, 2005a, 2005b), treatment induced impotence (Gray *et al.*, 2002, Oliffe, 2005a), diagnostic tests (Oliffe, 2004a, 2004b), hormone therapy (Chapple and Ziebland, 2002, Oliffe, 2006) and relationships with partners (Fergus *et al.*, 2002a) have demonstrated that men's masculine identities are significantly altered as a result of a diagnosis of prostate cancer and subsequent treatment.

# Suitability of IPA as a research method to this study

- Interpretative Phenomenological Analysis (IPA) was the chosen research method as it aims to capture the lived experiences of the participant without testing a hypothesis or making prior assumptions about the meaning of prostate cancer to younger men (Reid et al., 2005a).
- The goal of IPA is to construct a rich and detailed picture of the phenomenon under investigation, using a case-by-case or idiographic approach (Lyons, 2007), and to explore how younger men make sense of their personal and social world in order to understand the meanings they attach to the experience of prostate cancer.
- IPA is interpretative and takes into account the meaning attached to the phenomenon and acknowledges that different participants may attach different intimate meanings to the same phenomenon, which forms part of the participant's lived experience (Giorgi, 1992).



# IPA ~ Idiographic, inductive & Interrogative

- o The idiographic feature of IPA implies that the participant's 'lived experience' is coupled with a subjective and reflective process of interpretation in which the researcher enters into the research process.
- o IPA data analysis adopts a loose rationale approach and is therefore inductive in its search for meaning and facilitates the emergence of new and unpredicted themes.
- o Themes and patterns that emerge are considered not to exist in isolation and are linked to theoretical knowledge, thus the process is interrogative through critical evaluation and discussion.
- o It is a key commitment of IPA that data analysis is developed around substantial verbatim extracts (Reid, Flowers and Larkin, 2005).



# Ethical approval & recruitment

- o Ethical approval was gained from the SAOLTA Clinical Research Ethics Committee (C.A. 1044) and exemption from full ethical review from the Human Research Ethics Committee of UCD (LS-E-14-70-Mooney-Fealy).
- o Recruitment was undertaken through a territory prostate screening centre.
- o Permission and support was gained from a consultant urologist and consultant radiologist who both assisted in purposively selecting and recruiting 26 men that met the studies eligibility criteria.

# Eligibility criteria

Men were included if they:

- Were under the age of 60 years and had undergone treatment for prostate cancer within previous two years
- Were able to communicate in English and provide a written consent
- Were willing to participate in an interview
- Were living in Ireland
- Had no cognitive impairment

