

Perceived causes of prostate cancer among prostate cancer survivors in the Netherlands

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Abstract

Introduction

The aim of this study was to evaluate self-reported causes of prostate cancer among prostate cancer survivors in the Netherlands to obtain insight into the common beliefs and perceptions of risk factors for prostate cancer.

Materials and methods

A total of 956 prostate cancer survivors, who were identified from a population-based cancer registry and provided written informed consent, completed a questionnaire on socio-demographic characteristics, lifestyle, medical history and family history of cancer. The final question: 'You have been diagnosed with prostate cancer. Do you have any idea what may have been the cause of your cancer?' was evaluated for this study.

Results

Of the 956 prostate cancer survivors, 143 participants (15%) reported that they were aware of any factors that might have caused their prostate cancer. Participants reported factors related to heredity (37%), environmental factors (17%), nutrition or physical activity (13%) and stress (13%) as most likely causes. Interestingly, although a positive family history is established as a risk factor for prostate cancer, only

19% of the prostate cancer survivors with an affected first-degree relative reported this as possible cause.

Conclusion

Relatively few prostate cancer survivors were able to report possible causes of their prostate cancer. Furthermore, established risk factors for prostate cancer were not commonly perceived, not even among men with these risk factors. This finding might be taken into account, while developing future cancer education programs. Some causal factors reported by the participants may warrant further investigation, because current evidence for their role in prostate cancer aetiology is still missing or inconclusive.

Introduction

Prostate cancer is the most common cancer among men in Western countries^{1,2}. As for many other types of cancer, little is known about exact causes of prostate cancer. So far, old age, black race, a positive family history, and almost 80 low-penetrance genetic markers have been established as risk factors for prostate cancer^{3,4}. Understanding of what cancer survivors think about causes of their cancer and to what extent they are aware of these and other potential risk factors may provide valuable information for health education and prevention initiatives. Previous studies showed a low awareness of risk factors for prostate cancer among the general population⁵⁻⁷. Data on patients' perceptions of individual risk factors for prostate cancer, however, are scarce⁸⁻¹¹. Interestingly, previous research showed that patients with prostate cancer (41%) were least likely to specify factors contributing to their cancer as compared to patients with other

common cancers, such as bowel, breast or lung cancer (47-74%)¹⁰. These findings emphasise the need for comprehensive insight into the beliefs and perceptions among prostate cancer survivors.

The aim of this study was to evaluate self-reported causes of prostate cancer among prostate cancer survivors in the Netherlands to obtain insight into beliefs and perceptions of individual causes of their cancer.

Materials and methods

Self-reported causes of prostate cancer were evaluated in this study among Dutch prostate cancer survivors. Recruitment and characteristics of the study population have been described in detail previously^{12,13}. Briefly, men diagnosed with prostate cancer between 2003 and 2006 ($n = 1668$) were identified from the population-based cancer registry held by the Comprehensive Cancer Centre East in the Netherlands. Those men diagnosed with prostate cancer before the age of 76 years were invited in 2006-2007 to participate in a European study named Polygene which aimed to identify common genetic variants that influence the risk of developing breast or prostate cancer¹³. All eligible prostate cancer survivors ($n = 1330$) received an invitation letter and information brochure. The information brochure highlighted the need for aetiological research into risk factors for prostate cancer and breast cancer. Lifestyle factors (nutrition and physical activity) and genetic factors were mentioned as established risk factors for prostate cancer in this information brochure. Overall, 956 prostate cancer survivors agreed to participate and filled out a baseline postal questionnaire on socio-demographic

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and lifestyle characteristics, physical activity, occupational history, exposure to sun, medical history, use of medicines, and family history of cancer. The final question: 'You have been diagnosed with prostate cancer. Do you have any idea what may have been the cause of your cancer?' (No/Yes, namely...) was evaluated in this study.

