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## Defining Young in the Context of Prostate Cancer

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## Abstract

The experience of prostate cancer is for most men a major life stress with the psychological burden of this disease falling more heavily on those who are younger. Despite this, being young as it applies to prostate cancer is not yet clearly defined with varied chronological approaches applied. However, men's responses to health crises are closely bound to life course and masculinities from which social roles emerge. This paper applied qualitative methodology (structured focus groups and semistructured interviews with expert informants) using interpretative phenomenological analysis to define what it means to be young and have prostate cancer. Structured focus groups were held with 26 consumer advisors (men diagnosed with prostate cancer who provide support to other men with prostate cancer or raise community awareness) and health professionals. As well, 15 men diagnosed with prostate cancer and in their 40s, 50s, or 60s participated in semi-structured interviews. Participants discussed the attributes that describe a young man with prostate cancer and the experience of being young and diagnosed with prostate cancer. Chronological definitions of a young man were absent or inconsistent. Masculine constructions of what it means to be a young man and life course characteristics appear more relevant to defining young as it applies to prostate cancer compared with chronological age. These findings have implications for better understanding the morbidities associated with this illness, and in designing interventions that are oriented to life course and helping young men reconstruct their identities after prostate cancer.

## Keywords

prostate cancer, masculinity, life course, identity, social roles

## Introduction

Prostate cancer is the most common cancer in men in Western countries, apart from basal and squamous cell carcinomas (Jemal et al., 2011) with the high prevalence in these settings attributed to increases in early detection, a Western lifestyle, and an aging population (Baade, Youlden, & Krnjacki, 2009). The experience of any cancer is for most people a stressful life event accompanied by a range of negative psychosocial sequelae (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), and this is also the case for prostate cancer (Bill-Axelson et al., 2013). However, as well as being a potentially life threatening diagnosis, the impact of prostate cancer treatments on specific domains of physical quality of life is substantial, with many men experiencing decrements in sexual, urinary, and bowel function that for some will be persistent. For example, a population based study of Australian men reported that 77% of those who had a radical prostatectomy were impotent three years after

diagnosis and 12% were incontinent; and 14% of men who had external beam radiotherapy had moderate to

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severe bowel problems (Smith et al., 2009). While a subgroup of men with prostate cancer (up to 20%) will experience clinically significant distress in the form of anxiety, depression, and cancer-specific distress (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2013), this psychological burden falls more heavily on men who are younger (Chambers, Ferguson, Gardiner, Aitken, & Occhipinti, 2013).

Younger age has been linked to poorer psychological outcomes after prostate cancer. Bisson et al. (2002) assessed a sample of 88 men with newly diagnosed localized prostate cancer and identified heightened distress in up to 20% of these men: younger age, rather than treatment or clinical variables, was a significant predictor of higher cancer-specific distress. In a population based survey of 978 men with prostate cancer, undertaken by Smith and colleagues, 54% of men reported some level of unmet psychological need and 47% had unmet sexuality needs (Smith et al., 2007). Greater unmet needs in all domains except for physical and daily living were predicted by younger age: men aged below 50 years were five times more likely to have unmet psychological needs compared with those aged 65 to 69 years. Roberts, Lepore, Hanlon, and Helgeson (2010) prospectively assessed 234 men with localized prostate cancer and identified that younger men with poorer sexual functioning had greater depressive symptoms than both older men with poorer sexual functioning and younger men with higher sexual functioning. Blank and Bellizzi (2008) surveyed 509 men who had been diagnosed with prostate cancer between one and eight years previously. In open-ended questions men who were younger than 60 years reported more negative outcomes as a result of their cancer. Blank and Bellizzi suggested that a better understanding of the psychosocial aspects of aging and cancer was needed with attention to age-related aspects of life span and life course rather than chronological age.

This raises the question of how best to define young as it applies to prostate cancer. One approach has been to consider developmental life stage using chronological age. For example, in research examining how couples experience prostate cancer three cohorts were defined: 50 to 64 years nominated as late middle age, 65 to 74 years as young-old, and 75 years and older as old-old (Harden, 2005; Harden et al., 2008; Harden, Northouse, & Mood, 2006). Late middle age was described as characterized by greater financial security, care-taking for elderly parents, and experiencing the first signs of age-related physical change. Young-old was seen as a transition stage into retirement with reflection on life experiences, mental adjustment to retirement, and the development of comorbidities. Old-old was defined by a decline in physical ability, less mental

and physical adaptability, decreased social contact, and less independence. In this approach life stages were constructed by the researcher and then applied to the context of prostate cancer. Herold, Hanlon, Movsas, and Hanks (1998) applied a cutoff of 65 years of age to define young versus old on the basis of how groups such as Medicare, Social Security and the National Cancer Institute define who is elderly. Diverging again, Lin, Porter, and Montgomery (2009) examined outcomes for young men with prostate cancer by stratifying in 10-year blocks from the age of 35 years without a clear rationale. In summary, approaches to defining young as it applies to men with prostate cancer vary widely. Further, while the definitions applied may refer to life span or developmental stage, researchers ultimately apply chronological cutoffs that are not clearly referenced to the context of prostate cancer as a life experience.

