



Original Research

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



Ellen Westhoff^{a,1}, Julia Maria de Oliveira-Neumayer^{a,1},
Katja K. Aben^{a,b}, Alina Vrieling^{a,1}, Lambertus A. Kiemeny^{a,*,1}

^a Radboud University Medical Center, Radboud Institute for Health Sciences, P.O. Box 9101, 6500 HB Nijmegen, The Netherlands

^b Netherlands Comprehensive Cancer Organisation, Utrecht, The Netherlands

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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

* Corresponding author: P.O. Box 9101, 6500 HB Nijmegen, The Netherlands. Tel.: +31 24 3613745, +31 24 8186805; fax: +31 24 3613505.

E-mail addresses: Ellen.Westhoff@radboudumc.nl (E. Westhoff), Julia_Neumayer@hotmail.com (J. Maria de Oliveira-Neumayer), Katja.Aben@radboudumc.nl (K.K. Aben), Alina.Vrieling@radboudumc.nl (A. Vrieling), Bart.Kiemeny@radboudumc.nl (L.A. Kiemeny).

¹ These authors contributed equally.

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

the participants was male ($n = 1448$, 81%) and the median age at the completion of the questionnaire was 68 years (interquartile range: 61–74 years). Most of the participants were married ($n = 1439$; 80%) and had a low educational level ($n = 1388$; 77%). Almost two-thirds of the participants were former smokers

Table 1

Sociodemographic and clinical characteristics of Dutch bladder cancer survivors included in the study.

	All bladder cancer survivors (N = 1793)	Participants who reported a suspected cause (N = 366)	Participants who did not report a suspected cause (N = 1427)
Age at diagnosis (years) ^a	63 (56–70)	60 (53–66)	64 (57–70)
Age at completion of questionnaire (years) ^a	68 (61–74)	64 (58–71)	69 (62–74)
Time between diagnosis and completion of questionnaire (years) ^a	2 (1–6)	3 (1–7)	2 (1–6)
Body mass index (kg/m ²) ^{a,b}	25.3 (23.7–27.2)	24.7 (23.2–26.3)	25.4 (23.8–27.5)
Gender			
Female	345 (19%)	78 (21%)	267 (19%)
Male	1448 (81%)	288 (79%)	1160 (81%)
Marital status (%)			
Married	1439 (80%)	290 (79%)	1149 (81%)
Living alone	274 (15%)	51 (14%)	223 (16%)
Living together ^c	80 (5%)	25 (7%)	55 (4%)
Educational level (%) ^d			
Low	1388 (77%)	244 (67%)	1144 (80%)
High	391 (22%)	117 (32%)	274 (19%)
Unknown	14 (1%)	5 (1%)	9 (1%)
Currently employed (%)			
Yes	387 (22 %)	115 (31%)	272 (19%)
No	1406 (78%)	251 (69%)	1155 (81%)
Smoking status ^e			
Never smoked	211 (12%)	44 (12%)	167 (12%)
Former smoker	1164 (65%)	254 (69%)	910 (64%)
Current smoker	417 (23%)	68 (19%)	349 (24%)
Occupational exposure ^f (%)			
Yes	963 (54%)	223 (61%)	740 (52%)
No	830 (46%)	143 (39%)	687 (48%)
Positive family history of bladder cancer ^g (%)	103 (6%)	24 (7%)	79 (6%)

^a Median and interquartile range.

^b Self-reported average body mass index (kg/m²) during adult life.

^c Cohabiting or living with children.

^d Low (primary education, secondary education and vocational education), high (university and university of applied sciences) or unknown.

^e At the time of filling out the questionnaire

^f Based on questions regarding regular, current or past exposure to chemicals, radiation, and vapours/gases.

^g At least one reported first-degree family member with UBC.

($n = 1164$; 65%), 23% ($n = 417$) were current smokers and 12% ($n = 211$) never smoked. Self-reported positive family history of UBC was present in 6% ($n = 103$) and 963 (54%) reported occupational exposure. Comparing participants who did and did not report a causal explanation, those with a causal explanation were younger (median age 64 versus 69 years) and more likely to have a high educational level (32% versus 19%). Also, those who reported a causal explanation were more likely to have had occupational exposure (61% versus 52%).