Categories of perceived causes were based on answers given by the participants and were presented as clusters of risk factors (environment/heredity/stress/nutrition and physical activity/clinical interventions/voiding problems/vasectomy/infections/other physical problems/cycling/smoking/screening/other). Prostate cancer survivors were divided into subgroups to search for patterns among shared characteristics and reported causes. For these subgroup analyses, participants were stratified based on their age, family history of prostate cancer, educational level, body mass index (BMI), and reasons for prostate-specific antigen (PSA) testing. Strata of age were defined as below and equal or above 68 years of age, which was the median age of the study population. A positive family history of prostate cancer was defined as at least one reported first-degree family member (father, brother, son) with prostate cancer. Educational level was classified as low (primary school, secondary school, vocational education) or high (college and university), based on the seven response options in the questionnaire. BMI (kg/m^2) was calculated using self-reported weight (kg) and height (cm). Strata of BMI were below $25 \text{ kg}/\text{m}^2$ (normal weight) and equal or above $25 \text{ kg}/\text{m}^2$ (overweight and obesity). Reasons for PSA testing were either classified as screening and routine check-ups or as complaints and symptoms.

The institutional review board approved the Polygene study and all participants provided written informed consent. The Statistical Package for Social Sciences (SPSS,

version 16.0; Chicago, Illinois) was used for all analyses. Mann–Whitney *U* tests or chi-square tests were used for the comparisons between groups of prostate cancer survivors.

Results

Characteristics of the participants, stratified for those who did and did not report a causal explanation, are presented in Table 1. The median [interquartile range (IQR)] age at completion of the questionnaire was 68 (63–73) years. Median (IQR) time between diagnosis of prostate cancer and completion of the questionnaire was 26.9 (17.7–36.8) months. The majority of the prostate cancer survivors indicated that they were not aware of any causal factor that might have contributed to the development of their prostate cancer ($n = 809$; 85%), while only few did not answer this question ($n = 4$; <1%).

In total, 143 (15%) participants suggested a possible cause of their prostate cancer. These men were younger ($p < 0.001$), were more likely to have a positive family history of prostate cancer ($p < 0.001$) and were more frequently currently employed ($p = 0.003$) compared to men who did not report any cause. Table 2 summarises the perceived causes as mentioned by the prostate cancer survivors in this study. Results were stratified by age, family history of prostate cancer, educational level, BMI, and reasons for PSA testing.

Heredity was most commonly reported ($n = 53$; 37%) by the 143 participants who provided at least one possible cause of their prostate cancer. Men with a positive family history were more likely to mention heredity ($n = 41$; 75%) compared to men without prostate cancer in their family ($n = 12$; 14%) ($p < 0.001$). However, of all prostate cancer survivors with a positive family history in the first degree ($n = 211$), only 41 participants (19%) reported this positive family history as one of the potential causes of their disease, while 14 participants (7%)

mentioned other causes and 156 participants (74%) did not provide any cause. By contrast, 12 out of 745 participants without a positive first-degree family history indicated that heredity might have caused their prostate cancer. Some of these men reported second- or third-degree affected family members ('*a grandfather with prostate cancer*', '*cousins from my mother*'), referred to other types of cancer in the first-degree ('*father had testicular and lymphatic cancer*') or mentioned heredity in general ('*my father also was a 'prostate-person', he got several surgeries since he was 55 years of age*').

Environmental factors were frequently mentioned as well ($n = 25$; 17%). Most environmental factors were linked to current or previous occupations ('*occupational-disease for painters*', '*chemicals in rubber industry*', '*cold or sun exposure during work*') although incidental or accidental exposures were also reported ('*defect fridge*', '*Chernobyl disaster*'). Most prostate cancer survivors reported highly specific causes ('*DDT intoxication at young age*', '*mobile phone in right trouser pocket*', '*use of felt-tip pens*') rather than general environmental factors (e.g., '*air pollution*' and '*car exhaust*'). Environmental factors were more frequently reported among participants with lower education ($n = 22$; 24%) compared to participants with a high educational level ($n = 3$; 6%) ($p = 0.008$).