Applying a life course approach to the question of how cancer affects people at different ages would suggest that attention be directed toward the social context and the events that occur in different life domains across the life span (Mayer, 2003). On this view, the patterns that occur in the life course (e.g., employment and family development trajectories) are shaped by the systems in which a person is situated, the individual's experiences within their personal life history and social context, and the characteristics of the relevant birth or life cohort. Life courses then are dynamically related to social structures in the time period in which they are situated as well as the person's life trajectory (Clarke, Marshall, House, & Lantz, 2011). On this view, chronological age alone is insufficient to explain life experiences and individual responses in situations of adversity. In taking a life course approach to examine how a person might respond to a cancer diagnosis at a particular age, both the cancer context and social groups in which that person belongs and interacts need to be considered. In the case of prostate cancer as a disease that affects men, and in particular male sexuality, a consideration of gender identity then arises.

The commonly described dominant masculine ideology includes that men are stoic, unemotional, self-sufficient, powerful and independent, and these values are proposed to be influential in how men consume health care and how they respond to illness (Good & Sherrod, 2001; Wall & Kristjanson, 2005). Grunfeld, Drudge-Coates, Rixon, Eaton, and Cooper (2013) suggested that masculine ideals define how men interact socially and professionally to protect their gender identity. This includes behaviors such as hiding physical impairments (associated with urinary frequency and leaking concerns) which influence decisions to return to work, socialize and travel, showing a "strong face" (one with little emotion), and limiting disclosure of illness or maintaining social

boundaries. Previous qualitative research examining men and prostate cancer has described masculinity as being central to how men respond to prostate cancer. For example, the impact of erectile dysfunction on men's quality of life and intimate relationships undermines their perceptions of themselves as men (Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Chapple & Ziebland, 2002; Fergus, Gray, & Fitch, 2002; Klaeson, Sandell, & Bertero, 2012; Letts, Tamlyn, & Byers, 2010; Oliffe, 2005, 2006; O'Shaughnessy & Laws, 2009; Thomas, Wootten, & Robinson, 2013). Similarly, how men make decisions about prostate cancer treatment is influenced by how men prioritize their mortality and expected life span over potency and lifestyle changes, and this again interacts with gender identity and what it means to "be a man" (Broom, 2004). The question then arises as to how masculinity, in the context of a prostate cancer diagnosis, might intersect with the life trajectory and life course; and given this proposed intersection how men with prostate cancer themselves define young as it applies to this specific illness experience.

The current study proposes that an understanding of who is young in the context of prostate cancer and what attributes define young in this setting may be usefully explored in the context of life course and masculinities. By contrast to previous research, this study used qualitative methodology to draw on the experiences of men with prostate cancer as opposed to an a priori categorization based on chronological age, with chronological, life course, and masculine identity approaches to defining "young" contrasted.

## Method

### Study Sample

Multiple perspectives were obtained from expert informants (i.e., participants who are experts in the area in which the researchers are investigating; Keeney, Hasson, & McKenna, 2011) in different roles to inform a broad understanding of what it means to be young and be diagnosed with prostate cancer. In this study expert informants were *consumer advisors* (i.e., men diagnosed with prostate cancer who work and/or volunteer to represent the interests of or support men with prostate cancer and raise community awareness about prostate cancer), *health professionals* (e.g., urologists, nurses) who provide care or support for men diagnosed with prostate cancer, and *patients* who were men diagnosed with prostate cancer across three decades at diagnosis (40s, 50s, and 60s) and had received within the past four years or were currently receiving treatment for prostate cancer.

To ensure a variety of viewpoints a purposive and diverse sample of consumer advisors across a range of

ages and health professionals in multiple disciplines (urologists, continence nurses, prostate cancer specialist nurses, medical oncologists, and psycho-oncology researchers) were recruited from the professional and consumer networks of the Prostate Cancer Foundation of Australia (the peak national body for prostate cancer in Australia; Hussler, Muller, & Ronde, 2011). Patients were recruited from an existing trial cohort in Queensland (Chambers et al., 2008) and from support groups affiliated with the Prostate Cancer Foundation of Australia. Patients were purposively sampled to include men who were diagnosed with prostate cancer in their 40s, 50s, or 60s and were able to read and speak English. Recruitment of patients continued until data saturation was reached (i.e., when no new or relevant information emerged regarding defining young in the context of prostate cancer).