Table 2 summarises the categories of causal explanations among the ‘total’ study population. Smoking ($n = 184$; 10%), occupational exposure ($n = 85$; 5%) and heredity ($n = 29$; 2%) were the three most reported causal explanations among all participants. Environmental and chemical exposure was cited by 2% ($n = 28$) and stress, other medical condition/intervention, medication, lifestyle and micturition/fluid intake were each mentioned by approximately 1% of the participants. Medical condition/intervention comprises answers such as ‘The bladder tumours are caused by tumour in one kidney’, ‘Late-effects of radiotherapy for rectal cancer?’. Lifestyle encompassed answers related to alcohol and food intake as well as physical activity (e.g. ‘overuse of coffee’, regular alcohol user/often chips eater’, ‘lack of exercise’). Other causes that were reported by 0.6% or less of the participants are passive smoking, bladder infections, history of polyps, treatment delay, and don’t know/other. The category don’t know/other contained a variety of answers that could not be placed in other categories, e.g. ‘coincidence’, ‘burns accident at age 3.5’ and answers of participants that they did not understand

Table 2

Categories of perceived causes of bladder cancer among all included Dutch bladder cancer survivors and among those who reported a suspected cause.

Total of participants	No. giving explanation	% of all participants (n = 1793)	% of participants who reported a suspected cause (n = 366)
Smoking	184	10%	50%
Occupational exposure	85	5%	23%
Heredity	29	2%	8%
Stress	26	1%	7%
Bladder infections	8	0.4%	2%
History of polyps	4	0.2%	1%
Environmental and chemical exposure	28	2%	7%
Medication	22	1%	6%
Other medical condition/intervention	25	1%	7%
Lifestyle	22	1%	6%
Micturition/fluid intake	20	1%	6%
Passive smoking	9	0.5%	3%
Don’t know/other	11	0.6%	3%
Treatment delay	3	0.2%	1%

what caused their disease since they lived a healthy life. All answers are included in [Appendix I](#).

Table 3 summarises the three most cited categories of causal explanations among the total study population, stratified by smoking status, family history of UBC and occupational exposure. Former smokers seemed slightly more likely to suggest smoking (143 of 1164; 12%) as a cause than current smokers (41 of 417; 10%) ($p = 0.18$). Among all participants who had occupational exposure ($n = 963$), 83 participants (9%) reported occupational exposure as a cause of their disease. Two participants who reported occupational exposure did not have any occupational exposure according to the questionnaire. Lastly, participants with a positive family history for UBC were more likely to mention heredity as a causal explanation (5 of 103; 5%) compared to participants with a negative family history (24 of 1690; 1%) ($p = 0.02$). We also stratified these causal explanations by sex, age (≤ 67 versus ≥ 68), education and marital status (data not shown, all p -values < 0.05). Smoking was more often mentioned as a possible cause by younger participants, higher educated participants, and by participants who were living together. Occupational exposure was more frequently mentioned by men and younger participants and heredity by higher educated participants.

Table 4 presents examples of reported causes divided into three categories: ‘established risk factors for bladder cancer’, ‘unknown or unidentified effect on bladder cancer risk’ and ‘unlikely to have an effect on bladder cancer risk’.

4. Discussion

In this study, we evaluated self-reported causes of bladder cancer among UBC survivors. Only 20% reported at least one causal explanation for their cancer. The most common causal explanations reported among all participants were smoking (10%), occupational

Table 4

Selection of examples of perceived causes of bladder cancer of Dutch bladder cancer survivors.

