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Everyday life after a radical prostatectomy – A qualitative study of men under 65 years of age

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ABSTRACT

Purpose: The purpose of this study was to illuminate how men under 65 years of age experience their everyday Life one year or more after a radical prostatectomy for localised prostate cancer.
Method: Interviews with 19 men aged under 65 were performed 12–18 months after their radical prostatectomy. The interviews were analysed using a thematic content analysis.
Results: The analysis of the interviews revealed three categories of experiences: 'Paying a price for survival', 'Feeling sidestepped' and 'Living with death lurking around the corner'. The side effects of the prostatectomy, such as sexual dysfunction, resulted in a changed self-image with a loss of manliness and reduced self-esteem. The men felt sidestepped and that they did not receive enough support. Prostate cancer was experienced as an embarrassing disease and the men felt their fundamental needs could not be openly discussed. Having cancer was associated with death. Thoughts about death faded away during recovery after the operation, but grew stronger in certain situations and reminded the men about their cancer. Returning to work and to previous activities helped them cope with the thoughts about death.
Conclusions: Our study suggests a need for improved rehabilitation after a radical prostatectomy, including more structured sexual rehabilitation, and involving the partner. Sharing the experiences of other men who have undergone prostate cancer surgery may also be beneficial.

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1. Introduction

Prostate cancer is one of the most common cancers among men in western countries and a major health problem (Zhou et al., 2016). For example, the incidence in men younger than 55 years at diagnosis has increased from 2.3% in 1988–1991 to 9% in 2000–2003, and the mean age at diagnosis has decreased from 72 years in 1988 to 68 years in 2003 (Lin et al., 2009). Surgical treatment of localised disease often leaves the men with erectile dysfunction (henceforth abbreviated ED) and sometimes with urinary incontinence (Baker et al., 2016; Hugosson et al., 2011). The proportion of men with permanent postoperative urinary incontinence is reported to range from 0 to 87% (Hugosson et al., 2011). The large variation is probably related to differences in the definition of continence and of the methods used for assessing continence. Severe urinary incontinence is reported in around 5% of men (Hugosson et al., 2011). Long-term postoperative ED ranges from 13 to 89%, although the proportion of men with preoperative ED is often not reported. Whereas continence usually improves during the first year and erectile function may recover during at least two years postoperatively (Hugosson et al., 2011), the overall quality of life does not change from baseline to one year postoperatively (Acar et al., 2014).

Qualitative studies have reported that men who are recently diagnosed with localised prostate cancer initially focus on cure, and that the focus gradually turns to managing and coping with urinary incontinence and ED (Burt et al., 2005; Eilat-Tsanani et al., 2013; Gannon et al., 2010; Hedestig et al., 2005; Iyigun et al., 2011; Milne et al., 2008; Petry et al., 2004; Walsh and Hegarty, 2010; Willener and Hantikainen, 2005). One to three years after surgery, ED commonly caused frustration among men, and they expressed that their sexual rehabilitation was not satisfactory (Nelson et al., 2015). Urinary incontinence and ED have also been described as major

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sources of emotional tension affecting social interactions and sense of self-worth (O'Shaughnessy and Laws, 2009). Gannon and co-workers reported that men might normalise their inability to have penetrative sex by viewing it in terms of the ageing process (Gannon et al., 2010).

Although younger men aged <55 have been reported to have similar, or better, urinary and sexual function, with the exception of men with relationships who are at greater risk of severe worsening of sexual bother (Wright et al., 2008), there is a lack of studies that focus on men under age 65 who have passed the initial post-operative period. We identified six interview studies that included men aged 41–81 years (Burt et al., 2005; Eilat-Tsanani et al., 2013; Hedestig et al., 2005; Milne et al., 2008; Nelson et al., 2015; Walsh and Hegarty, 2010). The median age at the time of diagnosis of prostate cancer in Sweden is 69 years (The National Board of Health and Welfare, 2015). Although age is not a prognostic factor *per se* in men with non-metastatic prostate cancer, younger men are more likely than older men to be diagnosed with localised disease and to be treated with radical prostatectomy, which is the most common treatment for men under age 65 (Thorstensson et al., 2017).