For causes related to nutrition and physical activity an opposite pattern was observed; men with a lower educational level were less likely ($n = 7$; 8%) to report these factors compared to men with higher education ($n = 11$; 22%) ($p = 0.013$). Nutrition and related factors comprise both abundant intake ('*abundant alcohol intake*', '*salt*', '*excessive use of tomatoes*' '*I used sweeteners a lot*') and deficient intake of foods ('*low fruit intake*', '*not much fruit during childhood*'), as well as specific

Table 1 Sociodemographic and clinical characteristics of the study population.

| | All prostate cancer survivors | Participants with causal explanation for their prostate cancer | Participants without causal explanation for their prostate cancer |
|---|-------------------------------|--|---|
| Number of participants | 956 | 143 (15%) | 813 (85%) |
| Age at completion of questionnaire (years) | 68.2 (63.2–72.8) | 66.1 (60.7–70.7) | 68.8 (63.6–73.1) |
| Time between diagnosis and completion of questionnaire (months) | 26.9 (17.7–36.8) | 26.9 (18.7–34.9) | 26.9 (17.4–37.0) |
| Body mass index (kg/m ²) | 25.2 (23.8–26.9) | 24.8 (23.6–26.1) | 25.2 (23.9–27.0) |
| Marital status (%) | | | |
| Married/cohabiting | 858 (90%) | 126 (88%) | 732 (90%) |
| Single | 46 (5%) | 8 (6%) | 38 (5%) |
| Divorced/widowed | 52 (5%) | 9 (6%) | 43 (5%) |
| Educational level (%) ^a | | | |
| Low | 664 (70%) | 93 (65%) | 571 (70%) |
| High | 286 (30%) | 50 (35%) | 236 (29%) |
| Currently employed (%) | | | |
| Yes | 181 (19%) | 40 (28%) | 141 (17%) |
| No | 775 (81%) | 103 (72%) | 672 (83%) |
| Positive family history of prostate cancer (%) | 211 (22%) | 55 (39%) | 156 (19%) |
| Reason for PSA screening (%) | | | |
| Complaints | 484 (51%) | 71 (50%) | 413 (51%) |
| Routine check-up | 324 (34%) | 50 (35%) | 274 (34%) |
| Screening | 27 (3%) | 3 (2%) | 24 (3%) |
| Other ^b | 118 (12%) | 19 (13%) | 99 (12%) |

Data are presented as median (interquartile range) or numbers (%). Percentages may not add up to 100% because of missing values.

^aEducational level is defined as low (primary school, secondary school, vocational education) or high (college and university).

^bThe category 'Other' consisted of various explanations given by the participants and includes for example: '*prostate cancer diagnosis among family or friends*', '*article in newspaper*', '*other physical complaints or diseases*'.

food patterns ('*maybe an irregular life and eating pattern*', '*monotonous diet*', '*Mediterranean lifestyle with meat and wine*'). Also additives ('*chemicals in food*', '*hormones in meat industry*') and a sedentary lifestyle ('*sedentary occupation*', '*usually sitting behind my desk*') were reported as possible causes of prostate cancer.

One participant explicitly mentioned overweight, together with other possible factors, as a cause of his prostate cancer. Participants with overweight or obesity (BMI ≥ 25 kg/m²) did

not report causes related to nutrition or physical activity more frequently ($n = 9$; 13%) in comparison to men with normal weight ($n = 9$; 12%) ($p = 0.874$). However, prostate cancer survivors with overweight and obesity mentioned any sort of physical problems relatively frequently (Table 2). Their explanations appear not to be specifically related to overweight; for instance, '*hypertension*', '*thrombosis*', '*polyp*', '*cyst in prostate*' and '*deficient auto-immune system*' were mentioned.

Besides the previously discussed factors, many prostate cancer survi-

vors believed that stress has caused their prostate cancer. Participants gave causal explanations such as '*fatigue and stress caused prostate enlargement and subsequently cancer*', '*busy lifestyle*', '*high workload*', '*depression*', and '*burnouts*'. Stress-related explanations were common among young men with a high educational level, which may suggest that perceived stress is mainly related to current occupation.

Participants ($n = 7$; 5%) who mentioned infections as a possible cause of their prostate cancer either

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Table 2 Categories of perceived causes of prostate cancer among Dutch prostate cancer survivors.