Exclusion criteria:~

- Unable to meet any of the inclusion criteria

## Participant profiles

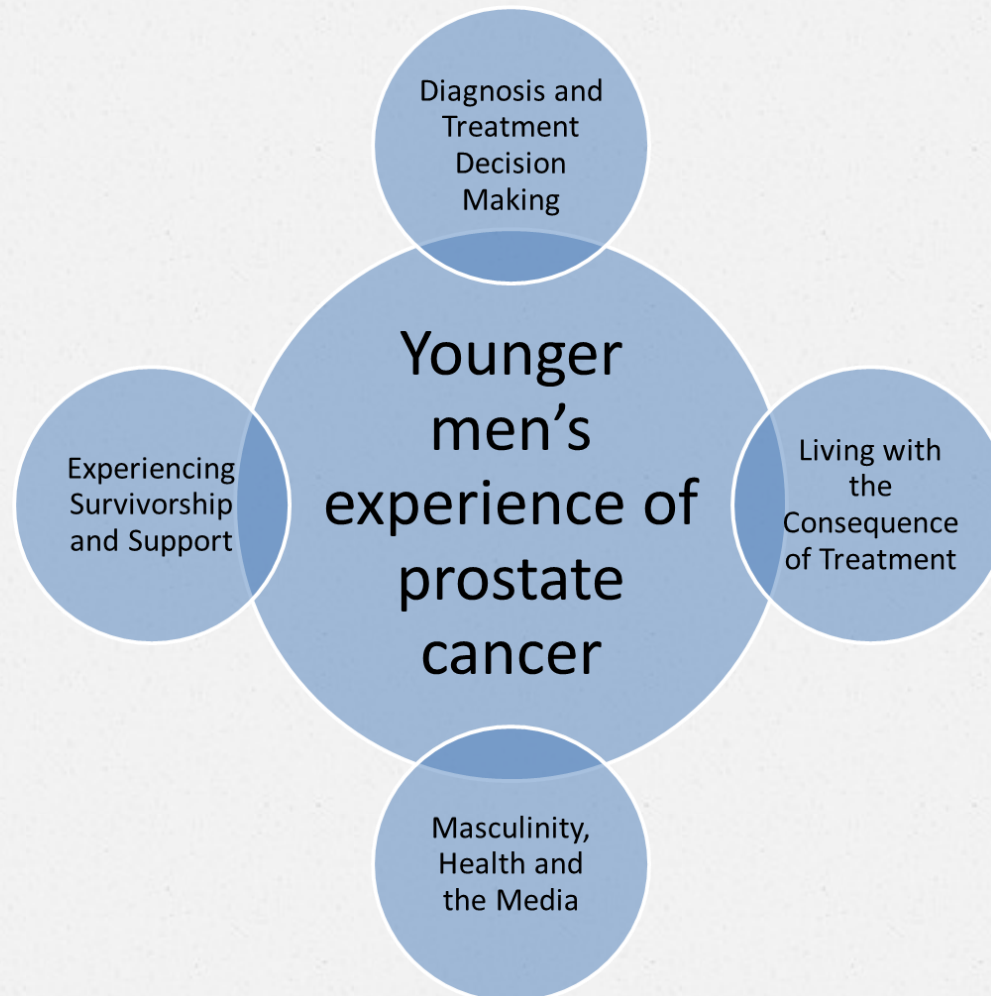
- 26 participants
- Male
- Middle aged (39-59 years)
- 22 married, 1 single, 2 separated & single, 1 separated with partner
- Treatment ~ 19 SX, 4 INV, 3 Both
- Education level ~ 11 3<sup>rd</sup> level, 15 2<sup>nd</sup> level
- Employed (16), not working (10)