All expert informants gave informed consent and completed a brief background questionnaire prior to participating. Ethical approval for the study was obtained from the Griffith University Human Research Ethics Committee.

### Structured Focus Groups With Consumer Advisors and Health Professionals

Structured focus groups (Dick, 2003) were used to obtain consumer advisor and health professional perspectives on the attributes and experiences that described a young man with prostate cancer. Dick (2003) defines structured focus groups as involving a highly structured process led by a facilitator to generate discussion with the content of the focus group remaining unstructured and determined by participant responses. Open-ended probe questions are used to elicit contextual and key information of interest with a focus on ensuring that participants have time to reflect, respond, and discuss their perspective. To conclude, the facilitator summarizes key themes emerging from the discussion and invites participant input and clarification. The facilitator then works in partnership with participants to interpret the information and a written record of the results is generated and agreed on by group members. Structured focus group approaches provide specific information directly targeted to the research question (O'hEocha, Wang, & Conboy, 2012; Sutton & Arnold, 2013) and also increase information quality and time efficiency (Dick, 2003).

Structured focus groups were led by an experienced male or female group facilitator (JD, SKC) with a note taker present (LZ, MKH). Sessions were approximately 90 minutes in length and held in three Australian states: Queensland ( $n = 13$ ; 5 consumer advisors, 8 health professionals [6 of whom were women]), New South Wales ( $n = 7$ ;

3 consumer advisors, 4 health professionals [2 of whom were women]), and Victoria ( $n = 6$ ; 4 consumer advisors, 2 health professionals [none were women]). In accordance with the structured focus group process (Dick, 2003), each session began with a broad probe question to tap contextual information "What are the characteristics of a young man?" followed by a probe question to obtain key information of interest: "What are the characteristics of a young man with *prostate cancer*?" At each step participants reflected privately on the question and then discussed their responses within a pair or small group. Responses were then shared with the larger group and recorded by the facilitator on paper and posted on a whiteboard. Following this, the facilitator synthesized and grouped similar responses and engaged in member checking with participants to confirm accuracy of data. In consultation with participants, grouped responses were labeled to form a theme and then recorded on separate sheets of paper and posted on whiteboards. Participants then prioritized their preferred themes using a voting procedure which facilitates the exchange of information about preferences in a group setting (Dick, 2003). From this a final list of prioritized themes was compiled in each group.

### *Semistructured Interviews With Patients*

Semi-structured interviews were used to obtain patient's perspectives on defining young in the context of prostate cancer and to capture personal experiences that may not be shared in a group setting. Three experienced female researchers (SKC, LZ, MKH) conducted telephone interviews with men diagnosed with prostate cancer ( $n = 15$ ; 54% response rate) from major urban centers and regional towns. Each interview focused first on the man's life before prostate cancer and then the impact of the cancer, leading to a consideration of how being young can be defined in the context of prostate cancer (refer to the appendix for the interview guide). Participants were free to speak at length with minimal interruption other than the interviewer seeking clarification as needed. Interviews were digitally recorded and took on average 45 minutes (min = 24:30/max = 54:07). Recorded interviews were transcribed verbatim with the exception of one interview which could not be transcribed due to technical difficulties. For this latter interview detailed notes were written for cross-reference to audio-recorded data.

### *Data Analysis*

As described in the Method section, the process of the structured focus groups involved the facilitator working in partnership with consumer advisors and health

professionals in each group to (1) interpret the information elicited in discussion; and (2) generate a list of descriptors which participants grouped and prioritized in a voting procedure to indicate characteristics that were most representative of a young man diagnosed with prostate cancer. In a further step, the researchers used visual inspection to compare these prioritized characteristics for convergence across focus groups and situated them within the superordinate themes of chronological age, life course, or masculine identities. No exceptions to these superordinate themes were noted.

Interpretative phenomenological analysis (Smith & Osborn, 2003) was applied to the data from interviews with patients. Interpretative phenomenological analysis is concerned with understanding the lived or personal experience of the participant (Smith & Osborn, 2003) and is widely used in qualitative health psychology and sociology research (Daly et al., 2007; Riessman, 2008). It acknowledges that multiple perspectives of the human experience exist and aligns with the aim of the current study to enrich understanding of what it means to be young and have prostate cancer. Initially, analysis involved becoming familiar with transcripts through several readings (Smith & Osborn, 2003). In accordance with quality guidelines for qualitative research (Elliott, Fischer, & Rennie, 1999) two researchers (MKH, LZ) coded each transcript independently and systematically to identify responses that defined or described the experience of young men with prostate cancer (i.e., themes) and corresponding representative quotes. To ensure consistency and rigor in approach, the two coders met and compared identified themes, and resolved any discrepancies via discussion, verification against the transcript data, or involvement of a third coder (SKC).

