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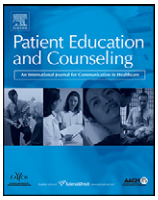

Patient Perception, Preference and Participation

Examining risk perception among men with a family history of prostate cancer

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ABSTRACT

Objective: This paper explores factors that influence the formulation of risk perception among men with a family history of prostate cancer who are currently attending a prostate cancer screening clinic.
Methods: Semi-structured interviews were conducted with fifteen participants. Interview transcripts were analyzed using interpretative phenomenological analysis.
Results: The following themes were identified: Risk Information Pathways, Experience with Other Prostate Disease, Exposure to Prostate Cancer Screening, Exposure to Affected Relatives, Lifestyle Factors, Illness Beliefs, and Health-Based Risk Comparisons.
Conclusion: Understanding the contributors to risk perception and applying this knowledge during screening visits and genetic counselling may help to reduce risk distortion and result in increased adherence to screening programs and reduced psychological distress.
Practice implications: Prostate cancer screening should incorporate counselling to address patient-specific risk concepts in order to increase the accuracy and maintain the stability of risk perceptions.

1. Introduction

Research has shown the majority of men with a family history of prostate cancer (PCa) understand that family history increases risk [1] but little is known about additional factors that influence risk perceptions in this population. The relevance of exploring these factors is underlined by two important associations: risk perception is associated with an individual's intention to participate in screening [2] and with psychological distress [3,4].

Past investigations demonstrate that men with a family history of PCa may distort personal risk estimates. Miller et al. demonstrated that individuals with a family history of PCa are more likely to overestimate risk when compared to men without a family history [5]. Bratt found that 40% of men with a family history of PCa were over-estimators. To the degree to which risk distortion reflects a fear of PCa, it may cause some men to avoid screening [3]. This association is bolstered by parallel research in women with family histories of breast cancer which has shown that overestimation of personal risk is common [6], and that over-estimators see less benefit in adhering to surveillance activities than women at population risk [7,8]. The possibility that risk distortion may influence screening intentions underscores the importance of examining factors that influence risk perception.

Perceived susceptibility to PCa has been linked with disease-specific worry in men with a family history of PCa [9]. Inflated risk has been associated with psychological distress [4] and depression and worry severe enough to affect daily life [3]. PCa risk perceptions can mitigate/exacerbate the relationship between

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family history of the disease and worry about PCa, suggesting that better risk management could be helpful in reducing worry about PCa [10]. In a comprehensive overview of the psychosocial issues experienced by men with a family history of PCa, Wakefield et al. comments on the importance of addressing the risk information needs of this population through counselling [11].

Research in chronic disease has demonstrated that inheritance is not the only contributing factor to risk perception; environmental and behavioral factors also play a role in an individual's conceptualization of risk [12]. A study by Walter and Emery illustrated that individuals with a family history of cancer felt they could reduce cancer risk by altering their lifestyle [13]. Personal experiences of signs or symptoms of disease have also been shown to activate risk perception [14]. Risk perceptions are also associated with disease severity, whereby individuals feel at greater risk of developing a disease if they witness a poor outcome in an affected relative or friend [13,14]. Lipworth et al. found that the process of conceiving personal risk is subject to cognitive processes (e.g. personal beliefs) [14]; suggesting that risk perceptions may be modifiable by moderating patients' emotional responses and reinforcing appropriate risk information.

Overall, there is sparse scientific literature specifically exploring the determining factors that give rise to risk perceptions in men with a family history of PCa.

The objective of this study is to explore factors that influence the formulation of risk perceptions among men with a family history of PCa who have initiated PCa screening. Understanding the contributors to risk perception, and applying this knowledge during screening visits and genetic counselling may help to reduce risk distortion and result in increased adherence to screening programs and reduced psychological distress.