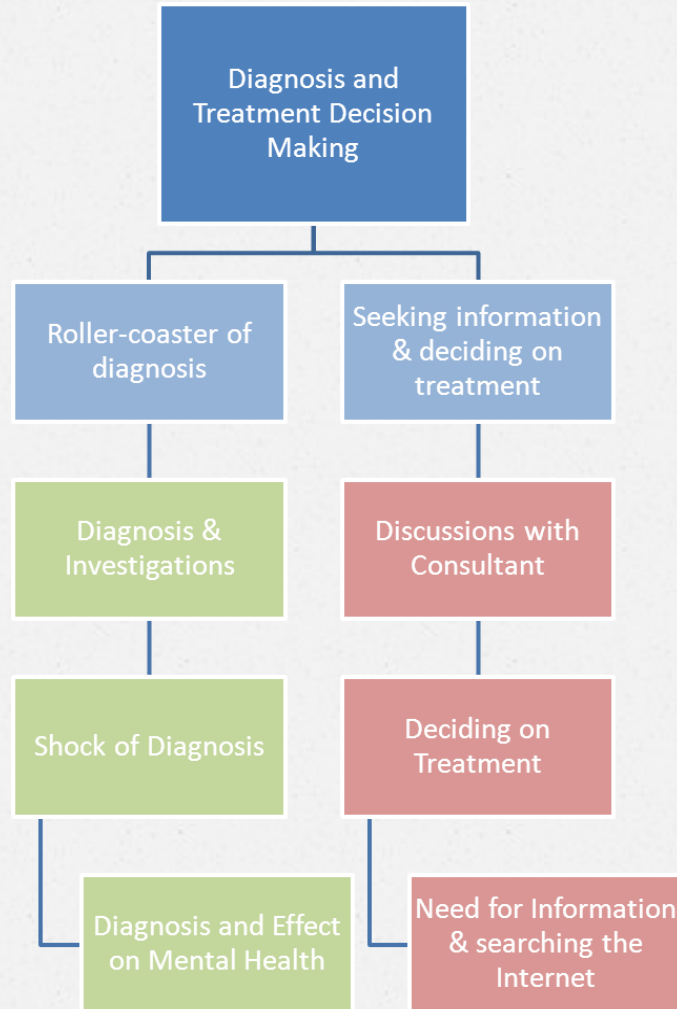
# Data analysis

- o I undertook transcription of 26 interviews followed by case-by-case analysis. Pseudonyms and a coding system were applied to each transcript. PCA – Surgery, INV – Intervention.
- o I utilised the IPA data analysis steps recommended by (Smith et al. 2009). This process involved the following stages in this study:
  - o Initial coding
  - o Development of emergent themes, recurrent themes, sub-ordinate themes, super-ordinate themes
  - o Analysis of raw data using NVivo 10.

# Framework of Super-ordinate themes



# Super-ordinate Theme One



# Prevalence of Sub-themes across Participants for Theme One

Code	Pseudo Name	Theme One Diagnosis and Treatment Decision Making (26)					
Sub-ordinate themes		Rollercoaster of Diagnosis (26)			Seeking Information and Deciding on Treatment (26)		
Recurrent Themes		Shock of diagnosis	Diagnosis and Investigations	Effect on Mental Health	Discussions with Consultant	Deciding on Treatment	Need for Information and Searching the Internet
PCA 1	Niall	X	X	X	X	X	X
PCA 2	Eamon		X	X	X	X	X
PCA 3	David		X		X		
PCA 4	Tighe	X	X		X	X	X
PCA 5	Oisín	X		X	X	X	X
PCA 6	Mark	X		X	X	X	X
PCA 7	Colin	X	X	X	X	X	X
PCA 8	Patrick	X	X		X	X	X
PCA 9	Fran	X	X		X	X	X
PCA 10	Paul		X				
PCA 11	Karl	X	X	X	X		X
PCA 12	Lorcan	X	X		X	X	X
PCA 13	Alan	X	X	X	X	X	X
PCA 14	Brendan	X	X		X	X	X
PCA 16	Tom	X	X	X	X	X	X
PCA 17	Frank	X	X			X	X
PCA 18	Rodger	X			X	X	
PCA 19	Des		X	X		X	X
PCA 20	Daniel	X	X		X	X	X
INV1	Peter	X	X			X	X
INV 2	Pat	X	X		X	X	X
INV 3	Richie	X	X			X	X
INV 4	Tony	X	X		X	X	
INV 5	Padraig	X	X	X	X		
INV 6	Philip	X			X	X	
INV 7	Lar	X	X			X	X
<b>Total</b>		22	22	10	20	22	20

## Summary of key findings - Theme 1

### ***'Diagnosis and treatment decision-making'***

- o Captured men's experience of being diagnosed with prostate cancer.
- o In the early phase of diagnosis, the shock of diagnosis and fear of cancer spread dominated men's thoughts.
- o The experience of prostate cancer was a life-changing event and men spoke of re-prioritising what was important in their lives and making major and minor life changes.
- o The time between diagnosis and treatment is a critical period in which younger men need to receive information which included a balanced picture of the pros and cons of available prostate cancer treatments and related side-effects.
- o For most men the attending urologist and the healthcare team were an important source of information and very influential in the treatment decision-making process. Personal values and situation in life also played a part in opting for one treatment choice over another.
- o The internet was a common source of information. However, men reported that information they read was often inconsistent and contradictory. Access to practical information from cancer organisations such as the Irish Cancer Society or other men was also highly valued and was a source of reassurance.