| Stratification | All participants | Age | | Family history of prostate cancer | | Educational level ^b | | Body mass index | | Detection ^c | |
|--|------------------|------------------|-----------|-----------------------------------|----------|--------------------------------|----------|-----------------------|-----------------------|------------------------|------------|
| | | <68 years | ≥68 years | Negative | Positive | Low | High | <25 kg/m ² | ≥25 kg/m ² | Screening | Complaints |
| Number of participants | 956 | 462 ^a | 492 | 745 | 211 | 664 | 286 | 449 | 499 | 351 | 484 |
| Number of participants giving a causal explanation | 143 (15%) | 85 (18%) | 58 (12%) | 88 (12%) | 55 (26%) | 93 (14%) | 50 (17%) | 74 (16%) | 69 (14%) | 53 (15%) | 71 (15%) |
| Causal explanations | | | | | | | | | | | |
| Heredity: 'Heredity, DNA mutations' | 53 (37%) | 31 (36%) | 22 (38%) | 12 (14%) | 41 (75%) | 35 (38%) | 18 (36%) | 26 (35%) | 27 (39%) | 23 (43%) | 19 (27%) |
| Environmental: 'Pesticides, air pollution' | 25 (17%) | 18 (21%) | 7 (12%) | 18 (20%) | 7 (13%) | 22 (24%) | 3 (6%) | 13 (18%) | 12 (17%) | 8 (15%) | 16 (23%) |
| Nutrition/physical activity: 'Food additives, alcohol meat, sedentary lifestyle' | 18 (13%) | 12 (14%) | 6 (10%) | 13 (15%) | 5 (9%) | 7 (8%) | 11 (22%) | 9 (12%) | 9 (13%) | 7 (13%) | 7 (10%) |
| Stress/psychological: 'Stress, burn-out, workaholic, depression' | 18 (13%) | 15 (18%) | 3 (5%) | 16 (18%) | 2 (4%) | 10 (11%) | 8 (16%) | 11 (15%) | 7 (10%) | 3 (6%) | 13 (18%) |
| Voiding problems: 'Urgent, frequent' | 8 (6%) | 4 (5%) | 4 (7%) | 7 (8%) | 1 (2%) | 5 (5%) | 3 (6%) | 5 (7%) | 3 (4%) | 1 (2%) | 5 (7%) |
| Vasectomy | 7 (5%) | 5 (6%) | 2 (3%) | 7 (8%) | 0 (0%) | 3 (3%) | 4 (8%) | 6 (8%) | 1 (1%) | 2 (4%) | 5 (7%) |
| Infection: 'Prostatitis, virus infection' | 7 (5%) | 5 (6%) | 2 (3%) | 7 (8%) | 0 (0%) | 3 (3%) | 4 (8%) | 3 (4%) | 4 (6%) | 2 (4%) | 4 (6%) |
| Other physical problems: 'Immune system, thrombosis, hypertension, digestion' | 7 (5%) | 3 (4%) | 4 (7%) | 5 (6%) | 2 (4%) | 2 (2%) | 5 (10%) | 0 (0%) | 7 (10%) | 2 (4%) | 5 (7%) |
| Cycling | 7 (5%) | 4 (5%) | 3 (5%) | 7 (8%) | 0 (0%) | 4 (4%) | 3 (6%) | 3 (4%) | 4 (6%) | 3 (6%) | 4 (6%) |
| Smoking | 6 (4%) | 3 (4%) | 3 (5%) | 4 (5%) | 2 (4%) | 6 (6%) | 0 (0%) | 4 (5%) | 2 (3%) | 3 (6%) | 2 (3%) |
| Clinical interventions: 'X-ray, light therapy for eczema' | 6 (4%) | 3 (4%) | 3 (4%) | 5 (6%) | 1 (2%) | 5 (5%) | 1 (2%) | 3 (4%) | 3 (4%) | 1 (2%) | 4 (6%) |
| Age | 5 (3%) | 1 (1%) | 4 (7%) | 4 (5%) | 1 (2%) | 2 (2%) | 3 (6%) | 2 (3%) | 3 (4%) | 2 (4%) | 3 (4%) |

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| Stratification | All participants | Age | | Family history of prostate cancer | | Educational level ^b | | Body mass index | | Detection ^c | |
|--|------------------|-----------|-----------|-----------------------------------|----------|--------------------------------|--------|-----------------------|-----------------------|------------------------|------------|
| | | <68 years | ≥68 years | Negative | Positive | Low | High | <25 kg/m ² | ≥25 kg/m ² | Screening | Complaints |
| Other: 'Use of drugs, high testosterone' | 4 (3%) | 3 (4%) | 1 (2%) | 3 (3%) | 1 (2%) | 4 (4%) | 0 (0%) | 2 (3%) | 2 (3%) | 3 (6%) | 1 (1%) |
| Screening | 2 (1%) | 0 (0%) | 2 (3%) | 2 (2%) | 0 (0%) | 1 (1%) | 1 (2%) | 2 (3%) | 0 (0%) | 2 (4%) | 0 (0%) |

Data are presented as numbers (%). Numbers might exceed the total number of participants in our study as some participants provided more than one answer to the question.

