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Gender Inequalities in Health Over the Life Course. Attitudes Towards Ill-Health in Men and Women Treated for Childhood Cancer

Agnes Dumas*

Abstract: Gender inequalities in health may result from differences in health care utilisation. This paper reports, using an interactionist approach, health-related beliefs of men and women treated for cancer in childhood and living with increased health risks ever since. We observed that normative masculine traits are sometimes used to legitimise a reluctance to undergo medical surveillance. Overall, men tended to express a passive attitude towards ill-health, resulting in a gendered health vulnerability.

Keywords: health care use, gender, inequalities, risk, interviews

Geschlechtsungleichheiten bezüglich Gesundheit im Lebensverlauf. Einstellungen zu Gesundheitsproblemen bei Männern und Frauen die als Kinder aufgrund einer Krebserkrankung behandelt wurden

Zusammenfassung: Geschlechtsungleichheiten bezüglich Gesundheit können sich aus dem unterschiedlichen Gebrauch medizinischer Versorgung ergeben. Mit einem interaktionistischen Ansatz untersucht diese Studie die Einstellungen von Männern und Frauen die in ihrer Kindheit aufgrund einer Krebserkrankung behandelt wurden. Wir zeigen, dass Vorstellungen von Männlichkeit gebraucht werden um den Widerwillen gegen medizinische Kontrollen zu legitimieren. Tendenziell zeigen Männer eine passivere Haltung gegenüber Gesundheitsproblemen, was zu einer geschlechtsspezifischen Gesundheitsanfälligkeit führt.

Schlüsselwörter: Pflegegebrauch, Geschlecht, Ungleichheiten, Risiko, Interviews

Inégalités de genre en matière de santé tout au long de la vie. Attitudes en matière de santé chez des hommes et des femmes traités pour un cancer durant l'enfance

Résumé : Les inégalités de genre en matière de santé résultent d'un recours différencié au système de santé. Dans une perspective internationaliste, nous explorons les croyances liées à la santé d'hommes et de femmes traités pour un cancer durant leur enfance, les risques pour leur santé s'étant aggravés depuis lors. Nous avons observé l'emploi de stéréotypes masculins pour légitimer des comportements à risque (refus de surveillance médicale, etc.) et une attitude passive des hommes à l'égard de leur santé, impliquant la construction d'une vulnérabilité genrée face à la santé.

Mots-clés : recours aux soins, genre, inégalités, risque, entretiens

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1 Introduction[1]

Gender inequalities in health reverse the established direction of social inequalities. While women are disadvantaged across a broad range of socioeconomic indicators as compared to men, they can expect to outlive men in almost every country (World Health Organization 2013). Female life expectancy has long exceeded that of males, especially in high-income countries: for instance in Sweden since the 18th century, and since the 19th century in Denmark, England and Wales (Barford et al. 2006). Nevertheless, the size of this gap, although still large, has been decreasing during recent decades in most European countries (Van Oyen et al. 2010).

1.1 Gender inequalities in health: the health-survival paradox

This "mortality advantage" (Bambra et al. 2009) of women is balanced by their higher physical and mental morbidity rate, resulting in a "health-survival paradox" (Verbrugge and Wingard 1987). This paradox, i. e. the contrast of higher mortality with lower morbidity for men than for women, is mainly explained by gender differences in the patterns of disease (Verbrugge and Wingard 1987). But sex differences in morbidity are not as simple to analyse as those in mortality, firstly because the male-female gap varies by disease and stage of the life cycle (Crimmins et al. 2002; Gorman and Read 2006), and secondly because of methodological challenges relating to disease definition, the severity measure used, and the age trajectories of particular diseases (Wingard 1984; Oksuzyan et al. 2008).