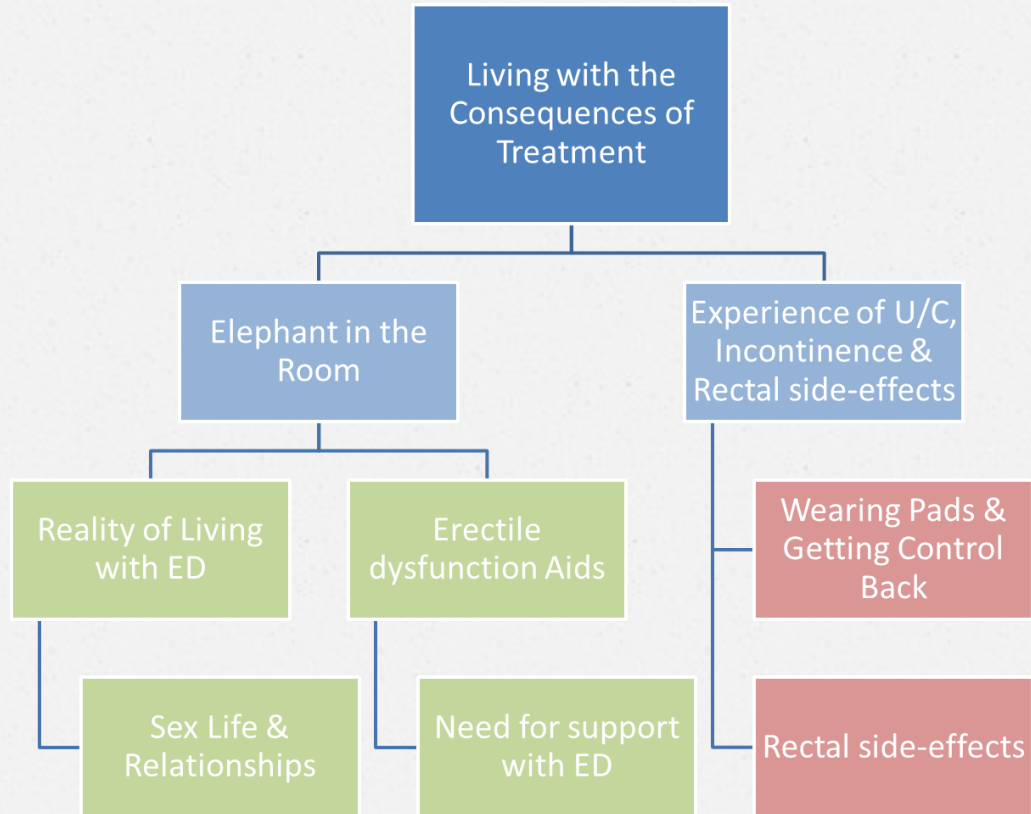
# Diagnosis

- o I was first diagnosed in August 2011; it wasn't a very nice experience. I was in Mayo the day before that climbing Croagh Patrick and feeling like I was on top of the world. Then to come down here the following day to be told I had progressive prostate cancer, it was just like it was the end (Slaps his knee), or a truck had just run over me, I couldn't believe it, couldn't believe it. I will never forget, just to be hearing the word cancer.*

*(Karl, age 48, Line 1-7)*



# Super-ordinate Theme Two



## Summary of key findings -Theme 2

# *‘Living with the consequence of treatment’*

- o Captured the lived experience of younger men with ED following treatment and their experience of wearing a urinary catheter, incontinence and rectal side-effects.
- o Loss of sexual functioning posed a new threat to the men and the presence of ED was a cause of distress and concern for all men and many were unprepared for the reality of living with ED.
- o Men viewed the need to achieve an erection as an essential component to facilitate intimate encounters with their partners and was no longer deemed to be a comfortable and familiar experience. This lead men to question their identity and compared to how they viewed themselves before treatment for prostate cancer.
- o Men also spoke about the experience of having a urinary catheter in place for a period of time after treatment. Fear of leakage, smelling of urine and the need to wear pads were a source of embarrassment and considered by some men to be more distressing than ED.
- o Wearing pads following removal of the catheter facilitated men to resume normal daily and social activities.
- o Bowel problems were also reported in men who had undergone radiotherapy treatment and men spoke of avoiding certain foods and the need to maintain a regular toileting regime to guard accidental incontinence.