^aFor two participants, age at completion of questionnaire is missing.

^bEducational level is defined as low (primary school, secondary school, vocational education) or high (college and university).

^cReasons for initial PSA testing are either related to complaints/symptoms ($n = 484$) or to screening/routine check-up ($n = 351$). Another, minor category in the questionnaire was 'other' ($n = 118$) and includes for example 'prostate cancer diagnosis among family or friends', 'article in newspaper', 'other physical complaints or diseases'.

specified infections related to the prostate or the urinary tract. Participants, who mentioned prostatitis, gave a clear cause of the infection ('prostatitis in adolescence because of cycling', 'frequent episodes of prostatitis because of poorly performed vasectomy', and 'chronic prostatitis during 2 years because of catheterization after a serious accident'). From the questionnaire, we identified 93 prostate cancer survivors with self-reported prostatitis. Only four of them mentioned infections or prostatitis as a possible cause of their prostate cancer, suggesting that most participants do not consider prostatitis as a main risk factor.

Other causes that were mentioned are related to voiding problems ($n = 8$; 6%), other physical problems ($n = 7$; 5%), vasectomy ($n = 7$; 5%), cycling ($n = 7$; 5%), smoking ($n = 6$; 4%), clinical interventions ($n = 6$; 4%), age ($n = 5$; 4%), screening ($n = 2$; 1%), and others ($n = 4$; 3%). The last category comprised a variety of causal explanations; 'it is a man-thing?', 'use of prednisone and azathioprine', 'an accident as testing engineer', and 'high levels of testosterone'. These and other examples of reported causes are presented in Table 3.

Many prostate cancer survivors reported possible causal explanations to which they apparently have been exposed during a long period ('thirty-seven years of unhealthy and dirty work', 'I have been a workaholic during my whole life', 'too little physical activity and sports during the last 25 years') or that has occurred during the past ('not much fruit during childhood', 'prostatitis in adolescence due to frequent cycling', 'frequent X-rays in the sixties and seventies'). Only few participants reported more acute or recent events that might have contributed to the development of their prostate cancer ('serious infection in bladder and prostate during the past 9 months').

If a causal explanation was given, this was frequently coupled with a measure of uncertainty. 'If I knew that! Perhaps a monotonous diet during the war in 1940-1945 or during my stay abroad in 1964-1995?' Almost one-third of the participants provided a causal explanation followed by a question mark, or used words as 'possibly' and 'perhaps'. These measures of uncertainty may suggest that many participants did not recognise one clear, outstanding cause of their prostate cancer.

Discussion

In this study among prostate cancer survivors, we evaluated perceived, self-reported causes of prostate cancer. Only 15% of the participants mentioned at least one causal explanation, whereas the majority of the participants (85%) indicated that they were not aware of any cause that might have contributed to the development of their prostate cancer.

Awareness of risk factors for prostate cancer among the general population has been studied in the past, however, only a few studies specifically examined perceived causes of prostate cancer among prostate cancer survivors⁸⁻¹¹. A previous study showed that patients with prostate cancer were least likely (41%) to report perceived causes, as compared to patients with other common cancers, such as bowel, breast or lung cancer (47-74%). This finding was explained by the authors by the lack of scientific evidence available for factors involved in prostate carcinogenesis¹⁰. In our study, even a lower percentage of prostate cancer survivors specified possible causes of their prostate cancer, which may be a result of the current awareness among Dutch versus Australian cancer patients. Another possibility is that the question in our study

Table 3 Selection of perceived causes of prostate cancer reported by Dutch prostate cancer survivors.