Following this in an iterative and consultative process all three coders developed and agreed on a coding scheme in which identified themes were grouped and situated within three superordinate themes as follows: chronological age (age cutoff seen as not relevant, age as a referent to when men typically get prostate cancer, age as referent to life expectancy), life course (young family, physical fitness, newly married, employment, disposable income), and masculine identity (mind-set, competitiveness, sexuality, physical strength, optimism about the future). Transcripts were then reviewed in accordance with the final coding scheme. An interpretative phenomenological analysis also promotes uncovering of novel themes (Riessman, 2008) and data were searched for exceptions whereby descriptions of a young man with prostate cancer diverged from chronological, life course, or masculine identity approaches and the final coding scheme. No exceptions in the form of divergent themes or superordinate themes were noted.

**Table 1.** Characteristics of Expert Informants (N = 41).

Characteristic	Consumer advisors (n = 12)	Health professionals (n = 14)	Patients (n = 15)
Sex			
Male	12	6	15
Female	0	8	0
Age (years)			
31-40	0	3	0
41-50	0	4	3
51-60	4	5	3
61-70	5	1	9
>70	3	1	0
Country of birth			
Australia	11	10	12
Elsewhere	1	4	3
Education			
High school degree	0	0	5
Technical trade or university degree	12	14	10
Relationship <sup>a</sup>			
Married	9	— <sup>b</sup>	15
Not married (single, separated, or divorced)	2	— <sup>b</sup>	0
Age (years) at diagnosis			
≤50	4	0	3
51-60	5	0	6
61-65	3	0	6
Treatment <sup>c</sup>			
Radical prostatectomy	12	0	12
External beam radiation	2	0	2
Androgen deprivation therapy	0	0	1
Watchful waiting	0	0	1
Active surveillance	1	0	2

a. One man in the consumer advisor group did not indicate his relationship status.

b. Health professionals did not report their relationship status.

c. Some men had more than one form of treatment.

## Results

The background characteristics (e.g., gender, age, relationship status) of the 41 expert informants are reported in Table 1. Consumer advisor's and health professional's descriptions of the attributes of young men obtained in structured focus groups included the following: energetic and active (sex, sport), bulletproof (invincible), risk-taking, confidence, independent, mental and physical strength, sex and libido (desire, opportunity, and ability), responsibilities (e.g., providing for family or children),

“still hunting” (e.g., physical, career opportunities), and enjoying life and having hope for the future. As displayed in Table 2, visual inspection showed a clear clumping of data in which particular themes were voted as priorities by ≥10% (representing convergence in themes across groups) and <10% of participants (representing divergence in themes across groups). Chronological age was identified as a characteristic in one focus group with suggestions from different group participants that a young man might be aged younger than 50 years, less than 60 years, or less than 30 years. However, in the voting procedure no participants endorsed any of these age cutoffs. Rather, participants endorsed a range of descriptors that sat within the superordinate themes of masculine identities (e.g., risk-taking, strength, virility) and life course (e.g., sexual life, family and career responsibilities; see Table 2).

Patient experiences regarding being a young man diagnosed with prostate cancer obtained in interviews are described below. In accordance with the final coding scheme, themes are situated within the superordinate themes of chronological age, life course, or masculine identities. The age group at cancer diagnosis (50 years or younger, 51-60 years, 61-65 years) of the participant is noted with each quote to contrast the views expressed across chronological ages.

### Chronological Age

Some men discussed chronological age when describing the experience of being young and having prostate cancer. In particular, themes related to age as a reference point for life expectancy or diagnosis of prostate cancer for the man personally, or for men in general. However, there was little consistency in age cutoffs mentioned. Other men either did not mention age or did not view age as relevant to the definition of a young man with prostate cancer:

**Age as Referent to Life Expectancy.** Some men discussed their age at diagnosis in relation to how long they expect to live (e.g., “I’m too young to die” [61-65 years], “my life is only half over” [50 years or younger]) whereas others used chronological age as an indication of their capacity to overcome the disease. For example,

So my choice was because at that age I was 59-60, I looked at—I was young enough to be able to, any type of cancer, cut it out and hopefully it will, um, address the situation, kill it off. (51-60 years)

**Age as a Referent to When Men Typically Get Prostate Cancer.** Being young as it relates to having prostate cancer was also defined using the age at which men are typically

**Table 2.** Descriptors for Young in the Context of Prostate Cancer Prioritized by Consumer Advisors and Health Professionals in Structured Focus Groups.