# Inco, Pads, Rectal S/E

- o *I'd say incontinence and ED were the two biggest ones, and incontinence to me was going to be the biggest one ... It's to regain control we'd say and be able to go somewhere and not having to worry. (Des, age 43, Line 651-2, 660)*
- o *And these nappies that you'd fit on an elephant you know? They were huge and I still have them upstairs! (Laughing). (Eamon, age 54, Line 272-273)*
- o *The bowel thing... I would be sceptical about going away on a coach tour with no toilet. It comes very quickly to me; I need to be close to a toilet. (Padraig, age 61, Line 76-78)*

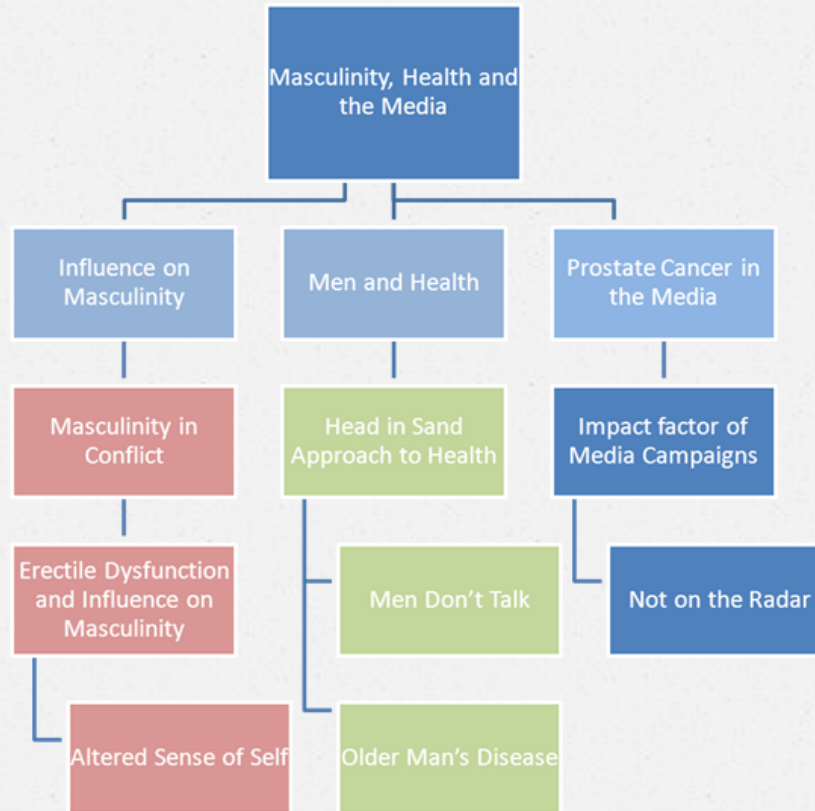
## Reality of living with ED

- o *I wasn't really; I'd be honest with you now. I wasn't prepared for the severity of it I had read all the booklets ... they suggested that you may experience ... But now I am living with the true extend of it and the reality is not pleasant. The reality doesn't dawn until afterwards, it is discussed with you beforehand, it's down the list, you have the cancer, get rid of same, hope it doesn't spread and we take care of everything else afterwards. Now it's afterwards. It disturbs me now, it does. Don't get me wrong, we had a very healthy sexual relationship myself and my wife ok. That's all but disappeared, I'm only 54 and my wife is 51, so you would expect to still have a healthy sex life, but that's all but gone. (Patrick, age 54, Line 128-138).*

# ED & self-confidence

- o *Erectile dysfunction. Well I am not in a relationship; my confidence wouldn't have been high to start with, so it just blows your confidence. (Peter, age 55, Line 127-128).*
- o *I don't socialise anymore because I've no ... I've no action down below or nothing you know like ... it's completely gone so, and I just feel like if I, say if I approach a girl, you know like and I get to like her, or if she likes me, you know (Fran, age 51, Line 136-139).*