| Perceived causes | Examples of perceived causes given by the participants |
|---|--|
| ...established as risk factors for prostate cancer | 'Heredity', 'Conform age incidence', 'My father; he was diagnosed with prostate cancer when he was 70 years', 'It is in my genes', 'It is a man-thing?', 'My father also was a prostate-person, he got several surgeries since he was 55 years of age', 'Hereditary mutation (father) could not be excluded', 'DNA', 'Heredity, therefore I asked for a screening', 'Because my father also had prostate cancer, I think that it is hereditary' |
| ...with an unknown or unidentified effect on prostate cancer risk | 'Sweeteners', 'Abundant intake of tomatoes', 'Little physical activity during the last 25 years', 'Fluid from defect fridge', 'Air pollution from the Ruhr district', 'Television switched on for 6 h/day', 'I assume because I was exposed to chemicals in rubber industry', 'Traffic jam during rush hours', 'DDT intoxication at young age', 'Electromagnetic radiation', 'Unknown retrovirus', 'Chronic voiding problems', 'Polyps in the rectum', 'Stress' 'Completely overtired because of family problems', 'Work-related stress and traveling by car', 'Sadness', 'Depression', 'Maybe stress and depression in the past', 'Fatigue and stress for years caused prostate enlargement and subsequent cancer', 'Many X-rays lower part of the body', 'Disorder of the autoimmune system?', 'Association with neuropathy and thyroid', 'Outdoor profession (cold)', 'Sun exposure during work', 'Light therapy for eczema in 1999/2000', 'Chronic prostatitis', 'Frequent episodes of prostatitis because of poorly performed vasectomy', 'Ignorance of voiding problems by general practitioner', 'Air pollution in Nijmegen-West' |
| ...unlikely to have an effect on prostate cancer risk | 'Vasectomy', 'Cycling', 'Smoking', 'Cyst in the prostate', 'Is there any relationship between vasectomy and prostate cancer?', 'Increased risk because of vasectomy, I have read that somewhere', 'A lot of cycling 5 years before diagnosis, pressure on prostate because of problems with saddle', 'Smoking and moderate alcohol intake', 'Cycled 65.141 km between 1993–2003', 'Smoking!!!' |

This table is provided in order to give insight into the types of perceived causes reported by the participants. The classification of perceived causes into the different categories is based on a rather arbitrary selection. Future research and new insights might result in a shift of perceived causes among the different categories. Some of the perceived causes reported by the participants may be proxies for other underlying risk factors.

('Do you have any idea what may have been the cause of your cancer?' (No/Yes, namely...) explicitly allowed a 'negative' response, whereas the question used by Willcox and colleagues ('What factors do you believe or suspect contributed to your development of cancer, if any?') did not.

Many of the studies among survivors of prostate cancer^{8,9} and other forms of cancer^{14,15} were based on a prompted list or closed, multiple-answer questions to identify causal perceptions. The prompted question format is considered to reflect recognition and usually indicates higher levels of knowledge compared to

open-ended questions¹⁶. Furthermore, the prompted question format does not allow unique, unexpected or new responses and is strongly directed by views of the health professionals¹⁰. Because the aim of our study was to evaluate beliefs and self-reported causes of prostate cancer, we used an unprompted question format.

In our study, we expected to find three categories of answers: factors that have been established as risk factors for prostate cancer, factors that are unlikely to have an effect on prostate cancer risk, and factors for which the effect on prostate cancer risk is unidentified or inconsistent.

Factors that have been established as risk factors for prostate cancer

Black race, old age, a positive family history and several low-penetrance genetic markers have been established as risk factors for prostate cancer^{3,4}. Race was not mentioned by any of the prostate cancer survivors in our study, which is expected because 99% of our study population was Caucasian. Although age is established as a main risk factor for prostate cancer, this was mentioned by only a few participants in our study, which is consistent with previous studies¹⁰. Reasons for the small number of participants reporting age may be related to lack of knowledge,

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the open-ended question format, or to the perception of 'old age'. Median age of our population was 68 years and many of the participants may not perceive themselves as 'old'.

A positive family history is another main risk factor for prostate cancer¹⁷. Although causes related to heredity were the most frequently reported aetiological factors in our study ($n = 53, 37\%$), only 19% of the prostate cancer survivors with a positive family history in the first degree reported this as a possible cause. This finding appears to indicate modest prostate cancer awareness among these men. Theoretically, education of high-risk men may stimulate alertness or adherence to screening and thus lead to early detection, improvement of prognosis and reduction of mortality. However, before any education program tailored to these high-risk men can be implemented in clinical practice, it should be carefully considered whether these benefits balance the possible harms (i.e. complications of treatment, mental burden) of early detection and treatment of prostate cancer.

