



Original Research

Low awareness of risk factors among bladder cancer survivors: New evidence and a literature overview



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Abstract *Background:* Data on urinary bladder cancer (UBC) patients' perceptions about causes of bladder cancer is limited, while this may be important knowledge for health prevention and education. We evaluated self-reported perceptions and beliefs about the causes of bladder cancer among UBC survivors in the Netherlands.

Methods: UBC survivors identified through the Netherlands Cancer Registry from 2007 to 2012 were invited to participate. Patients who consented were asked to fill out a questionnaire, including questions on lifestyle characteristics, occupational and medical history, and family history of cancer. The final question was 'You have been diagnosed with bladder cancer. Do you have any idea what may have been the cause of your cancer?'.

Results: Of the 1793 UBC survivors included, 366 (20%) reported a possible cause for their bladder cancer. The most frequently reported suspected causes were smoking (10%), occupational exposure (5%), and heredity (2%). Smoking, occupational exposure and heredity were mentioned only slightly more frequently by participants with these risk factors (11%, 8%, and 5%, respectively) compared to the total population.

Conclusions: Most UBC survivors did not suspect any cause that might have contributed to the development of their cancer. Even among participants with established risk factors for bladder cancer, these risk factors were not commonly perceived. This finding probably reflects

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the superficial knowledge of risk factors for bladder cancer in the population and highlights the importance of effective education on cancer prevention.

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1. Introduction

Urinary bladder cancer (UBC) is the ninth most frequently diagnosed malignancy in the world [1]. Due to intensive follow-up and treatment, it has the highest lifetime treatment costs per patient of all cancers [2,3]. Cigarette smoking is the best-established risk factor in the development of UBC and is involved in the aetiology of approximately 50% of all cases [4,5]. Other risk factors associated with UBC are occupational exposure to carcinogens like aromatic amines and polycyclic aromatic hydrocarbons, chronic urinary tract infection, schistosomiasis infection, pelvic radiation, cyclophosphamide treatment, family history and specific low-penetrance germline genetic susceptibility [4]. Although some studies showed that fluid intake and fruit and vegetable consumption may also influence UBC risk, evidence is inconsistent [6–8].

Knowledge of what cancer survivors perceive as causes of their cancer may provide valuable information for health education and prevention initiatives, especially with regard to modifiable risk factors that are under the control of patients. Awareness of the association between such a risk factor and the disease can enhance the motivation to change it [9]. For example, patients' knowledge that tobacco use contributed to their disease can help in their motivation to quit smoking (and advise others to do the same). This information is important since risk factors for cancer development may also be associated with prognosis [10]. Continuation of smoking after diagnosis, for instance, may be related to higher rates of recurrence and increased risk of morbidity and mortality [11,12], although the literature on this topic is inconsistent [13].

Despite the importance of knowledge on this topic, the literature is sparse. Five previous studies suggested poor knowledge regarding smoking as a risk factor for UBC among urological [9,14] and, more specific, UBC [9,15–17] patients. In this study, we evaluated self-reported perceptions and beliefs about the causes of bladder cancer among UBC survivors in the Netherlands. We took a different approach from most of the previous studies and did not ask about knowledge of bladder cancer risk factors in general. Instead, we inquired about factors that might have led to the patients' own disease and investigated whether the answers differed according to their reported risk factors.

2. Materials and methods

Self-reported causes of bladder cancer were evaluated among Dutch UBC survivors. Data from the Nijmegen

Bladder Cancer Study (NBCS) were used [18]. The population consisted of men and women diagnosed with UBC in one of seven hospitals in the eastern part of the Netherlands between 1995 and 2011 and recruited for the study between 2007 and 2012. Participants had to be younger than 75 years at diagnosis. Patients were identified through the Netherlands Cancer Registry held by the Netherlands Comprehensive Cancer Organisation. All eligible UBC survivors received an invitation letter and information brochure. The information brochure highlighted the need for aetiological research into risk factors for UBC. Lifestyle factors (e.g. nutrition), smoking and heredity, were mentioned as established or probable risk factors for UBC in this information brochure. The response rate to the questionnaire was 65%. The questionnaire included questions on sociodemographic and lifestyle characteristics, physical activity, occupational history, medical history, use of medicines, and family history of cancer. The final question: 'You have been diagnosed with bladder 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 groups of risk factors (smoking, passive smoking, environmental and chemical exposure, occupational exposure, heredity, history of bladder polyps, bladder infections, other medical condition/intervention, medication, lifestyle, micturition/fluid intake, stress, treatment delay, don't know/other). Participants were allowed to give multiple answers to the final question. We also stratified the answers by smoking status, family history of UBC, and occupational exposure status to verify whether patients who were 'exposed' to these risk factors acknowledged these as potential causes. We further stratified for sex, age, education and marital status.

The institutional review board approved the NBCS and all participants provided written informed consent. The Statistical Package for Social Sciences (SPSS, version 20.0) was used to create the tables and compare groups using Pearson chi-square test. P-values less than 0.05 were considered statistically significant.

3. Results

In this study, 1793 UBC survivors were included and only 366 (20%) participants reported one or more possible causes for their cancer. Table 1 summarises the sociodemographic and clinical characteristics of the total study population and of patients who did and did not report a suspected cause, separately. The majority of

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