Perceived causes	Examples of perceived causes given by the participants
Established or probable risk factors for bladder cancer	<p>Smoking</p> <p>According to physician due to smoking</p> <p>Genetically determined</p> <p>I think because of many bladder infections</p> <p>Pipe smoking</p> <p>Late-effects of radiotherapy for rectal cancer</p> <p>Worked with paint for car spraying for 32 years</p> <p>Paint spraying</p> <p>Industrial fabrics</p> <p>exhaust fumes, maybe paints/dyes</p> <p>During my work in the clothing industry, I came into contact with chemical washing products</p> <p>Bad luck</p> <p>Coincidence</p> <p>Because of prolonged use of first an indwelling catheter and then a suprapubic catheter</p>
Unknown or unidentified effect on bladder cancer risk	<p>Hair dye; working with pesticides</p> <p>Working with silkscreen printers, cleaning products, thinners/ink</p> <p>Cleaning up asbestos</p> <p>Lots of contact with asbestos</p> <p>As a child exposed to “passive smoking” a lot</p> <p>Use of immunosuppressive medication</p> <p>Use of hormones for half a year during menopause transition</p> <p>Stress</p> <p>Use of Selsun shampoo against head lice</p> <p>Used to prepare ties unprotected</p> <p>Worked in roofing</p> <p>Perhaps holding in urine for too long</p> <p>Fears/anxieties</p> <p>Benign polyp</p> <p>Little drinking and urination</p> <p>Prolonged use of medication against bladder spasms</p> <p>As a painter, worked extensively with dilutions especially methylene</p> <p>Laboratory work with the use of many kinds of solvents, e.g. benzene, chloroform, acetone, etc.</p> <p>Spend a lot of time in traffic (20 years)</p> <p>Frequent antibiotics due to inflammations</p> <p>Lifestyle nutrition related</p> <p>Food</p> <p>Often French fries eater</p> <p>Can the chickenpox virus have had an effect?</p>
Unlikely to have an effect on bladder cancer risk	<p>Damage of urethra after prostate surgery</p> <p>Coffee</p> <p>Sedatives (Diazepam)</p> <p>Always worked in a cooling compartment</p> <p>Heart surgery Geneva, where inner penis was damaged. Thereafter several surgeries on penis</p> <p>Too much erythrocytes/proteins in urine</p> <p>Sunburn</p> <p>Drank a lot of diet sodas with aspartame</p> <p>Sweeteners</p>

Table 3

Perceived established causes of bladder cancer among Dutch bladder cancer survivors stratified by presence of these causes.

Stratification	Total number of participants	Participants giving the risk factor as a causal explanation (%)
Smoking	1792	184 (10%)
Never	211	0 (0%)
Former	1164	143 (12%)
Current	417	41 (10%)
Occupational exposure	1793	85 (5%)
Yes	963	83 (9%)
No	830	2 (0.2%)
Family history of bladder cancer	1793	29 (2%)
Positive	103	5 (5%)
Negative	1690	24 (1%)

exposure (5%) and heredity (2%), all established risk factors for UBC. Most patients who were exposed to these risk factors failed to report these factors as potential causes of their disease. This is even more striking given the fact that these risk factors were named in the invitation brochure as established risk factors.

Five studies investigated awareness of smoking as a risk factor for UBC among urological [9,14] and UBC [9,15–17] patients (Table 5). All studies used a closed question and asked about bladder cancer in general, except for one study [16], that only asked about the patient's own disease. Two studies [9,15] additionally asked about beliefs regarding their own bladder cancer. In a study with 280 urological patients [14], the participants were asked to indicate whether smoking, as well as other factors, increased the risk of UBC. Only 36% reported smoking as a risk factor for UBC. In a study with 202 urological patients [9], 118 (58%) of them were aware of the relation between smoking and bladder cancer, and 22 of 39 (56%) of currently smoking UBC patients believed that smoking was related to their disease. In both studies, no difference by smoking status of the patients was observed. Three studies were conducted exclusively among UBC patients [15–17]. In a study with 78 participants, 12 of 55 ever smokers (22%) were aware of smoking as a risk factor for their disease [16]. A study with 71 participants reported that 85% was aware of smoking as a risk factor for UBC [17]. Lastly, a larger study ($n = 790$) showed that 68% of the patients cited tobacco use as a risk factor for UBC in general (90%, 64% and 61% for current, former, and never smokers, respectively) [15]. Regarding perceived causes of their own disease, tobacco was mentioned by 84% of the current smokers, 48% of the former smokers, and 8% of the never smokers. In our study, we found that a strikingly low percentage of both former and current smokers reported smoking as a causal explanation for their own cancer (12% versus 9%, respectively). This suggests that the association between smoking and bladder cancer is largely unknown. The open-ended format of the question used in our study might have played a role, as well as the choice of answering 'no', possibly giving participants an easy opportunity to avoid thinking about an explanation. Furthermore, ignoring risk factors that might have been within the patients' control may be a strategy to shield themselves against negative emotions, such as self-blame [19].