2. Methods

2.1. Participants

The Prostate Centre at Princess Margaret Hospital supports a PCa Prevention Clinic (PCPC) which provides PCa screening for unaffected men deemed to be high risk (e.g. having one affected first-degree relative). Referrals are made to the PCPC clinic through General Practitioners who have identified patients that have a familial risk of PCa. Patients attending PCPC appointments have access to a Uro-Oncologist, Genetic Counsellor, Psychologist, Nutritionist and Exercise Physiologist. Participants for the present study were approached between January 2006 and April 2008 while attending regular PCPC screening appointments. Eligibility requirements included no personal diagnosis of PCa, at least one first-degree relative diagnosed with PCa, current engagement in screening/testing for PCa and no previous genetic counselling (Genetic Counselling is a relatively new and limited service in the PCPC at this time, hence many patients have not met with the Genetic Counsellor). For qualitative research, sample selection is guided by theoretical considerations specific to the objective of the study and by the need to achieve saturation. Research examining qualitative approaches to focused research questions confirms that saturation is commonly achieved with sample sizes as small as 10–20 participants [15,16]. In this study, through consecutive sampling saturation was reached with 15 participants. This means that data collection and analysis continued until no new or relevant data seemed to emerge regarding a theme and relationships between themes were well established. Demographic characteristics of the participants are presented in Table 1. In total, 24 men were approached: 15 men consented and completed the semi-structured interview and 9 men declined. Of the men declining participation, 5 indicated they would not be available to complete the interview, 2 did not want to be audiotaped and 2 men did not see sufficient personal benefit for participation.

Table 1
Demographic characteristics of study participants.

Participant age in years: mean (range)	58 (39–85)
Duration of PCa screening, *n* (%)	
$\leq$5 years	8 (53)
>5 years but <10 years	3 (20)
$\geq$10 years	4 (27)
Marital status, *n* (%)	
Single	2 (13)
Married	13 (87)
Educational level, *n* (%)[a]	
Less than secondary school	1 (7)
Secondary	4 (27)
University	10 (67)
Fathered at least one son, *n* (%)	
No	5 (33)
Yes	10 (67)

[a] Does not equal 100% due to rounding.

2.2. Procedures

The study was reviewed and approved by the University Health Network Research Ethics Board. Study participation involved one interview lasting 30–45 min. Semi-structured interviews were conducted by two interviewers (CP, KC) by telephone or face-to-face, depending on participant preference. The initial interview was investigator-developed and consisted of 19 questions based on the pooled knowledge and clinical expertise of several members of the investigative team (AM, CP, CS, SH, DC, JT, PR). Questions were designed to explore the participants' conceptualization of their risk of developing PCa and factors they take into account when considering their risk. Serial analysis of the initial seven transcripts led to modification of the interview for use on subsequent participants. The interviews were audio-tape recorded and transcribed verbatim for data analysis.

2.3. Data analysis

This study employed interpretative phenomenological analysis (IPA), as described by Smith [17], Smith et al. [18] and Willig [19], to explore the participants' thoughts and beliefs about factors influencing risk of developing PCa. IPA is used extensively in health psychology research [20,21]; specifically in examining disease-specific risk perceptions [22]. The IPA approach allows for expansion of knowledge by providing insight into how individuals attempt to make meaning of their disease-specific risk [23].

Interview transcripts were used as the source of data. Analysis of the transcripts was performed by five of the study investigators (AM, KC, MEH, LT and CP) using Microsoft® Office Word [24] table and bolding features to highlight and organize meaning units (Column 1 – Interview Transcript, Column 2 – Coding). The analysis consisted of breaking the text into meaning units consisting of individual words, sentences, or paragraphs, followed by clustering related meaning units into appropriate themes. Within and between each transcript, the investigators cross-referenced each theme to derive the minimal number of distinct themes necessary to capture the participant's experience. When unanimous agreement on a theme was not reached, the investigators met to review the specific participant quotes used to develop the theme. Attention was paid to the context of the quote to make certain that the interpretation was strongly grounded in the interview data [25]. In each case, this process effectively led to consensus on