	Superordinate theme	Descriptors
Prioritized by $\geq 10\%$ of participants in each group	Masculine identities	Risk-taker (fewer ties, fewer responsibilities, freedom), seeking challenge, still hunting, dreaming of what is possible, anything is possible, optimistic
		Strong, physical (physically active, recovers well), bulletproof, invincible, immortal, hope for a future
		Virile
	Life course	Sexual life (desire, opportunity, ability), sexually active, young partner Responsibilities (emotional, practical), breadwinner, family, working Future expectations for career, family, business
Prioritized by $< 10\%$ of participants in each group	Masculine identities	Conscious of physical self-appearance Enthusiastic, energy "She'll be right" <sup>a</sup>
		Forging identity
	Life course	Family circumstances (heritability) More choices (for future)
		Socially connected and interactive Technology savvy (users)

a. "She'll be right" is a widely used Australian expression denoting "all will be well" and representing jocular toughness and optimism in Australian culture.

diagnosed with prostate cancer. Although for some men there was awareness that young men can be diagnosed with prostate cancer, these men still felt that comparatively they were too young to be diagnosed:

Um, when I got it [diagnosed with prostate cancer] I wasn't more like I'm too young for this, I was more like oh shit, I'm—oh excuse me, I'm like [laughs] I was more like I'm one of those young guys that get it, you know what I mean? So I think I'm on the young, young end of the whole thing. (50 years or younger)

Everywhere I went I was significantly younger than every man in the room, significantly younger. And I just kept saying to my wife, "This just seems just ridiculous," because every single person I was coming into contact with would've been 30 years older than me—25 years to 30 years older. These were guys well into their 70s and maybe into their 80s, I suppose. So, yeah, at the time in the initial stages I was seeing myself as being particularly young. (51-60 years)

Other men commented that they felt too young to be diagnosed because prostate cancer, as far as they knew, was an "old man's" disease and to be expected at an older age such as 70s or 80s:

Far too young. . . . Because it's an old [laughs]—it was renowned to be an old man's disease . . . ; "Very unexpected

[the diagnosis] because I didn't know. I knew a little bit about prostate cancer but I was of the awareness that it was an old man's disease. (50 years or younger)

On other occasions men quoted a variety of ages that they believed to be young for a man in general to receive a diagnosis of prostate cancer with little consistency among responses. Specifically, responses ranged from "guys in their 20s" (61-65 years), "30s" (50 years or younger), "below 40 years" (61-65 years), "40 years" (61-65 years), "below 62 years" (61-65 years), to "65 years" (61-65 years).

**Age Cutoff Seen as Not Relevant.** Some men stated that chronological age was not relevant or was a poor indicator to define young as it relates to prostate cancer with lifestyle factors more relevant:

Age is not necessarily a good indicator, I don't think. There'd be no reason to think we were much different in our lifestyle, other than our age I guess, to people probably ten or 20 years younger. (61-65 years)

### Life Course

Men in the sample discussed how various life events or circumstances were relevant in defining who is young



with prostate cancer. These events included: having a young family, being at the stage of life when one is physically fit, being newly married, being employed, and having a higher disposable income.

**Young Family.** Although not part of their own personal experience, some men described that the diagnosis and treatment of prostate cancer would impact significantly on men who had a young family and associated responsibilities or were thinking about beginning or expanding their family. For example,

Yeah, I mean, if—you know, if you had—if you had family responsibility—if you were younger and—and—and had a young family, for instance and you were diagnosed, ah, at that stage, mate, I think that would be pretty worrying. (61-65 years)

Older people are probably past the age of, ah, desiring children, for example. Whereas somebody—in the under-40 age, is probably not. (61-65 years)

I know when they came to visit me in the hospital once; my youngest one became quite withdrawn. Just didn't talk much, didn't look around. Didn't look—he wasn't there, he wasn't present. Yeah. So, I guess, I thought about long-term consequences and I want to be there for them. (51-60 years)

**Physical Fitness.** Men reflected on physical fitness and strength as associated with being a young man and contributing to their ability to recover and remain resilient after treatment. For example,

Well, um, I think it [being young at diagnosis] probably helped me because I suppose, because of what the doctor said to me at the time of diagnosis was that because you are young you will recover and you know um, your functions will all come back to you. (50 years or younger)

**Newly Married.** Men commented that having a new marriage or being married for a short period of time were stages in life when prostate cancer may have a greater impact on younger men compared with older men who had more mature relationships:

