In their own words: A narrative analysis of illness memoirs written by men with prostate cancer

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Abstract
By drawing on a narrative analysis of 11 autobiographical illness memoirs, this article investigates the complexities of what it means to live with prostate cancer over a period of time. Acknowledging how cancer disrupts everyday life, we focus on the day-to-day experiences and struggles that take place inside and outside the hospital. By building on illustrative quotes from the memoirs, we discuss different facets of cancer as a lived experience. Our findings show that men reconstruct their identity in the memoirs in response to the disruptive nature of cancer by including various identities from previous times. They describe a relationship with their cancer that is fluid and fitful and often depends on place, time and circumstances. We also found that the ‘not knowing’ of prostate cancer creates uncertainty, which can take different forms, transcends time and is shaped through medical technologies, continual testing and disagreeing doctors. Prostate cancer is often seen as easily treatable, but our findings call for a different way of looking at its impact. We argue that memoirs, written by men themselves, make it palpable what it means to...
Among men, prostate cancer is the second most common cancer worldwide (Barsouk et al., 2020; Nanton et al., 2009). Depending on the stage of diagnosis, which can be diagnosed with the help of diagnostic biomarkers (e.g. PSA test) or a digital rectal examination and biopsy, men have to decide on treatment, such as active surveillance, prostatectomy (possibly robot-assisted with the da Vinci Surgical System) and hormone, radionuclide, radio- or chemotherapy (Barsouk et al., 2020; Hedden, 2018; Nanton et al., 2009; Yates et al., 2011). Research already showed that treatment is associated with mental and physical health effects, such as incontinence and impotence, requiring among others new care relations between men and their partners. Moreover, as pointed out by Broom (2004), Oliffe (2009) and Schultze et al. (2020) prostate cancer causes many men to search for what it means to be a man as they are confronted with feelings of embarrassment, loss of manhood and affected sense of masculinity (Chapple & Ziebland, 2002; Ettridge, 2017; Oliffe, 2009). Up till now, the mental and physical health effects experienced by men with prostate cancer are primarily investigated via questionnaires or single interviews, which only provide a picture of the situation at a fixed moment in time (e.g. Korfage, 2006; Wittmann, 2014). These studies, although worthwhile, do not cover the temporal dimensions of living with prostate cancer over time, nor do they shed light on everyday experiences including its ambiguities. Due to often enduring diagnostic and treatment trajectories, men live in an ongoing haze of uncertainty, anxiety and stress (Barsouk et al., 2020; Nanton et al., 2009; Pietilä et al., 2018). Moreover, as part of their diagnostic and treatment trajectory, men also have to continuously rearrange daily activities and plans to attend hospital appointments and undergo treatment. As such, we argue in line with Bury (2001), prostate cancer can be a ‘major instance of “biographical disruption” in which the relations between body, mind and everyday life are threatened’ and call for repair (264). To better understand how men experience the diagnostic and treatment trajectory of prostate cancer over a longer period of time, we turn to unsolicited voices of men themselves as written down in book-length illness autobiographies. As autobiographies are written over time, they can show how the present changes every day, including differences in experiences, feelings and thoughts (Bell, 1998; Meth, 2003).

As Bury (2001) argues, ‘narratives take many forms, have many uses and serves many purposes’ (282). Writing about illness can benefit patients who are searching for explanations and a new shape to their lives (Frank, 2017; Jurecic, 2012; Kenny et al., 2017). Bury (2001) illustrates how patient narratives ‘are means by which the link between body, self and society are articulated’ (281). Patients narrate, for example, how a disease affects their ability to work as well as how a disease influences their relationships and conversations with family members. Patients can describe how, for instance, clinical explanations of disease, such as test results or medical consultations, are experienced by them (Bury, 2001). Moreover, Kenny et al. (2017)
showed that living with cancer consists of multiple yet contradictory experiences, for example simultaneously experiencing fear and hope, and autobiographies as such can account for these ambiguities. Historically, illness autobiographies had different functions and effects in society. For example, autobiographies were written as counter-narratives to dominant biomedical explanations (Riessman, 2015; Frank, 2013: 39–41). The emergence of illness narratives is a fascinating biosocial moment, since the combination of medical knowledge and someone’s experiences creates a way for people living with illness to find support and information and connect to peers (Stage et al., 2020). Since we have analysed different types of illness autobiographies, which we will comment on further in the methods section, we will use the term ‘illness memoir’ in this paper. By focusing on illness memoirs, we extend the literature on the mental and physical effects of prostate cancer by directing attention to unsolicited stories written by patients themselves. Inquiry in these stories, as we will argue, makes it palpable what it means to live with cancer, and as such enhances our sociological understanding of cancer-as-lived experience.