Factors that are unlikely to have an effect on prostate cancer risk

For several causes identified in our study, there is no or only limited evidence that these factors increase prostate cancer risk³. Vasectomy, for example, was perceived as a cause of prostate cancer among several prostate cancer survivors. Although early studies suggested vasectomy as a risk factor for prostate cancer^{18,19}, other studies refuted this^{20,21}. We assume that participants remember the 'old rumours' (*increased risk because of vasectomy, I have read that somewhere*) or that they associate prostate cancer with other disorders or procedures in the genitourinary system (*when I was 44 years of age, I had a vasectomy. Since then I had pain in that area during ejaculations*). From that perspective, it is reasonable that several participants also reported voiding problems

(which might refer to benign prostate hyperplasia), prostatitis or cycling as possible causes of their prostate cancer. However, for none of these factors there is consistent evidence that they increase the risk of prostate cancer³. Also smoking and alcohol intake were sometimes perceived as potential causes of prostate cancer. Since smoking and alcohol are common risk factors for other types of cancer and a variety of other diseases, it appears reasonable that prostate cancer survivors link these factors to prostate cancer as well.

Factors with an unknown or unidentified effect on prostate cancer risk

Many of the suggested causes have shown inconsistent results in previous studies or have not yet been extensively studied in relation to prostate cancer. In parallel with the studies of Willcox et al.¹⁰ and others^{9,11,22}, stress and stress-related causes such as burnouts, depression and fatigue were reported by relatively many participants in our study. From either an epidemiological or biological perspective, the role of psychological stress in prostate cancer development has not been uniformly confirmed²³. The common hypothesis states that stress impairs the immune function, which in turn may increase susceptibility to malignancies²⁴. Although psychological stress has been previously associated with specific types of cancer in some²⁵⁻²⁷, but certainly not all (e.g.,²⁸) studies, only a few studies specifically examined the relationship between stress and prostate cancer risk^{29,30}. In our study, we cannot rule out the possibility that prostate cancer survivors perceived and reported high levels of stress as a consequence of their recent cancer diagnosis or treatment. Ideally, future prospective studies on psychological stress and prostate cancer risk should include both stressful life events and chronic stress as measures of stress, wherever possible supported by reliable biomarkers, and reflecting a relevant timing of exposure. Also infections

and inflammation have been specified as possible causes of prostate cancer by the prostate cancer survivors in our study. However, despite extensive research in this field, the exact role of inflammation in prostate carcinogenesis remains debatable³¹.

Limitations and strengths

The relatively small number of participants who provided a causal explanation should be considered in the interpretation of our findings. This small number, however, may also be a plausible indication of the current state of awareness among prostate cancer survivors. Furthermore, causal explanations of the participants might be biased by the design of the provided questionnaire. Since the question on the causes of prostate cancer was the final question, previous questions on exposures to chemicals, smoking, physical activity, sun exposure, baldness, medical history or family history might have influenced thoughts of the participants. However, we assume that addressing these topics in the questionnaire did not discourage the participants from reporting new and unique causes. In addition, among the reported causal factors, we did not observe a striking overrepresentation of the topics addressed in the questionnaire. The median time between diagnosis of prostate cancer and completion of the questionnaire was 26.9 months. We cannot rule out the possibility that prostate cancer survivors changed their perception during this period of time. Strengths of our study are the population-based design and the open-ended question format, which gave the participants the opportunity to provide their own answers, without being led by suggested causal relationships from a prompted list.

Conclusion

The results of this study show that most prostate cancer survivors were not aware of any causal factors that might have contributed to the development of their prostate cancer.

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Established risk factors for prostate cancer were not commonly perceived, not even among prostate cancer survivors with these risk factors. This finding might reflect the current state of knowledge on risk factors for prostate cancer and emphasises the need for development of effective education or prevention initiatives. Some of the common suggestions reported by the participants may warrant special attention in future studies, as there is still insufficient scientific evidence available for the possible role of these and many other factors in prostate carcinogenesis. Or as stated by one of the participants: *'I can mention some things here, but science does not know the answer itself.'*

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Abbreviations

BMI, body mass index; IQR, interquartile range; PSA, prostate-specific antigen.

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