To date, only two studies examined perceived causes of UBC among urological or UBC patients covering causal explanations other than tobacco [14,15]. Unfortunately, one of these studies did not report these results [14]. In the other study [15], tobacco was the most cited risk factor (68%), followed by chemicals (54%) and age (45%). In our study, only 7% of all participants believed chemical or occupational exposure might have caused their disease, and a mere 8% of occupationally exposed participants mentioned this as a cause, even though

certain types of occupational exposure are established risk factors. Surprisingly, none of our participants mentioned ageing even though this is an established risk factor for cancer in general [20,21]. An explanation may be that only patients younger than 75 were recruited. The large difference with the Basset study [15] might be explained by the type of question used (true/false question as opposed to our open question) or the level of education (higher educated as opposed to the low educational level of our study population). Ageing has been reported to be an unknown risk factor in patients with other types of cancer as well, e.g. in only 2 of 22 studies on breast cancer participants mentioned age as a risk factor [22].

With 2%, heredity was the third most cited explanation, indicating that the role of genetics in bladder cancer aetiology is not very well known among UBC survivors either. As expected, the percentage of participants who reported heredity was higher among survivors with a positive family history (5%) compared with participants with a negative family history (1%). Still, 5% is almost negligible. In a similar study that we performed among patients with prostate cancer, the percentage of patients with a positive family history mentioned heredity was four times higher (19%). In a study that described survivors' beliefs about the causes of prostate, colorectal and breast cancer, in general, awareness of heredity was much higher than in our study (>75%) [10]. This might be explained by the role of heredity in these types of cancer being more generally known but, again, also by the use of a true/false instead of open question.

For some of the causes mentioned by the participants, there is no or inconsistent evidence for an association with UBC or an association is unlikely (Table 4). An explanation for this might be that the mentioned cause is a well-known risk factor for other cancers or is frequently suggested to be a risk factor for cancer by the media, leading patients to believe that there is a link with UBC as well. This was also found by previous studies on other cancers [10,23–25]. It may be important to proactively address the lack of evidence for these factors as certain beliefs may prevent patients from changing real-risk behaviours [23].

Even though a strikingly low percentage of our participants mentioned a possible cause for their UBC, this is not an unusual finding. In a systematic review on perceived causes of breast cancer among breast cancer survivors [22], the percentage of perceived causes mentioned in the different studies varied greatly, even for well-established risk factors. For example, heredity was reported as possible cause by only 4% in one study, while 71% cited it in another study. Comparing two studies on melanoma also reveals a large difference in perceived causes [23,26]. One study [26] found that only about one-third of the participants thought sun exposure could have caused their melanoma, while in the other study [23] 80% mentioned this as a possible cause.

Table 5

Overview of literature on perceived causes of bladder cancer in urological and bladder cancer patients.

Author (year), country	Study sample	Bladder cancer in general or own cancer	Open or closed question	Question ^a	Main results
Dearing (2005), United Kingdom	55 Smoking non-muscle invasive bladder cancer patients, year(s) of diagnosis unknown	Own bladder cancer	Closed	Are you aware of smoking as a risk factor for development of your disease? Are you aware that continued smoking could worsen prognosis?	Answered yes: 22% 13%
Nieder (2006), USA	280 Urological patients presenting in the clinic in 2005	Bladder cancer in general	Closed	Which of the following factors can increase the risk of bladder cancer? Increasing age, a high fat diet, a low fibre diet, smoking, family history, multiple sex partners, none of these factors and do not know.	Perceived smoking as a risk factor: bladder: 36%
Anastasiou (2010), Greece	202 urological patients of whom 39 currently smoking bladder cancer patients, year(s) of diagnosis unknown	Total population: bladder cancer in general Smokers: own bladder cancer	Closed	All patients: Are you aware of relation between smoking and... ... bladder cancer? Smoking bladder cancer patients: Do you believe smoking is related to your present problem?	Answered yes: 55% 56%
Guzzo (2012), USA	71 Bladder cancer patients diagnosed 2008–2009	Bladder cancer in general	Closed	Smoking is risk factor for bladder cancer. Smoking is leading cause of bladder cancer in the USA.	Answered true: 85% 51%
Bassett (2014), USA	790 Non-muscle invasive bladder cancer patients diagnosed 2006–2009	Bladder cancer in general and own bladder cancer	Closed	Based on what you know or believe, can any of the following cause bladder cancer in anyone?	Answered yes ^b : Tobacco use: 68% Chemicals: 54% Age: 45% Alcohol: 25% Holding urine: 20% Sexual activity: 12%
Current study, The Netherlands	1793 Bladder cancer patients diagnosed 1995–2011	Own bladder cancer	Open	Based on what you know or believe, did any of the following cause your bladder cancer? You have been diagnosed with bladder cancer. Do you have any idea what may have been the cause of your cancer?	Answered yes to tobacco use ^{b,c} : Active smokers: 93% Former smokers: 48% Never smokers: 8% Smoking: 10% Occupational exposure: 5% Heredity: 2% Environmental and chemical exposure: 2% Stress: 1% Medication: 1% Other medical condition/intervention: 1% Lifestyle: 1% Micturition/fluid intake: 1%

USA, United States of America.