**Illness narratives, biographical disruption and temporality**

The concept of time plays an important role in the lives of people living with cancer. To inquire into longitudinal experiences of men living with prostate cancer, we particularly build upon the work of Bury (1982, 2001) regarding biographical disruption and the analytical framework for waiting, haunting and temporality proposed by Broom et al. (2018).

In 1982, Bury reported how illness causes biographical disruption by breaking up the structures of everyday life, since pain and suffering dominate living with illness. Authors writing since Bury’s research have described the different relationships between illness, a sense of time and one’s life story (e.g. Charmaz, 2002, Frank, 2017, Kenny et al., 2017, Pietilä et al., 2018, Riessman, 2015). For example, creating explicit stories can help someone make sense of their world because humans understand their lives as lived stories with a beginning, middle and end (Bury, 2001; Kenny et al., 2017), which represent our past, present and future. Frank (2013: 55), however, shows how someone’s story can be wrecked after a life-threatening diagnosis is received, because the past has not developed into what that person thought it would be and there is no longer a definite future to think about. According to Riessman (2015), illness disrupts someone’s sense of temporal continuity. She states that stories might have a beginning and an ending but that these temporal boundaries are not clearly present in the lived experience. Locock et al. (2009) focus on biographical disruption, arguing that narratives reveal that illness disrupts daily activities, such as work, damaging one’s purpose in life. In response to the descriptions of disruption, several scholars including Bury (2001) shed light on the potentially beneficial aspects of writing narratives for people with illness. Particularly, Bury (2001) explains that dealing with chronic illness forces someone to rethink their own biography. He argues that narrating illness can repair the disruption in a patient’s life and can result in self-discovery (Bury, 2001). Similarly, Locock et al. (2009) discuss biographical repair, through which patients recreate their sense of normality and control. Pietilä et al. (2018) describe how biographical disruption and repair can coexist when dealing with prostate cancer, because of the variety of uncertainties associated with prostate cancer (regarding diagnosis, progression, recurrence and side effects) impacting men’s narratives.

In the section above, we discussed that illness can disrupt one’s sense of time within their live. Another important aspect of time while living with cancer focusses on how the past and the future become entangled in the present (Broom et al., 2018, Gordon, 2011, Kenny et al., 2017). Gordon (2011) describes how past experiences make themselves known in the present
in the form of haunting and come alive as spectres or ghosts that are not always visible but are constantly lurking in the dark. Jain (2007: 80) uses the words ‘ghostly presences’ [emphasis added], which demonstrates the idea that it feels as though the ghosts are truly present and take up space in a room. Broom et al. (2018) build on the theoretical framework of Gordon (2011) by pointing out that haunting is part of ‘cancer-as-a-lived-experience’ (Broom et al., 2018: 686). Their research shows that cancer patients experience haunting between medical appointments or before they receive test results; they refer to these periods of time as waiting (Broom et al., 2018). People experience waiting differently: some wait longer, more frequently and in poorer situations than others (Foster, 2019). In the case of living with cancer, waiting can remove someone’s ability to be productive and forces them to passively await the passage of time, for example when waiting for medical test results (Broom et al., 2018). People experience waiting differently: some wait longer, more frequently and in poorer situations than others (Foster, 2019).

In this paper, we build upon the work of Broom et al. (2018) in which solicited diaries of cancer patients are analysed to reveal ‘the tussles between normative influences over time, and between moments in illness, wellness and care’ (2018: 686). Yet, where Broom et al. (2018) focussed on people living with different types of cancer who wrote diaries for one month, we explore the longitudinal and unsolicited stories of men living with prostate cancer over a longer period, ranging from several months to years. These longitudinal narratives give the opportunity to gain insight into behavioural and emotional changes.

**METHODS**

The memoirs were searched for via websites focused on autobiographical books written by patients, patientvervaringsverhalen.nl and Prostate Cancer Foundation of Australia and via search engines of university and public libraries, as well as via commercial websites and the search engine Google. We used the following search terms: prostate cancer, patient stories/autobiography/narrative/book and layman/own words. The illness memoirs were only selected if they could be described as follows:

- A published book written by a man with prostate cancer and
- A first-authored account and
- Written in Dutch or English and
- Only available for purchase via a publishing house.
| Author               | Age at writing | Residence | Occupation                             | Prostate cancer stage | Treatment                      |
|----------------------|----------------|-----------|----------------------------------------|-----------------------|--------------------------------|
| Joseph W. Lintzenich | 56             | United States | President at a consulting company     | Localised            | Prostatectomy                  |
| Hero Moorlag         | 58             | The Netherlands | Teacher                      | Locally advanced | Hormone therapy Radiotherapy  |
| Ivan Wolffers        | 56             | The Netherlands | Professor of healthcare and culture | Locally advanced | Hormone therapy Radiotherapy  |
| Robert Hill          | 47             | United States | Owner of a public relations firm      | Localised            | Da Vinci robotic prostatectomy |
| Craig T. Pynn        | 62             | United States | Engineer                                | Locally advanced | Hormone therapy Radiotherapy  |
| Hans Frederiks       | 64             | The Netherlands | Journalist                           | Localised            | Hormone therapy Radiotherapy  |
| Henri Pieter         | 69             | The Netherlands | Retired                                | Locally advanced | Da Vinci robotic prostatectomy |
| Alan White           | 66             | Australia  | Natural health practitioner           | Localised            | Active surveillance Da Vinci robotic prostatectomy |
| Bob Tierno           | 70             | United States | Retired                                | Localised            | Da Vinci robotic prostatectomy |
| JP Mac               | 61             | United States | Scriptwriter                         | Localised            | Da Vinci robotic prostatectomy |
| Arjen Sevenster      | 71             | The Netherlands | Acquirer for scientific publishing and writer | Distant metastasis | Hormone therapy Chemotherapy Radionuclide therapy |
| Author                  | Book title                                               | Year of publication | Publisher               | Number of pages |
|------------------------|----------------------------------------------------------|---------------------|-------------------------|-----------------|
| Joseph W. Lintzenich   | Oh no, not me!                                          | 2001                | Writers Club Press      | 174             |
| Hero Moorlag           | Mijn ikste ik (My deepest me)                           | 2002                | Servo uitgeverij        | 152             |
| Ivan Wolffers           | Walvis spelen (Play like a whale)                        | 2004                | Uitgeverij Contact      | 98              |
| Robert Hill            | Dead men don’t have sex                                  | 2010                | CreateSpace             | 135             |
| Craig T. Pynn          | One man’s life-changing diagnosis                        | 2012                | Demos Health            | 218             |
| Hans Frederiks         | Prostaatkanker wacht niet op Pasen (Prostate cancer doesn’t wait for Easter) | 2014                | Mastix Press            | 77              |
| Henri Pieter           | Prostaatkanker: Hoe ontkik je het en dan? (Prostate cancer: How do you discover it and then?) | 2014                | Free Musketeers         | 78              |
| Alan White             | We’ve lost my prostate mate... and life goes on          | 2016                | Busybird Publishing     | 117             |
| Bob Tierno             | The prostate chronicles                                 | 2019                | Smashwords              | 221             |
| JP Mac                 | They took my prostate                                   | 2019                | Cornerstone Media       | 91              |
| Arjen Sevenster        | De wind van morgen (Tomorrow’s wind)                     | 2020                | In de Knipscheer        | 231             |
Based on these criteria, 11 books were included in this research (see Tables 1 and 2 for further details). These books had varying amounts of diary components and reflections on the past. For example, one memoir was composed of letters written in real time to family and friends, while another author reflected on his own thoughts at a later moment in time. The memoirs were written by men with different diagnoses who were undergoing different treatments, subjected to different healthcare practices and social environments. This allowed us to examine the breadth and uniqueness of prostate cancer narratives.

Moreover, each man recorded a different time period through which they had lived with cancer; some described years, months or it was not documented. The memoirists had diverse social set-ups and wrote for different audiences. All of them described the importance of their partner, both in daily life and during medical appointments, but placed different values on family composition or friendship.

To study the memoirs, we used a narrative approach. Narrative analysis is the interpretation of storied texts in which particular histories of individuals are preserved (Riessman, 2008). As Riessman notes, narrative inquiry comes in different forms and shapes, but in essence, whole ‘stories’ (or ‘accounts’ (Bury, 2001)) are analysed rather than fragments of them that are divided into different categories. We used a combined deductive and inductive approach to analyse the data. First, we used the framework of Broom et al. (2018) for waiting, haunting and temporality to make sense of the data. Authors van der Kamp and Betten approached the men’s stories with questions such as ‘how does uncertainty penetrate all aspects of living with prostate cancer?’ and ‘what forms of temporality are men with prostate cancer undergoing?’. We read through the memoirs and noted patterns, striking passages and differences within and between memoirs. We inductively identified new facets of living with cancer and collected literature to make sense of the data, which repeated itself throughout the process of analysis. These new-found facets and literature steered us away from the concept of waiting because they revealed that waiting is interwoven with the concept of uncertainty. We therefore examined uncertainty further in relation to temporality, and the concept of waiting moved into the background. Other examples of facets that emerged from our inductive approach are (re)constructing identity and the relationships between the men and their cancer, and between their cancer and the technology surrounding treatment. The data, notes and ideas were discussed weekly to identify different facets of living with prostate cancer.