# Super-ordinate Theme Three

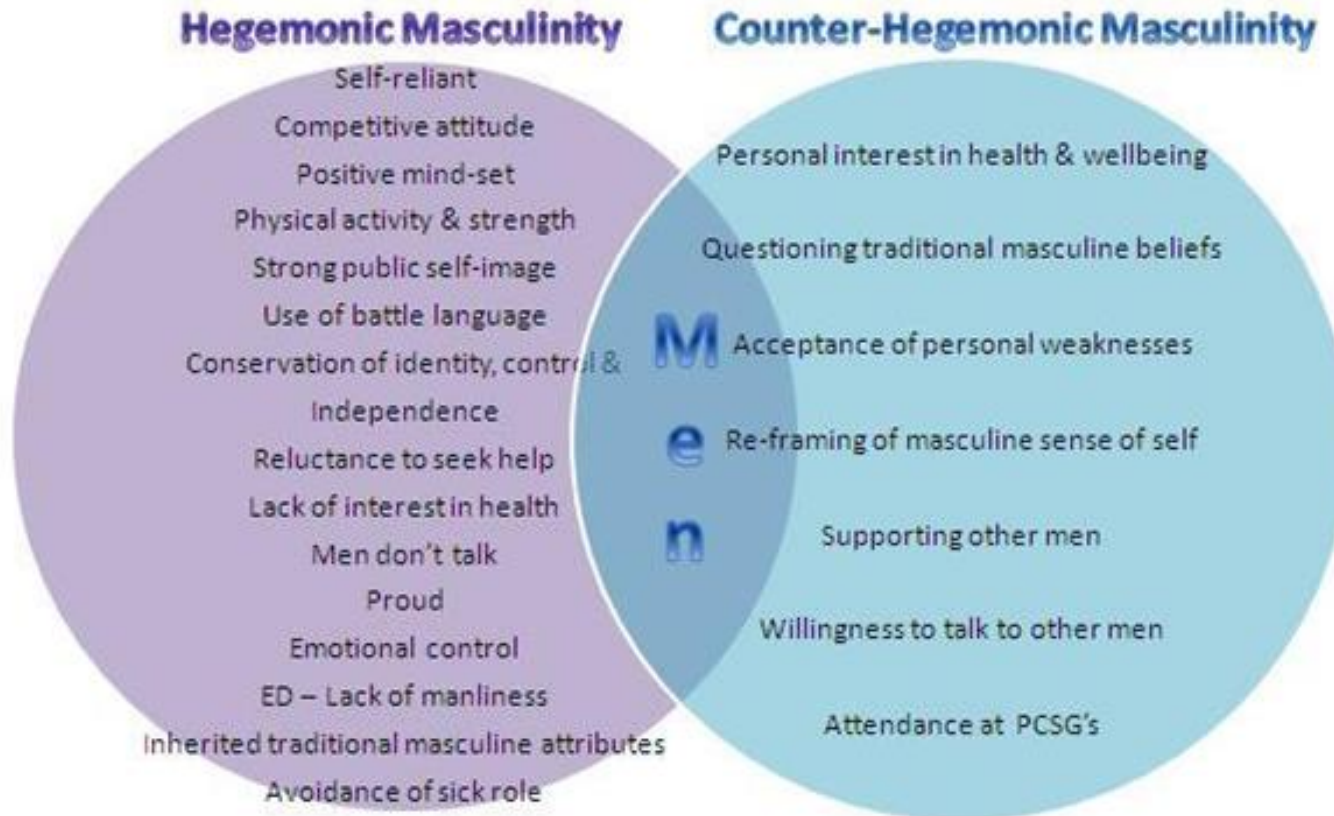


## Summary of key findings - Theme 3

### ***‘Masculinity, health and the media’***

- o Captured the influence prostate cancer had on men’s sense of masculinity and sense of self.
- o The experience of ED was a concern for all and a burden which men struggled to come-to-terms with. A degree of loss and grief associated with the experience directly influenced their sense of masculinity, which required men to re-examine and come-to-terms with an altered sense of self.
- o How men are socialised into gender roles was also influential in the men’s help seeking behaviour and willingness to talk about health matters. Some men chose to deal with their emotional concerns in a stoical manner and described themselves as ‘typical men’ in their approach to coping with prostate cancer, ED and altered sense of self.
- o The men in this study exhibited a general lack of interest in health matters and avoidance of self-care, irrespective of education level or occupation.
- o All of the men considered prostate cancer a disease of older men and it did not register on their radar of health issues to be concerned about. This view was influenced by how the disease was portrayed and represented in the media.
- o The view that there is a need to change the focus of media attention and public perception of the disease from that of an older man’s disease to one that encompasses all men was highlighted with the aim of increasing awareness of the incidence of prostate cancer in all men irrespective of age.