You know, younger, possibly unmarried, possibly married for a, relatively speaking, short time. As opposed to somebody at, say, the post-60 age group, who—well traditionally [laughs] would've been married for a substantial period of time. (61-65 years)

... in terms of my life at this stage being a newly-wed with a young baby and everything because you know people get married in their 30s and their 20s and their—and so in terms

of my lifestyle, I feel like I'm, um, I feel like I'm way, way too, um, young. (50 years or younger)

**Employment.** Another indicator for defining young in relation to prostate cancer was employment. Particularly, the impact of a diagnosis and treatment on their career and productivity at work was discussed:

So and then of course the next thing is oh crikey, what am I going to do for work? I suppose, because one thing, you're told at your age, the best option was to have the prostate removed by surgery and you have up to three to four months off work. And you think, oh, crikey, that doesn't kind of play with my life at the moment. (50 years or younger)

Defining young, I suppose, non-retired. You have a career. Young family and young friends. Yeah. And stresses of life, mortgages, car payments—things that wouldn't be there if you were retired perhaps. (50 years or younger)

As well, one man described the challenge of negotiating work-related demands, managing side effects at work and looking after his health while feeling pressured to provide income to support his family:

I guess, it is—as a younger person, you feel you have to live up to expectations. I suppose, in spouse or with the community. And you can't walk around with—I mean, you are expected to be fitter and not have—I know—when I had that—what is it called? Oh, damn. The catheter. And you wear the leg bag and I was trying—I am trying to do work and income producing work, so you go into work and you feel you probably, you should be looking after yourself more, rather than going out to work. So there is a bit of that, because you are a younger person, so you have still got to bring home the bacon, sort of thing. Yeah, yeah. I mean, here you are going out in the workforce, and you have got a bag strapped to your thigh, and your calf. Just—it is pretty—it is a bit of a downer. (51-60 years)

**Disposable Income.** Related to employment, having disposable income for spending or saving was viewed as an indicator of being young. For example,

It's all about how you feel about yourself. I was doing all the young things. I was working hard, ah, enjoying life, um, disposable income, um, very satisfied, ah, personally and professionally. So I consider myself—I considered myself when I was diagnosed to be young I suppose. (61-65 years)

### **Masculine Identities**

Men's perceptions of themselves and the roles they occupy (i.e., identities) emerged as defining features of young in relation to prostate cancer. Themes strongly

aligned with masculine ideals embodying determination, physical strength, stoicism, potency, and competitiveness. Other themes described included mind-set and optimism about the future.

**Mind-Set.** Men described the importance of “mind-set” in their approach to coping with prostate cancer and particularly, the presence of a “forward thinking” and “can do” and stoic mind-set as an indicator of a person who is young. For example:

I guess mind-set might be another issue. You know, I'm forward-looking. I don't think about what's, dwell on what's past. (61-65 years)

Well, exactly. Exactly. And I think that's the advantage of also being young, that you're going, oh, “I can do it.” (51-60 years)

... it's just my sort of personality, um. If there was a stone in my shoe I'd take it out. Um, I'm an ex-soldier; there was a saying—if there's a boil on your bum you lance it and get on with it. (61-65 years)

Also, men often discussed the concept of psychologically “feeling young” or “thinking young” despite acknowledging that their body was ageing:

I'm 66-plus and, um, I—mate, I still—I still feel like I'm 45, really. (61-65 years)

If you think young, you are young . . . I still think young so I am young; You are talking about being young. Yes, I am psychologically very young but the body sometimes doesn't . . . you know to me I'm still doing everything I used to do physically and everything but I know one of these days I've got to slow up. And I try to associate with people who are younger so I can stay young as well! I'm still a young person and I don't want to be anything else! (51-60 years)

How do you put this? I still see me-self as young [laughs]. Probably 30 or 40 years ago I would have seen me-self then oh, as I am now as a very old person but, ah I think as you get older it's only the outside of the body that changes not the mind so much . . . which is me looking outwards, not someone looking back at me. (61-65 years)

**Competitiveness.** One man perceived himself to be young based on his competitive drive and ability to compete physically with those who were younger than himself:

I'm still competing with people that are a lot younger that are working. So they've kept me young because of the type of exercise I do [swimming]. I just try to swim with the better athletes so that keeps me going. I try to associate myself with winners. (51-60 years)

**Sexuality.** Men in the sample discussed the impacts of prostate cancer on sexuality as being greater for younger men. For example:

I would say for someone much younger, um,—because there are other options that you can do I think. I think you can go and see, um, someone who specialises in those fields, um, but it [sexual function] would certainly be an issue for younger people. (61-65 years)