The most commonly proposed explanations of the health-survival paradox in biomedical research refer to differences in biological risks, lifestyle behaviours, and in risks acquired through social roles, and to reporting biases and differential healthcare access and utilisation (Macintyre et al. 1996; Oksuzyan et al. 2008). Differences in lifestyle behaviours are often highlighted, since cigarette smoking is the largest identifiable factor contributing to contemporary gender differences in mortality in western countries (Pampel 2003). Biases in reporting of symptoms and diseases may also account for the morbidity differential: as compared to men, women tend to report more symptoms (Ladwig et al. 2000) and also more trivial and often medically unexplained symptoms (Verbrugge and Wingard 1987). Moreover, variations in health complaints between boys and girls have been observed in adolescence (Hetland et al. 2002). But is this bias related to *reporting* of symptoms (because women feel more comfortable with reporting) or does it reflect more profound gender differences in pain or symptom *perceptions,* resulting in differential health care use? By health care use we mean what can be observed from health services

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data; but these represent only the final endpoint of complex social processes (Addis and Mahalik 2003).

Previous research has explored these pathways in terms of problem recognition and labelling or of help-seeking behaviours, using different designs aimed at controlling for different social and medical contexts. In trying to assess the role of social norms, Caroli and Weber-Baghdiguian (2016) found that individuals working in female-dominated environments tended to report worse health than individuals employed in male-dominated work environments. Some studies examining the attitudes and behaviours of individuals living with severe or life-threatening conditions such as cancer have not found sex differences in reporting symptoms (Macintyre et al. 1996) or in health care utilisation (Verbrugge 1985; Mor et al. 1990), while other studies have reported a gender differential in help-seeking behaviours (Fish et al. 2015). Others have found that the difference between men and women lies in the *timing* of symptom recognition, with men taking a longer time to recognize the seriousness of their symptoms, for instance in the context of rectal cancer (Ristvedt and Trinkaus 2008), or myocardial infarction (White and Johnson 2000). When controlling for symptom reporting, i. e. when comparing men and women reporting the same symptoms, women have been found to exhibit higher rates of health care utilisation (Ladwig et al. 2000).

Mechanisms explaining differences in lifestyle behaviours, symptom recognition and subsequent health care use have been studied within two distinct conceptual frameworks, namely *role theory* and *gender stereotypes.*

1.2 Health, gender role and stereotypes

Men's shorter life expectancy has been attributed to the influence of sex-role socialisation in encouraging men to put their health at risk (Harrison 1978). Differences between the sexes in symptom reporting are said to arise because women are more sensitive to bodily discomforts than men, while men are less expressive in disclosing somatic or psychic pain. Additionally, women may be expected to report more ill-health because the sick role is more socially acceptable for them.

This sex role socialisation theory has been extensively criticised by interactionist and feminist theories for being too essentialist and thus reductionist, presenting the role as something stable and inherent to every man and woman (West and Zimmerman 1987; Connell 2012). What has been called the "difference model," which argues that men and women are inherently different in their psychological traits and in behaviours such as verbal communication skills, has been refuted (Hyde 2005). Against gender essentialism, constructionists and interactionists have shed a light on the multidimensional and dynamic aspects of gender (Goffman 1977; West and Zimmerman 1987; Butler 1990; Hyde 2005; Ridgeway 2009). In this view, gender is not a static category but a situational and a "performative" one (Butler 1990), socially embodied within everyday interactions (Krieger 2005).

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By looking at interactions rather than identities, constructivist theories have highlighted the importance of *gender stereotypes* in the *doing of health* (Courtenay 2000; Connell 2012). Gender stereotypes are characteristics that are generally believed to be typical either of women or of men. They provide "collective, organised and dichotomous meanings of gender and often become widely shared beliefs about who women and men innately are" (Courtenay 2000, 1387). For instance, the strongly health-related beliefs that men are independent, self-reliant, strong, robust, autonomous, and tough render being sick, expressing pain (i. e. showing weakness), asking for help or looking for information (i. e. confessing ignorance) less acceptable for men (Courtenay 2000).

Studies examining gender stereotypes and health have shown that holding traditional masculine values has been associated with increased engagement in health-risk behaviours and decreased engagement in health-promoting behaviours (Mahalik et al. 2007; Marcell et al. 2007; Springer and Mouzon 2011). In the context of cancer, machismo, self-reliance, stoicism or perception of health as a feminine issue have been associated with delayed help-seeking (Fish et al. 2015). In contrast, men who are highly feminine exhibit the highest health concerns (Kaplan and Marks 1995) and are more likely to use health services (Mitchell 1987). Moreover, a study has shown that men with higher femininity scores have a lower risk of death from cardiac disease, while men with more stereotypical masculine scores are at higher risk of premature mortality (Hunt et al. 2007).