^a When exact question was not specified in the article, we formulated a question as accurately as possible based on the information provided.^b Answer options for both questions: age, family history, alcohol, diet, tobacco use, ‘holding’ urine, chemical exposure, bladder infections or stones, and sexually transmitted diseases. No information available for risk factors not mentioned in the table.^c Information only available stratified for smoking status (never, former, and active).

These differences in knowledge may be partly explained by factors, such as age, education and country of origin.

In conclusion, the results of this study show that most UBC survivors were not aware of any causal explanation for the development of their cancer. Even among participants with established risk factors for bladder cancer, these established risk factors were not commonly perceived. This finding might reflect the superficial knowledge on risk factors for bladder cancer in the population and highlights the importance of effective education on bladder cancer risk factors.

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Conflict of interest statement

None declared.

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Appendix I. Perceived causes of bladder cancer reported by Dutch bladder cancer survivors.

Categories of perceived causes	Participants' answers
Smoking	'Smoking', 'According to physician due to smoking', 'Smoking according to my urologist', 'Probably because of smoking', 'According to specialist smoking is one of the causes', 'Doctor claims that smoking could be a cause or at least an important contribution', 'According to the doctor: smoking', 'I think smoking', 'Could be smoking', 'According to my urologist smoking is the primary cause of my mouth disease in 1981 and the bladder polyps in 1994', 'People say because of smoking', 'At the time I smoked ± 20 cigarettes per day', 'Much smoking', 'According to the urologist, smoking might be a cause', 'My wife thinks smoking', 'My smoking behavior', 'Smoked lots of cigarettes', 'Possibly smoking', 'Perhaps smoking behavior', 'Perhaps due to smoking', 'No certainty, but sometimes I suspected an association with smoking home-grown cannabis', 'Cigar / pipe smoking. Did this intensively for many years before the bladder tumour was discovered', 'Smoking in the past', 'Smoking? Haven't smoked much in my younger years, from about the age of 40 to 59 I smoked 1 pack per day. Two weeks before my retirement in 1993 I quit and never smoked again', 'Perhaps smoking', 'Smoking, 9 per day', 'It turns out smoking can be a cause', 'In hindsight my smoking can be a possible cause', 'Smoking can be a cause', 'Smoking is also a cause', 'Not sure, might be smoking', 'According to people in Radboudumc: smoking?', 'Prolonged smoking', 'It is said smoking', 'Probably a lot of smoking', 'According to the doctors it is because of smoking', 'Smoked for too long and too much in my life', 'Maybe smoking?', 'Smoking for about 20 years', 'Too much smoking', 'Pipe smoking causing tar juice to be swallowed (frequently)', 'I suspect by smoking', 'Of course, smoking behavior', 'Presumably smoking', 'Possible contamination of smoking', 'Smoked profusely for 38 years', 'Used to smoke firmly for 26 years', 'Smoked from the age of 16 to 51', 'Long-term smoking', 'Smoked in early childhood', 'Smoking at a younger age'.
Occupational exposure	'At NV Philips we worked with various pollutants like Clophen (hydrochloric), araldiethardens, various solvents', 'Employment history', 'Working with highly toxic substances', 'During my work in the clothing industry, I came into contact with chemical washing products', 'During study (chemistry) and work (paint industry) certain chemicals that I have been in contact with can be the cause', 'Worked with textiles?', 'Worked a lot with arsenic, selenium and iodine at the factory', 'Work was not always clean, probably due to my work activities', 'Working with chemicals', 'Working with Bison Kit (glue)', 'Work', 'Working with Bison Kit (glue)', 'Have worked a lot with harmful substances (glue, etc.)', 'As a painter, worked extensively with dilutions especially methylene', 'Perhaps working with asbestos', 'Very carelessly handling photo chemicals', 'Washing hands with benzene (in 1954) + pesticides (1960)', 'Work at the plant nursery, worked a lot with pesticides without protective measures', 'Lots of contact with asbestos', 'Worked many years (± 20) as a project manager in mostly aluminium processing industries (aluminium melting furnaces) and ceramic and metal hardening furnaces', 'My work with toxic substances. Carelessly handling these substances for more than 35 years', 'Worked a lot with unhealthy stuff', 'Welding fumes and metal vapours, lead poisoning', 'Possible contamination due to chemicals during laboratory work', 'Occupation as painter maintenance', 'Worked with photocopier, suffered a lot especially from coughing', 'Cleaning air handling units, working with diesel due to cleaning oil boilers, working with detergents', 'Paints, turpentine, paint thinners, paint removers used as a painter', 'I think the reason for this lies in the period of 1981–1985 (work)', 'During the period (1955–1967) I worked in a graphics company and worked a lot with printing inks stained-solvents such as gasoline, diesel and kerosene', 'Smoking solvents. I spent 15 years on average 8 hours per month making prints in a poorly ventilated area', 'The use of pesticides', 'During home furnishing I worked with Novilon carpet. Which contained asbestos and the handling of glue', 'At the age of 16, worked near a paint shop for 6 months.', 'Occupational disease through work', 'Due to autogenous and electric welding work, not the right safety measurements taken (unsafe, low ventilation)', 'Because of