I didn't realise how much being able to have sex makes you feel like a man and how much this would affect me. (51-60 years)

A substantial concern mentioned by men in the sample was the effect of prostate cancer treatment on their sex life and partner relationships and how this made them feel about themselves as men:

I suppose that by having erectile dysfunction at least—that probably makes me feel old and maybe gives me—I don't know what happens to old blokes but maybe that's what the future for old blokes is that, you know, that that part of your life is gone and it's a part of your life all blokes that I know cherish and it gives them great enjoyment and yeah it's like chopping our legs off I suppose. It's like not being able to run, that's what I think. Well ah yeah, it's part of being a man you know, being a man, yeah it's what blokes do . . . ah, yeah, but, but I, you know, I've just got no erectile function at all, it's just dead. So that's not good. (50 years or younger)

The erectile dysfunction. I mean you are younger, I have a beautiful wife, you're more attracted to each other, I suppose. Yeah, it was an issue because—a funny thing is when you come out of hospital, what they said was very supportive—you tend to reject everybody around you because you feel—because erection paths don't happen, you feel inadequate. (50 years or younger)

Another man discussed how he weighed up treatment options and their side effects and described how considering potential prolonged decrements in quality of life (in terms of impotency and incontinence) made him feel distressed:

If I'd been 70—I think if someone's 70 and they go, look if we take your prostate out, it won't do much for your erectile function and your urinary function, but you'll probably live to—well, as long as you're going live, another 10, 15 years. Then I'd go, oh, well, the benefit—probably the costs outweigh the benefits. When you're 50, that's a long—so you might live for another 30 years going to the toilet every half an hour and going, really, do I actually want to do that? So, to me, that's more of a dilemma. (50 years or younger)

**Physical Strength.** Many men described their physical fitness and strength as an indicator that they were too young to be diagnosed with prostate cancer. For instance:

My general view was probably giving me confidence that I didn't have anything, 'cause I'm thinking this is a bit too early, even though my mate had passed away. So I'm still thinking, well, there's nothing wrong with me, I don't feel like there's anything wrong with me and I'm relatively fit and reasonably young for this to be happening. So back then I would've said, too young. (51-60 years)

**Optimism About the Future.** Another aspect discussed was that being younger allowed men to have a positive outlook about recovery and a chance at life as well as optimism about what the future may hold. As one man described:

So I think being young helped me probably and, um, and it still does. You know, I still am optimistic about what the future holds so, ah, yeah. I'm not—you know, I haven't chucked the towel in so, um ah yeah, I think being—you know, considering myself as being young has ah yeah, been a benefit. (50 years or younger)

## Discussion and Conclusion

The present study suggests that life course and masculinity are highly salient in defining young as it applies to the experience of prostate cancer in contrast to chronological age. First, chronological approaches where a defined age cutoff is applied did not strongly emerge in either research method. Rather, when chronological age was discussed in the focus groups and the interviews a diversity of views about what might be an age cutoff emerged (a range for younger than 30 years to younger than 65 years). In the focus group process age was not confirmed by any groups as an important characteristic for defining who is young in the context of prostate cancer. In the interviews, when age in years was considered it was from a personal perspective relative to attitudes more closely linked to the untimeliness of the diagnosis, life course, and masculine identities. Specifically, while some men did report a sense of prostate cancer being “an old man's disease,” and a lack of connection to other older men with prostate cancer, the dialogue that emerged in both the focus groups and interviews was more closely aligned to life events and what it means to be a man. Chronological age cutoffs have been applied in other cancer types, such as breast cancer (Sunnybrook Health Sciences Centre, 2014), as criteria for inclusion in support programs for patients and cancer survivors identified as young. The present results suggest that a specific and externally derived age criteria to denote who is young to have prostate cancer (e.g., younger

than 45 or 50 years of age at diagnosis) will exclude many men who see themselves as young and whose life course makes them vulnerable to poorer psychosocial outcomes.

The life events that were described as defining young as it applies to prostate cancer focused on work and family responsibilities, sexuality, and physical strength as central themes and these are largely consistent with the themes of middle life proposed by Oliffe (2009) and others (Evans, Frank, Oliffe, & Gregory, 2011). From a practical point of view, this highlights the difficulty of applying a chronological age cutoff to decide who is young as it applies to prostate cancer and then targeting services to that group. A man who is 49 years old, newly married, and with small children, will likely report the same life events as critical to his experience with prostate cancer as the man who is 59 years old, newly married perhaps for the second time, and with a second emerging family (“50s as the new 40s”). Orienting services to life course rather than age per se may be more responsive to unmet support needs for men with prostate cancer. For example, targeting support programs to managing work stress and career planning, maintaining family relationships, and strength-focused approaches may be more acceptable and consumer relevant to men with prostate cancer.