All publishers, authors or their family members were contacted regarding this paper and agreed to publication. Our findings are supported by illustrative quotes that are either direct quotes from the books written in English or have been translated from Dutch to English. To give more context, relevant details from Table 1 are included below the quotes.

**FINDINGS**

**Reconstructing identity**

Bokhour et al. (2007) argue that a diagnosis gives someone the identity of a patient, removing all pre-existing identities. Disease disrupts the coherency of one’s life story and the perception of ‘self’ (Bokhour et al., 2007, Kenny et al., 2017). For prostate cancer specifically, this causes men to search for what it means to be a man due to failing and changing bodily functions (Schultze et al., 2020). In reaction to this loss of ‘self’, individuals reconstruct their identities by referring to other periods in their lives (Bokhour et al., 2007). One thing that stood out during our research was
that men with prostate cancer describe events in their memoirs in which their sense of identity was represented. Previous identities were included in their illness narratives to reconstruct their identity from patient to self. The following quote illustrates how a previous identity, in this case being a soldier, can be included in an illness narrative:

Every few hours my life is interrupted by a hot flash. Inexplicable mood swings (...) I often find myself welling up with tears during certain sentimental scenes in movies. (...) I have lost much of my body hair, my genitals have shrunk, and my breasts have enlarged. (...). Nevertheless, I remain very much a male. I still need to shave (...) and my voice remains unchanged. And I’ve undertaken some efforts to compensate for the feminizing process. A few weeks following the completion of radiotherapy, I visited the barbershop. Seated in the chair, I suddenly and unaccountably blurted out ‘a number two buzz cut, please.’ In just a few moments my grey and white hair lay on the shop's floor with only millimetres of fuzz remaining on my head. Looking in the mirror, it was suddenly 1969 again. I was back at the Navy base in Newport, Rhode Island, living through my first day at the Officer Candidate School. My companions and I had watched appalled, as our 1960s, Beatles-inspired locks were replaced by the regulation military-style haircut given to all new officer candidates. We glanced warily at each other’s newly shorn heads, almost too embarrassed to make eye contact. Forty years later, there was no embarrassment. That buzz cut somehow restored a bit of my diminished masculinity; I felt empowered and manly

(Craig T. Pynn 2012: 189, partner and (grand)parent, engineer, locally advanced prostate cancer, hormone and radiotherapy).

We saw that reconstructing identity consists of memoirists referring to previous identities and connecting them to their current identity of being a prostate cancer patient. Including previous identities in illness narratives is a way of representing a complete version of oneself. For example, the present identity of the patient is connected to a healthy self-image from the past, often portrayed as hegemonic masculine, a fighter and strong, to ‘compensate for the feminizing process’, as described by Craig. While normally men can challenge idealised masculine performances throughout their lives (Wenger & Olliffe, 2014), prostate cancer shapes an ambiguous sense of masculinity, creating reconstruction of hegemonic masculinity from the past. In sum, past and present self-images become interwoven and portray a sense of self that is layered and complete.

A shifting relationship with prostate cancer

In the memoirs, we often saw accounts of relationships between men and their cancer, described by Frank (2017: 2) as ‘living with illness as a companion’. These relationships were ambivalent, clashing and coexisting between men and their cancer. This contrasts with contradicting images of cancer, as a cultural phenomenon, that is embedded in our language (Kazimierczak & Skea, 2015). On the one hand, cancer is seen as something that develops stealthily inside the body – an invader or a death sentence which patients should fight against (Bell, 2012, Jain, 2007, Kenny et al., 2017). On the other hand, people focus on cancer survivorship, emphasising recovery or post-traumatic growth to create a better self (Bell, 2012, 2013). Both cancer survivorship and
post-traumatic growth demand that cancer patients are positive, live life to the fullest and make plans for the future (Bell, 2013; Broom et al., 2020). In our study, we saw that the lived experiences of men with prostate cancer do not constantly satisfy either discourse; instead, their sensations shift between the two or even coexist:

A friend, who has now been cured of cancer, told how at one point the cancer was sitting next to him in the shape of a goblin-like man. As my friend had accepted the presence of that little man, I think of the cells in my bones [metastasis] more like mischievous boys who don’t know what they’re doing rather than terrorists that I have to fight with fire and sword
(Arjen Sevenster 2020: 6, partner and (grand)parent, acquirer for scientific publishing, distant metastasis, radionuclide and chemotherapy).