(continued)

Categories of perceived causes	Participants' answers
	my job, daily contact with fuels and auto gas', 'Always worked in a cooling compartment', 'Preparations cytostatic for chemotherapy', 'Use of toxic substances', 'Using gun oil PX10 during period 1965–1995', 'Exposed to trichloroethylene, fine asbestos dust, many other solvents', 'Working with silkscreens printers, cleaning products, thinners/ink', 'Roofing/roof covering', 'Processed asbestos. Sawing in the years 1969–1970. Shielding heaters', 'Preparation and distributing cytostatic', 'Maybe paints/dyes', 'Worked with paint for car spraying for 32 years', 'Worked with hazardous substances (Argon, Eldrin etc.)', 'The use of pesticides', 'Working with pesticides', 'Suggested that this may be related to exposure to chemicals in the laboratory (formaldehyde, etc.). Two colleagues at the lab have been diagnosed with bladder cancer', 'Paint (painting)', 'Radiation, used to prepare cytostatic unprotected', 'Worked with epoxy resin, Perspex adhesives, processing Perspex, solvents (thinner, toluene, turpentine), polystyrene, acrylic', 'Spraying cars without proper protection', 'Paint spraying (lacquer)', 'Handling X-rays in my profession, handling chloralactofinol in my profession', 'Worked in a laboratory from the age of 16 to 26', 'Working with asbestos (which was formerly used in brake lining)', 'Perhaps dyes/colorants (painter)', 'Pesticides or disinfectants', 'Use of spray bottle when ironing', 'Inhaling solvents for ink', 'Chemicals during work', 'Plastic processing vapours (styrene)', 'Working with photo processing chemicals, inhalation of lead-containing substances/gases during the firing of ammo', 'Printing', 'Asbestos', 'Due to profession', 'Chemicals due to spraying and welding', 'Temporarily handling photographic chemicals in poorly ventilated areas', 'Worked with some regularity with duplicator during the job', 'Carelessly working with chemicals', 'Uranium in mission area', 'Prolonged contact with printing inks, adhesives bookbinding', 'Inhaled formaldehyde vapors for 8 years?', 'Electromagnetic radiation (radar equipment)', 'Laboratory work with the use of many kinds of solvents, eg. Benzene, chloroform, acetone etc', 'Work', 'Cleaning up asbestos', 'Paint chemistry (components), industrial fabrics', 'Exposure to hazardous substances', 'Possible cause that I do not rule out: sanding plate with asbestos', 'Welding fumes', 'Laboratory activities'.
Passive smoking	'As a child exposed to "passive smoking" a lot', 'Second-hand smoking, when staying in smoky environments (frequently) it seems that the polyps come back', 'Second-hand smoking for many years', 'During work I was always surrounded by smokers, even after I had quit myself', 'Second-hand smoking', 'Always smoked passively', 'Father was a smoker. Been exposed to smoke a lot via passive smoking', 'Passive smoking in the office', 'Smoked passively for 20 years'.
Environmental and chemical exposure	'Nuclear testing in the years 1945–1980 and spraying pesticides', 'Used to go swimming frequently in the IJsselmeer near iron foundry, a lot of iron in water', 'Chernobyl (radiation), cows had to go inside, was not necessary for us and our children. Or pesticides', 'I have lived on the site of a paint factory from birth until the age of 16', 'Perhaps zinc plant in Budel?', 'I lived in a house at the Schaapsdrift in Arnhem for 36 years. The soil or ground water was contaminated', 'Lived in Heveadorp from birth till the age of 21. We lived near a rubber