For masculine identities, the themes reported by men as characteristic of being young (e.g., stoic or problem-focused mind-set, sexuality, competitiveness, and physical strength) were consistent with the previous research about how masculinity intersects with the overall experience of prostate cancer (Burns & Mahalik, 2007; Cecil, Mc Caughan, & Parahoo, 2010; Oliffe, 2005, 2006). These findings may be seen as further evidence for the centrality of masculinity to this illness experience and draws further attention to the extent to which cancer care services are responsive to how men construct health. Men remain underrepresented as users of mental health and support services after cancer (Hewitt & Rowland, 2002). Addis and Mahalik (2003) have suggested that men's health help seeking could be enhanced by orienting services toward masculine values and norms by setting them in context or increasing the perception of normativeness. For example, health services could reinterpret stoicism as acceptance, self-reliance as an attribute that underpins self-management, and strength as a value for approaching threat as challenge in a proactive way.

As in previous research, the impacts of prostate cancer treatment on men's sexuality was described as central to masculine identity and of heightened importance for men who are young (Oliffe, 2005, 2006; Roberts et al., 2010). Several studies have described long term erectile difficulties in excess of 80% of men diagnosed and treated for prostate cancer (Fujita, Landis, McNeil, & Pavlovich,

2009; Johansson et al., 2011; Kyrдалen, Dahl, Hernes, Smastuen, & Fossa, 2013), and given the steady increase in prostate cancer internationally this presents as an enormous looming men's health problem (Baade et al., 2009). While medical treatments for erectile dysfunction remain the mainstay of treatment, many men do not seek these therapies after treatment, and if they do longer term maintenance of treatment is poor (Kimura et al., 2012; Pahlajani, Raina, Jones, Ali, & Zippe, 2012; Prasad et al., 2010). Further, while sexual rehabilitation approaches appear effective, limited uptake and high attrition are problematic (Schover et al., 2012). The gap between unmet need for support in this domain of men's lives and the acceptability of current interventions this remains largely unresolved. As an alternative approach, Cormie et al. (2013) reported improvements in libido in men on androgen deprivation therapy who participated in a structured physical exercise program and from this now propose and are trialing an integration of a sexuality intervention within a strength-based exercise regimen. Underpinning this approach is the proposal that new approaches to the deleterious effects of erectile dysfunction and sexual changes in men with prostate cancer are needed, and that these need to intersect with masculine values if they are to be widely acceptable to men. The present results suggest that life course also needs to be considered and this includes the importance of sexuality within the man's personal and social context and his perceptions of himself as young.

A limitation of the current study is the high educational and income level of many of the participants. Socioeconomic factors may well influence how life course is experienced and how masculinity is expressed, although views across our sample were highly consistent. The high educational level of participants also makes it likely that our samples were also high in health literacy. Low health literacy has been reported to be associated with poorer knowledge about prostate cancer in men with this disease (Kim et al., 2001); and educational level influences how men with prostate cancer respond to psychosocial intervention (Badger et al., 2012; Chambers, Ferguson, et al., 2013; Lepore, Helgeson, Eton, & Schulz, 2003). The extent to which health literacy and education level influence men's construction of what it means to be masculine, young and, have prostate cancer may require further research. As well, although the interview sample did include men from regional areas, there was no representation of men from rural and remote areas or from non-English speaking backgrounds. It is also likely that interviews with gay men would have provided different insights. Further research with these groups is needed to check for unique themes that may arise from living in a rural area, different ethnicities, and the experience of being gay and having prostate cancer. Finally, two of the three focus

groups and all interviews were undertaken by experienced female researchers. It may be that male interviewers might have elicited different data. However, a key strength of the study is the use of a two-stream process of enquiry (structured focus groups and semistructured interviews) that included multiple perspectives of both men with prostate cancer and health professionals. In this regard, the consistency of findings across both research methods and within each sample demonstrates the rigor of the study approach and robustness of the results.

In conclusion, masculine constructions and life course perspectives are important concepts that help expand our understandings of "being young with prostate cancer" beyond chronological age. It is essential that these perspectives be included in the orientation of supportive and psychosocial health care after prostate cancer. This may be especially important for younger men with prostate cancer whose adjustment outcomes are poorer.

## Appendix

### Interview Guide

1. Before you were diagnosed with prostate cancer how would you describe your life?
2. What were the main impacts on your life of being diagnosed?
3. How would you define young as it relates to having prostate cancer?
4. How does being young at diagnosis affect how you respond to the experience of prostate cancer?

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