The metaphor that best encompasses my personal relationship with cancer is ballroom dancing. (…) On the dance floor, it takes two parties to comprise the whole. I am cancer’s partner, it’s equal. It requires adroitness and mastering a wide variety of different moves. There are times when the partners are holding each other in a tight embrace. There are other times when they are farther apart, dancing in synchronicity, or sometimes dancing in contrast, against one another. The most important quality of this metaphor, though, is that the partners are engaged in a constantly changing dynamic relationship. Some days it seems as if the cancer is breathing right over my shoulder, ready to grab me at the first sign of weakness. Other days, the cancer will be farther away, and I’m dancing solo (…). But I must always remember that it has never left the ballroom floor
(Craig T. Pynn 2012: 75, partner and (grand)parent, engineer, locally advanced prostate cancer, hormone and radiotherapy).

Interestingly, it becomes clear from the memoirs that the relationship between men and their prostate cancer is ambiguous. Cancer is not something to merely ‘fight with fire and sword’ or to ‘hold in a tight embrace’. The men can accept that cancer is present, in body and in mind, because cancer is more than an intruder – it is a ‘partner’ that does not know what it is doing. Craig reports moments in which his cancer is ‘breathing right over my shoulder, ready to grab me at the first sign of weakness’. This is similar to characteristics of dysfunctional relationships: Craig and his cancer are partners, but cancer is in control.

**Relationship with technology**

As noted above, men wrote in their memoirs about their ambivalent and often clashing relationships with cancer. These relationships and other experiences were influenced by medical technology available at that time, such as diagnostic biomarkers (e.g. the PSA test, first used in 1986) and the da Vinci Surgical System to perform prostatectomies (since 2000) (Barsouk et al., 2020; Yates et al., 2011).

The memoirs revealed that cancer is more than a bodily condition: it is also a series of hospital appointments and treatments which together form cancer-as-a-lived-experience. The following quotes illustrate how medical technology becomes part of this experience:
We [Ivan and the radiotherapy machine] have been doing it together for a couple of weeks now and my prostate must now look like Dresden after the Allied bombings [during WWII]. My intestines and bladder are also hit and have all kinds of complaints, but that makes me happy, because it only underlines how effective those rays are in destroying what comes their way. 'Collateral damage', I hear my action hero say carelessly. The nurses leave the room for fear of the radioactivity and then we are alone. Bzzzzzzzzz. The sound is not startling. For the few seconds that the buzz sounds, I try to inhale to absorb as much of the destructive rays as possible. Then there is a short pause and again I hear the caressing sound of the terminator. This is done nine times from that position. Then there are four more positions in which we make love, in which he sometimes plays his pleasant sound eleven times, but at least seven

(Ivan Wolffers 2004: 61, partner, professor of healthcare and culture, locally advanced prostate cancer, hormone and radiotherapy).

I had finally completed all forty-two radiation treatments (...). It was certainly a relief to no longer have to make the daily 52-mile round trip between my home and the Radiation Oncology Centre. But completing radiotherapy left a void. (...) The entire process had become a predictable and comforting liturgy. For a few minutes each weekday, I became the centre of attention of a highly skilled and personable cadre of caregivers from whom no bodily secrets were hidden. It was their expertise that ensured six million electron volts worth of energised photons were aimed at precisely the right spot 'down there'. (...) Undergoing radiotherapy had another valuable quality. It demonstrated tangibly that something significant was being accomplished: the cancer cells were being attacked aggressively with high-powered photons, and I was on the road to a cure. This sense of ‘doing something’ helped maintain my morale

(Craig T. Pynn 2012: 184, partner and (grand)parent, engineer, locally advanced prostate cancer, hormone and radiotherapy).

The men wrote about medical technology in terms of intimate relationships. Ivan's description is intimate and sexual, using words such as 'caressing' and 'we make love'. The machine is described as if it communicates via sounds, similar to how humans communicate via language. Additionally, the men seemed to experience a partnership with the machine that is removing cancer from their bodies. Pols (2012: 35, Pols, 2017) shows, in different studies regarding telecare, that patients can develop love for the technologies in their lives and some even saw them as friends. This reveals a relationship between humans and technology, because technology became 'an “end” rather than a “means”' (Pols, 2012: 36). This is similar to our findings in that technology is not seen as just a tool that helps someone to be cured but also as a partner and companion in a joint act against prostate cancer.