factory, where I used to play as a child', 'Is drinking water not the cause?', 'Exhaust fumes', 'Exhaust and gasoline fumes', 'Cycled to and from work for 20 years (14 km there and 14 km back) along cars, traffic jams and industrial areas (AKZO, BASF, Billiton). Used extra effort right at the place that contained a lot of harmful dust', 'Air pollution, environmental pollution', 'Prolonged exposure to exhaust fumes', 'Asphalt plant in the immediate surroundings', 'Inhaled fireplace fumes for 20 years', 'Exhaust fumes', 'Particulate matter (highway/power plant)', 'Motor/air pollution in Hong Kong. I have lived in Hong Kong for four years', 'The use of chemicals in food such as growth hormones, etc', 'Possibly: have been drinking water (during sports) from a disposable plastic bottle, which was melted in the sauna, for a long time (year)', 'Chemical stuff', 'Chemicals', 'Chemicals darkroom', 'Hair dye (hairdresser denied this)', 'Used cyanide acrylate (superglue) for nails regularly for 30 years'.
Heredity	'Presumably hereditary predisposition; my father died of acute renal failure', 'Genetically determined', 'Heredity, my father had them', 'Grandpa and uncle?', 'My father also had bladder polyps, but my siblings don't', 'Maybe because of the genes (maternal)', 'Possible hereditary', 'Hereditary', 'During the war father in hospital because of bladder. Paternal aunt diagnosed with polyp at age 60 and lived till the age 85. They all used to work in the textile industry. Hereditary?', 'Perhaps inherited father's side?', 'Hereditary, paternal side', 'Hereditary, father and mother', 'Possibly hereditary', 'According to the urologist I was born with it', 'Runs in the family', 'Hereditary: father had stoma because of bladder cancer (deceased from lung cancer)', 'Hereditary defects in DNA', 'Maternal side', 'It runs in the family (grandfather and second cousin)', 'Genetic determination can also be the cause', 'Gene defect', 'Hereditary factors'.
Other medical condition/intervention	'First kidney and everything that goes with it, and two years later bladder tumour', '1997 first symptoms, physician found no passage from urethra to bladder. Had to wait? 2001 severe bladder bleeding, surgery, cancer (specialist)', 'Heart surgery Geneva, where inner penis was damaged. Thereafter several surgeries on penis', 'Too much erythrocytes/proteins in urine. Had regular kidney tests from the age of 15', 'Because of prolonged use of first an indwelling catheter and then a suprapubic catheter', 'Dauer catheter (DC)', 'The bladder tumours are caused by tumour in one kidney', 'Diagnosed with cancer of stomach/liver in 1989, by removing the left lobe of the liver, the liver may not be working properly, causing polyps to arise?', 'Damage of urethra after prostate surgery', 'Sensitive membranes?', 'Can the chickenpox virus have had an effect?', 'Kidney cancer?', 'Malignant tumor', 'Maybe because I've had prostate cancer. And after two years 28 radiation treatments', 'Late-effects of radiotherapy for rectal cancer?', 'Violence from the outside on the bladder', 'The residue of my rotten gallbladder', 'Because of large prostate', 'Worm disease associated with living in very primitive conditions', 'Malignant tumor', 'Radiation', 'In 2005, 2/3 of the stomach removed due to malignant cancer. According to Dr. at Radboudumc, where I was still under treatment at that time, this is not the cause for the bladder cancer', 'I always had to squeeze urine out, perhaps I never emptied my bladder sufficiently'.