Yet another rationale to focus on men under 65 years of age is that they fear cancer recurrence to a greater extent than their older counterparts (van de Wal et al., 2016). Thus, our purpose was to illuminate how men under 65 years of age experience their everyday life one year or more after a radical prostatectomy for localised prostate cancer, when the remaining side effects are likely to be permanent.

2. Methods

The study was designed as a descriptive qualitative study with an inductive approach including interviews. This approach was chosen as it is recommended when the focus of the study is on full understanding of individual cases as well as of those combined and aggregated thematically (Patton, 2002). Subsequently elicited data were analysed by hand using a thematic content analysis by Burnard et al. (2008).

2.1. Participants

The inclusion criteria were men younger than 65 years old who, 12–18 months previously, had undergone an open or a robotic radical prostatectomy at either one of two hospitals in southern Sweden. Consecutively selected patients (n = 34) who fulfilled these inclusion criteria were asked to participate. Men who were not fluent in Swedish were excluded. Men eligible for the study were given written information about the study and a consent form by a nurse at their postoperative outpatient visit. The men were then contacted by telephone by one of the authors (A-KJ). After being given at least two weeks to consider the invitation to participate, the men responded by returning in a pre-addressed envelope the consent form with a notification of whether they agreed or declined to participate. Additional information about the study was given by telephone to those agreeing to participate. This resulted in 19 eligible participants aged 49–65 years (median 62 years; mean 60.7 years), of whom 14 had undergone open and 5 robotic radical prostatectomy. Fourteen were co-habiting with a partner and five were living alone. Sixteen had children and three had no children.

2.2. Interviews

Semi-structured interviews were conducted 12–18 months postoperatively to allow recovery from short-term side effects. All interviews were conducted by the same author (A-KJ), a nurse with several years' experience of oncological nursing, in a location and at a time chosen by the participant: a secluded room at the urology department (n = 13), at the participant's home (n = 5) or at the participant's workplace (n = 1). The interviewer, who was wearing civilian clothes during the interviews, worked at a different department and, thus, had not been involved in the care of any of the men.

An interview guide was used, based on three main questions: 'What do you think about your illness now?', 'How do you experience your everyday life today?' and 'Do you experience life as it was before surgery?' with related follow-up questions: 'Could you give an example?' or 'How did that affect you?' The interview guide was tested and considered functional in a pilot interview, and was therefore used unchanged for the remaining 18 interviews. The pilot interview was included in the analysis. During the interviews, the men were encouraged to freely develop and expand on their answers. The interviews started with an opening question about the man's current life situation and the collection of data continued until no new data shed any further light on how men under 65 years of age experienced their everyday life one year or more after a radical prostatectomy for localised prostate cancer. All interviews were audio-recorded by agreement with the men and lasted 46–60 min.

2.3. Data analysis

The interviews were transcribed verbatim and analysed using thematic content analysis, following Burnard et al. (2008). The analysis started with three of the authors (A-KJ, AW, KS) independently reading the transcripts for an open coding where irrelevant information was excluded from the analysis. In the second stage of the analysis, notes that had emerged from the data were compared and summarised on a whiteboard, and duplicates crossed out. The list of notes was worked through and categorised by two of the authors (AW, KS). In the final stage, the two authors discussed the categories, which were then condensed into three. Lastly the analysis was verified by the author who performed the interviews and participated in the open coding (A-KJ), and by yet another author (OB) for a third-party verification.

3. Ethical considerations

At the time of the interview, all men received oral information about the study so that the interviewer (A-KJ) could be certain about their willingness to participate. They were also informed that they could withdraw their consent at any time without giving any reason and that all data would be kept confidential and not handed over to the health care professionals. Subsequently, the participants were given information about whom to contact if the interview raised further questions or thoughts. The Ethical Review Board of the Health Sciences Centre at Lund University approved the study (Ref. No.: 94-09).

4. Results

The analysis of the interviews revealed three categories of experiences: 'Paying a price for survival', 'Feeling sidestepped' and 'Living with death lurking around the corner'. The categories are described below, with quotations from the interviews to support the confirmability of this categorisation.

4.1. Paying a price for survival

Although postoperative urinary incontinence was inconvenient to begin with, continence gradually improved and, with time,

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