Some men explained that completing therapy ‘left a void’ in their life. Undergoing therapy provided routine, stability and meaning to everyday life. Specifically, the ongoing partnership with the relevant machine gave them the opportunity to actively ‘do something’ about their cancer. In this sense, treatment can be experienced as supportive and protection against cancer, and when it is completed, this safeguard and stability are suddenly shattered or removed, presumably leaving someone in a state of vulnerability and disorientation.

The narratives regarding diagnostic and therapeutic interventions differed depending on the type of treatment received. Some men underwent longitudinal treatment, such as radiotherapy, which involved multiple appointments over a fairly long period of time. Others underwent a
singular treatment moment such as a prostatectomy. Unlike the men who had radiotherapy, those who underwent a prostatectomy did not describe forming relationships with technology. This discrepancy might be linked to the difference in the time spent with the technology. Radiotherapy is repeated every day for several weeks, whereas a prostatectomy is a single event carried out while the patient is anaesthetised. Carsten (2003: 35) describes how shared time and space develops kinship between humans, and we saw via the memoirs that shared time and space resulted in relations between the men and technology. During radiotherapy, men are repeatedly left alone with no company other than the radiotherapy machine.

What if? Uncertainty, incoherence and haunting

The memoirists often seem to be preoccupied with ‘What if?’ questions caused by the ‘not knowing’ while living with prostate cancer. This creates uncertainty, which can appear in different shapes and come from different places, but which transcends time and changing circumstances. The memoirs also revealed that uncertainty can take the shape of uncontrollable thoughts or run-throughs of expected situations. These run-throughs are prospective and imaginary yet clearly visualise a possible experience:

> Because I feel good. So good that I sometimes wonder if I really have cancer. Could it be that the diagnosis is wrong (unlikely after the biopsy and CT scan), or that my cancer, like [his friend’s], has been miraculously healed? That the doctors would only find healthy cells and bones free from metastasis if they were to cut me open right now

(Arjen Sevenster 2020: 71, partner and (grand)parent, acquirer for scientific publishing, distant metastasis, radionuclide and chemotherapy).

As this quote shows, men experience uncertainty due to discrepancies between their sense of health and their actual health, because men do not always feel ill. Mol and Law (2004) explain that the body is not merely an object, which can be examined using medical technology such as CT scans, but is also a subject, because it embodies who we are as humans. Through our living bodies, we experience the world around us, making day-to-day reality a ‘fleshy affair’ (Mol, 2002: 27, Mol & Law, 2004). The body can have some or no symptoms, but until the disease is confirmed through diagnostic interventions, the living body does not yet have the disease (Bell, 2013; Hofmann & Svenaeus, 2018; Jain, 2007; Mol, 2002; Mol & Law, 2004).

Another important facet of this sense of health is how it represents the temporal incoherence of living with prostate cancer. This incoherence stems from contradictions between cancer diagnosis and feeling healthy. Individuals can be asymptomatic and therefore do not know that they have cancer. Jain (2007: 77) calls this ‘a seemingly healthy person’ [emphasis in original]. Being diagnosed with a life-threatening disease while feeling healthy results in a temporally incoherent narrative because the present and the future seem to be contradictory (Jain, 2007, Kenny et al., 2017). Men who are diagnosed with prostate cancer face these contradicting and incoherent realities that will become entangled.

As mentioned earlier, uncertainty was visible in the memoirs in the shape of uncontrollable thoughts or imaginary, yet visual, run-throughs of situations. This resembles haunting, previously described as experiences that constantly come alive in the present in the form of ‘ghostly
presences’ [emphasis added] (Broom et al., 2018; Gordon, 2011; Jain, 2007); the following quotes exemplify this:

‘Please sit down,’ [the doctor] said, ‘you shouldn’t have had surgery at all.’ That set the tone. We came to be informed about the institute, the possibilities, course of events, risks, and so on. But it turned out differently. There were minimal answers to the questions we asked. There was no nuance or feeling [from the doctor] for the emotions, tension, and uncertainties that such a treatment (at least six weeks, five days [a week]) entails for the both of us [Henri and his partner] (Henri Pieter 2014: 58, partner and parent, retired, locally advanced prostate cancer, Da Vinci robotic prostatectomy and radiotherapy).

Human nature being what it is made it impossible to stop my mind from playing the ‘what if’ game. Realistically there was a myriad of what ifs lurking down the road, most beyond my control, to be resolved by the sometimes unsympathetic roll-of-the-dice. What if the tests were wrong and the cancer had actually spread? What if I made the wrong decision as to how I was to be treated? What if I had to wear adult diapers for the rest of my life? What if I could never enjoy sex with my wife again? The questions rattled through my brain like thunder, and only time would provide the answers (Joseph W. Lintzenich 2001: 19, partner, director, localised prostate cancer, prostatectomy).