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Categories of perceived causes	Participants' answers
History of polyps	Benign polyp', 'Benign polyp (August 2007)', 'Polyps in the bladder', 'Bladder polyp'.
Bladder infections	'Maybe because of the many bladder infections', 'I think because of many bladder infections', 'I think because of the bladder infections', 'Already had bladder problems (bladder inflammation) as a child', 'Neglect of urinary tract infection', 'Had ± 25 bladder infections', 'Prolonged bladder infections after returning from the tropics'.
Medication	'Used Resdan tar shampoo for 10 years until it became known that it can be carcinogenic', 'Had tuberculosis, used the drug PAS for two years', 'Prolonged use of "temporarily allowed" medication to relax the bladder', 'Medications?', 'Because of the drug Endoxan', 'Used Endoxan daily because of MS (1980–1982)', 'I always had the Yttrium injection into the knee as a possible cause in mind. Just a presumption. Further no idea', 'Due to my urologist I got the idea that it can come from the use of malaria pills', 'The use of acenocoumarol', 'Resistance reduced by using means (Prograf) against organ rejection', 'Medication use?', 'I might be DES-daughter', 'Use of Selsun shampoo against head lice?', 'Sedatives (Diazepam) since 1970', 'Medications for blood pressure', 'Used 50 mg of Oxazepam daily for ± 12 years', 'Prolonged use of Denorex R shampoo', 'Medications', 'The use of hormones for half a year during menopause transition', 'Frequent antibiotics due to inflammations', 'Too often antibiotics from GP'.
Lifestyle	'Overuse of coffee', 'In 2002, I used a diet, Super Energy Method without carbs, low fat and high in protein', 'Possibly because of a too limited and too monotonous diet during the war years (1940–1945)', 'Used artificial sweeteners (1975–1979)', 'Lifestyle nutrition-related', 'Regular alcohol user, regular/often chips eater', 'Excessive drinking for a certain period of time', 'Alcoholic beverage', 'Coffee', 'Perhaps biking too much because of commuting', 'Possible contamination of alcohol', 'Not being conscious about your health and healthy lifestyle namely exercise etc', 'Drinking, lack of exercise', 'Sweeteners? Final years before tumor daily drinking of Amstel beer', 'Drank a lot of diet sodas with aspartame', 'Food', 'Alcohol', 'Drinking', 'Overeating', 'Lifestyle'.
Micturition/fluid intake	'Having to hold in urine for prolonged periods of time due to profession', 'Perhaps holding in urine for too long', 'Probably failed to empty bladder often enough', 'During my profession as a truck driver often held off going to the bathroom. I have the idea that that has something to do with it', 'Did not urinate on time', 'Insufficient drinking in the past', 'Probably drinking insufficient water?', 'Take too little fluid', 'Little drinking and urination (long residence time of tar in the bladder', 'Drinking insufficient water', 'Not drinking enough', 'Not enough drinking/concentrated urine', 'Driving 65,000 to 80,000 km per year', 'Insufficient drinking', 'Drinking alcohol in the evening and not urinating at night', 'Driven for more than 1 million kilometers', 'Drinking relatively little, years of living and working in Malaysia (warm climate and little drinking)', 'Spend a lot of time in traffic (20 years) commuting between Leiderdorp and Amstelveen (passing Schiphol)'.
Stress	'Stress', 'Stress, living in Neerbosch-Oost', 'Stress, "a bad disease"', 'With some hesitation I note that a lot of stress and responsibilities could have had an influence', 'Fears/anxieties', 'Stress, uncertain future?', 'When prisoner of war haemorrhage occurred (in feces/urine). Construction Sumatra Airport dragging trunks, earthwork, forest work', 'Can stress be a cause? It happened 4 months after my husband passed away', 'Stress after son getting cancer in 2005 and wife in 2006', 'Survivor guilt', 'Lots of stress', 'Psychosocial factors that we still know little about', 'Worked nightshifts every week. Disruption biorhythm/melatonin deficiency', 'Due to intensively taking care of my husband. An illness of nearly three years (cancer). First bleeding on the day of the funeral', '40 years of living under severe tension', 'Stress and overloaded?', 'Too much work', 'Years of stress due to conflict with boss (since 2000)', 'Less relaxation', 'Very heavy childhood trauma (rape) must also have something to do with it'.
Treatment delay	'Waited too long to visit GP', 'GP should referred me sooner',
Don't know/other	'I live a very healthy lifestyle and cannot understand that I have it', 'Did not smoke, drank very little alcohol, still got cancer', 'Coincidence', 'Bad luck', 'Burns accident at the age of 3,5', 'Sunburn'.

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