# key masculine attributes and patterns in younger men with prostate cancer





## Masculinity in conflict

- o *I just don't want to be sick. That's it. Just, as a man, the concept of not being able to do what you want, the restrictions, it's just very difficult for someone to take that on board, so as soon as I could get out of bed, I got out of bed and started exercising and I started putting on my clothes and just telling people "I'm ready to go", you know? ... I didn't want to see anybody see me in the sick role.*

*(Brendan, age 42, Line 266-268, 275)*

## ED & influence on masculinity

- o *How would I put it now, if, if I cut my finger off, or somebody cut their finger off, people can see they're missing a finger but, no-one can see this and, you're joining in with the lads at work talking about like, women or whatever, but, you have to go along with them, you can't tell them, do you know? There's a big part of you missing, and you think about it after ... I'm not the man I used to be if that makes any sense ... Well it's like something inside you dying, do you know? just feels like a part of me is gone now ... I said if you cut your finger off they'd say "Oh Mark lost his finger" but they couldn't see he had his prostate taken out or do you know, ... they don't know what actually happened, or is happening you know? (Mark, age 47, Line 441-446, 462, 509-511, 562-566).*

## Men, health & the media

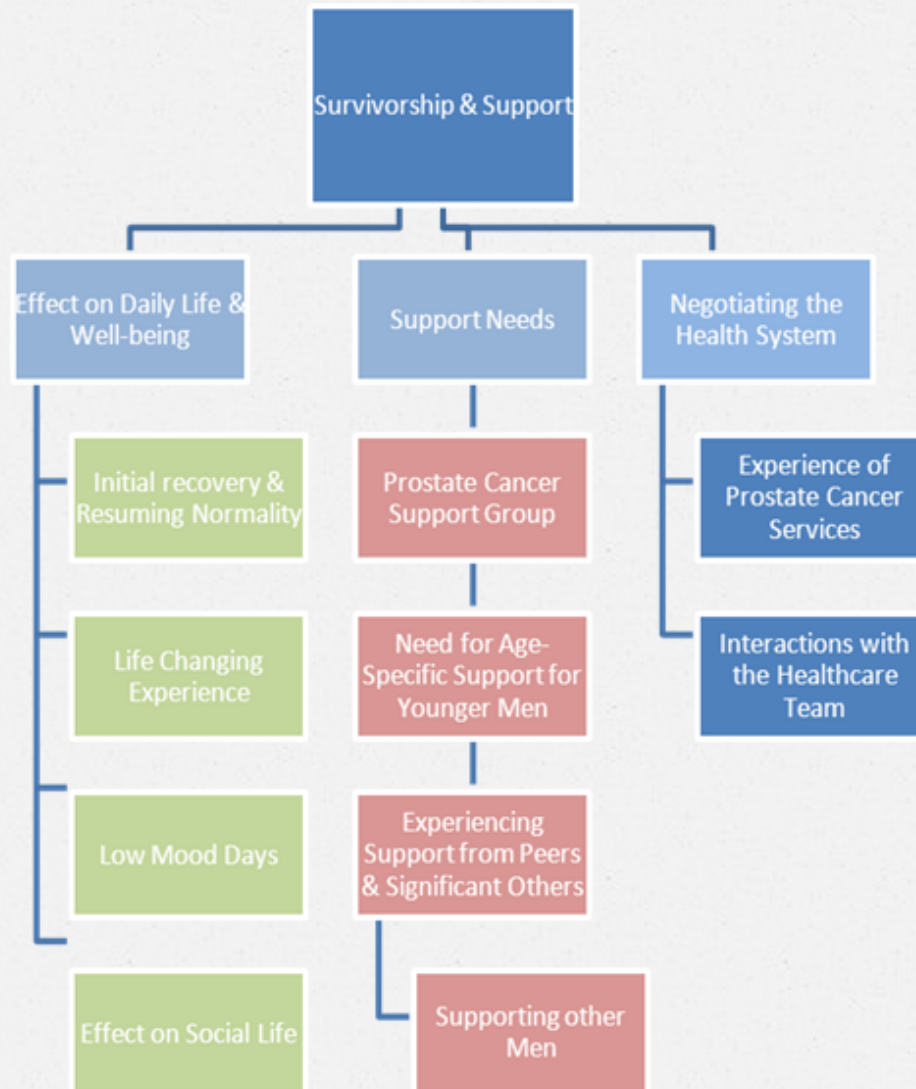
- o *You know yourself being a nurse us blokes are brutal when it comes to anything like that, we'd leave it off, we'd wait till our arm to be hanging off before we'd go anywhere.*