These quotes show how hauntings (Broom et al., 2018; Gordon, 2011) can stem from the uncertainty of living with prostate cancer. Specifically, this uncertainty, which is caused by medical appointments, doctors disagreeing with each other and test results, can become a dominant presence in someone’s thoughts. A common concern in the memoirs was that prostate cancer can spread to other parts of the body, resulting in the men constantly playing ‘the “what if?” game’ in their minds. This game involves the almost endless questioning of the past, present and future. These questions will never be completely answered, because the solutions are as uncertain as whether a flipped coin shows heads or tails, resulting in continual speculation about possible outcomes.

Thus far, we have described how blurred boundaries between the sense of health and actual health can lead to uncertainty. We have shown how uncertainty can also cause feelings of haunting. We will now discuss another dimension in which the uncertainty that causes haunting can stem from the external world. The external world is defined in different ways in psychology. For example, the triggering of flashbacks after a trauma in which someone experiences sounds, or other sensations which were part of the traumatic experience, can be defined as depicting the external world (Scaer, 2014: 74). Another example is provided by Simard et al. (2010) in which external cues, such as television shows about cancer, can cause an emotional reaction.

The memoirs illustrate how uncertainty, incoherence and haunting are separated from and entangled in the lives of men with prostate cancer. The following quotes confirm this:

It’s a toss-up which hurts more, the actual biopsy or the anxiety waiting a week for my results as the roulette wheel spins. Will that ball land on high, low, or moderate-grade results? Post-biopsy, it only hurts when I think about it. Click, click, click [to represent the sound of the biopsy]

(Bob Tierno 2019: 64, partner, retired, localised prostate cancer, Da Vinci robotic prostatectomy).
[The nurse] appeared around the corner. ‘Great job, Craig. You did really well.’ Of course, doing ‘really well’ under the [radiotherapy machine] meant doing absolutely nothing at all. ‘Now that we know everything is lined up and working, let’s make those alignment points permanent.’ (...) With three sharp pin pricks, I had just received my first tattoos at the age of 62. Just three tiny black dots that, like the gold balls in my prostate [to mark the place of radiation], I would now carry as permanent souvenirs of my time on the Oncology Adventure Ride

(Craig T. Pynn 2012: 123, partner and (grand)parent, engineer, locally advanced prostate cancer, hormone and radiotherapy).

Technological interventions have permanent impacts on the lives of men with prostate cancer. Despite the events finishing in ‘objective clock time’, they continue in ‘subjective lived time’. Sounds and physical ‘souvenirs’ are continuous reminders of the past. These reminders are more than just memories because men can hear and see the results of the interventions every day. The embodied and permanent aspects of these experiences trigger haunting, thereby confirming the presence of prostate cancer.

DISCUSSION

The aim of this paper was to gain insight into the breadth and uniqueness of everyday experiences of men living with prostate cancer by investigating personal illness memoirs. Our analysis of cancer-as-a-lived-experience confirms many findings of previous scholarship on temporality and haunting, for example Kenny et al. (2017), Broom et al. (2018) and Pietilä et al. (2018). We add to this body of knowledge a deeper insight into longitudinal experiences of cancer, showing how men develop, over time, ambivalent relations with their identity, cancer and medical technologies. The narration in men’s own words, in which they combine life shaping and mundane moments (Baena, 2017; Bolaki, 2016), allow to acquire this deeper insight. Here we agree with Baena (2017) who argues that ‘the intensity of [the memoirists] prose, the sharing of intimacies, as well as the strength of their metaphors and their explicit demands for understanding’ as characteristics of memoirs’ allows readers to become active witnesses (2017: 11). Based on our findings, we conclude that prostate cancer affects all aspects of life, both inside and outside the hospital: experiences are not isolated moments but entangled. First, we found how men reconstructed their identity by connecting past and healthy self-images to their present identity of being a patient. Some men narrated about embodied changes due to treatment, which can create an ambiguous sense of masculinity as previous scholarship has shown (e.g. Broom, 2004, Chapple & Ziebland, 2002, Oliffe et al., 2009, Schultze et al., 2020). Here, we agree with Connell and Messerschmidt (2005) who describe that masculinity is a complex concept and ‘criticized for being framed within a heteronormative conception of gender that essentializes male-female difference and ignores difference and exclusion within the gender categories’ (836). We showed how the illness memoirs created spaces to unveil that these complexities differ per person and can change throughout one’s illness trajectory. Second, men’s relationship with cancer fluctuated and coexisted between being a friend and a foe. Third, regarding medical technology, we saw descriptions of intimate relationships and of therapy giving routine and meaning to life, depending on treatment duration. These ambivalent relationships can strengthen the experience of uncertainty that is sometimes caused by the external world, resulting in, as Gordon (2011) and Broom et al. (2018) mention, feelings of being haunted by past or future events. Like Broom et al.
(2018), we found that feelings of haunting become apparent in everyday life while waiting for medical interventions. This resonates with the work of Fox (2000: 409) in which she points out that ‘scientific, technological and clinical advances change the content of medical uncertainty, and alter its contours, but they do not drive it away’. We conclude, based on our findings, that haunting is interwoven with uncertainty, which transcends time and changing circumstances. Our findings support the results of Broom et al. (2018); they found that the time that elapses between surveillance appointments increases feelings of being haunted, but we add that embodied and permanent aspects of experiences continue to trigger feelings of haunting beyond the ‘objective clock time’ of treatment and surveillance. Our findings have relevance to other disease areas as well as to previous research that has already shown how haunting, waiting and anticipation appear in other types of cancer (Adams et al., 2009; Broom et al., 2018).

**Strengths and limitations**

While we tried to be as complete as possible in our analysis of prostate-cancer-as-lived experience, we acknowledge, in line with Charmaz (2002) and Frank (2017), that illness memoirs as stories can be interpreted in different ways, which means that they can never be the complete truth. While writing the illness memoirs, the men must have made decisions about which parts of their experiences would end up in their writing. So, while studying illness memoirs allowed us to capture the breadth and uniqueness of everyday experiences, we cannot claim that our study covers all the relevant facets of living with prostate cancer. Moreover, even though it was our aim to show the added value of recognising complete individual stories (rather than generalising experiences), we think it is important to acknowledge that the illness memoirs we studied were written by white heterosexual men. This has implications in terms of how recognisable the narratives are but (perhaps) more importantly, this is emblematic of the underrepresentation of different cultures, ethnic backgrounds, sexual orientation and genders in research. For example, with a few exceptions (e.g. Blank, 2004, Dowssett, 2008, Torbit et al., 2015, Ussher et al., 2016), limited scholarly attention has been devoted to prostate cancer and side effects of treatment among a broader spectrum of genders and sexualities (Rosser et al., 2016). Such research would produce valuable and deeper insight into whether and how culture, gender and sexual orientation influence the daily experiences of those living with prostate cancer.

Despite its limitations, this study has gone some way towards enhancing our understanding of living with prostate cancer over a long period. It is often said that ‘more men die with prostate cancer than because of it’. Although this is statistically correct, it hides a more subtle truth. The comment reflects the prevalent idea within healthcare that prostate cancer grows slowly and is not fatal, which is based on the average life expectancy of prostate cancer patients (Kazimierczak & Skea, 2015). Urological cancers are regarded as easily treatable, but aggressive tumours and personal experiences are often overlooked (Jacklin et al. 2020, Kazimierczak and Skea, 2015). In reality, no one is guaranteed complete recovery, that is, a life in which cancer does not return after treatment, or protection against premature death (Kazimierczak & Skea, 2015; Pietilä et al., 2018). Overall, the illness memoirs showed that men with prostate cancer experience haunting because of uncertainties regarding diagnosis, progression, recurrence and side effects of treatment. Therefore, the blunt comment ‘more men die with prostate cancer than because of it’ marginalises the experiences of men with prostate cancer and does not take into account the fact that although many men are successfully treated for this cancer, they remain vigilant about cancer for the rest of their lives, aware that they might die if they do not act against it.
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AUTHOR CONTRIBUTIONS
Jill van der Kamp: Conceptualization (lead); Formal analysis (lead); Investigation (lead); Methodology (lead); Validation (lead); Writing-original draft (lead); Writing-review & editing (equal). Afke Wieke Betten: Conceptualization (lead); Formal analysis (lead); Investigation (lead); Methodology (lead); Validation (lead); Writing-original draft (lead); Writing-review & editing (equal). Lotte Krabbenborg: Conceptualization (supporting); Supervision (lead); Writing-original draft (supporting); Writing-review & editing (equal).

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ENDNOTES
1 During a biopsy, tissue is removed to investigate the presence and stage of cancer (Barsouk et al., 2020).
2 Active surveillance is an option when the cancer is at a low risk stage and no active treatment is necessary (Nanton et al., 2009).
3 A prostatectomy is performed to surgically remove the prostate and surrounding lymph nodes (Barsouk et al., 2020).

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