*(Tom, age 46, Line 73-75)*

- o *It's going to need to be a lot more direct. It's like those crash ads on TV; you know ... they're quite graphic aren't they? I think if you're going to try and get men to ... take health seriously at a younger age, it's going to need to be like that. You're really going to have to hit them over the head with it, do you know? So, other than that, then you're wasting your time. I think the message is, is very weak.*

*(Brendan, age 42, Line 621-626)*

# Super-ordinate Theme Four



## Summary of key findings - Theme 4 *'Experiencing survivorship and support'*

- Captured the experience of men as they recovered from prostate cancer treatment and resumed normal activities of daily living.
- Key areas relating to their experience of early recovery and survivorship were identified and ranged from their initial experience on returning home to their need for support during this period.
- Participants spoke in-depth about their experience of negotiating the health system throughout their cancer journey and their relationship and admiration for the support they received from the healthcare team.

# Fatigue & work

- o *I'm looking to apply for the disability benefit, I'm not well enough to drive a lorry, to be driving a 40 tone lorry, you wouldn't want to be dosing off, my energy levels are very low since the treatment ... Oh you would miss aspects of it ... you miss the comradery of your work mates, getting out, doing deliveries and meeting people. If you said to me three years ago that you'd pack in the lorry before you were 60, I'd have laughed, you would think about it sometimes.  
(Padraig, age 61, Line 5-7, 98-102).*

# Life-changing experience

- o *I'm back into the gym doing weights, walking, I'm doing the chores. I'm eating healthy and juicing vegetables, have you heard of wheatgrass? I grow it myself and bought a juicer. If you keep your mind right it's half the battle. (Karl, age 48, Line 128-130).*
- o *In the end I'm just glad to be alive; I feel I've won the lotto. I think it has been, the whole thing has made me re-evaluate my life, kind of say to myself "look, you mightn't have that much longer" you know, in a sense, who's going to say you're going to live to be 60, 70, 80 or a 100? So if you want to be something, do it now. (Brendan, age 42, Line 361-366).*

# Closing remarks

- IPA allows and facilitates the development of a rich and detailed picture of a phenomena using an interpretative and idiographic approach. Nvivo was essential to categorise raw data with a large sample size.
- Findings in this study broadly support findings from previous studies on all men with prostate cancer, but differ in terms of age related experience and need.
- This study details how prostate cancer causes disruptions to energy levels, physical strength, mental health, sexual and urinary function and the need for younger men to reformulate gender performances in their daily lives as they adjust to and accommodate the impact of disease specific side-effects.
- It is apparent that men's adjustment to treatment for prostate cancer is influenced by their adherence to traditional masculine narratives, which may both assist them in recovery and deprive them of important sources of social and emotional support.