1.3 Representations of health and ill-health in adolescents living with a health risk

Chronic conditions are characterised by unpredictability and by a range of uncertainties (Bury 1982), which together may represent a threat to traditional masculinity (Charmaz 1995). So investigating how ideals of masculinity are enacted by men and women situated within particular social and health contexts can make a substantial contribution to the understanding of health-related stereotypes. A singular way of investigating this issue is to examine representations of health and ill-health in adolescents who are living with a chronic condition (Prout 1989; Sweeting 1995; Williams 2000). Even though men and women are continuously learning gender-appropriate behaviours, including health and illness behaviours, gendered values may be most strongly enforced during childhood and adolescence socialisation processes (Montgomery 2005). Studies have found that adolescent boys with a chronic disease perceive ill-health as a threat to their masculinity which should therefore be hidden, particularly in the public, peer-based context of school (Prout 1989; Williams 2000). The thinness resulting from chronic illness has been found to be more stigmatising for boys because of the importance for them of being "physically fit and tough" (Prout 1989). Therefore, because of the importance of having an athletic body for performance of masculinity in the context of puberty (Swain 2003),

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holding masculine values may act as a positive leverage for health because doing physical activity is highly valued in boys and of benefit to them (Williams 2000).

This paper sets out to contribute to this field of research by exploring the health-related beliefs and stereotypes of men and women who have experienced childhood cancer, by using a life course perspective (Giele and Elder 1998). We used qualitative methods, which have been widely used to depict biographies (Thomas et al. 1918) or trajectories (Becker 1963; Corbin and Strauss 1988), because they provide in-depth insight into the embedding of actors into social constraints and opportunities (Mayer 2009).

1.4 Living with a health risk after childhood cancer

Cancer in children is a rare event. It accounts for only 1% of all cancers. Each year, in Europe, 15 000 children are diagnosed with cancer; it is estimated that there are currently over 300 000 individuals in Europe who were treated for childhood cancer (Vassal et al. 2014). Survival rates of childhood cancer have drastically improved over the last few decades, from 30% to 80% (Trama et al. 2016). However, given the high toxicity of cancer treatments, late effects are numerous, and "survivors," as they are called in the biomedical literature, live with an increased health risk from childhood. The late effects of cancer and its treatments are various, and increase over time. They include functional limitations related to amputations or surgeries after osteosarcoma or soft tissue sarcoma; hearing loss or cognitive dysfunction, especially after cranial irradiation; and vision problems, especially after retinoblastoma. But there are also severe, life-threatening or disabling late-effect health conditions such as cardiac or cerebrovascular diseases or second cancer (Oeffinger et al. 2006). Data from a US cohort study have shown that less than 20 years after diagnosis, two-thirds of survivors reported at least one chronic condition related to childhood cancer therapy, of which half were severe or life-threatening (Oeffinger et al. 2006). The risk of dying from a cancer or a cardiac disease is greatly increased when compared to the general population of the same age and gender (Tukenova et al. 2010a; 2010b), resulting in a significant reduction in life expectancy.

2 Methods

Study participants were French members of the Euro2K cohort, an international multicentre cohort study which started to assess adverse effects of cancer treatment in the 1990s. Participants in this cohort were treated for solid tumours or lymphoma when they were children or adolescents (< 18 years old) in five French cancer centres (but not for leukaemia, which was not treated in these centres). All the patients diagnosed with these tumours in these five centres between 1948 and 1985 were included in the cohort. The detailed description of the cohort can be found

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elsewhere (Dumas et al. 2017). For the qualitative study, a sample was constructed using random selection. Patients treated for brain tumours were excluded because of the specific challenges they face, due to the cognitive late effects of treatment (Boydell et al. 2008). Among the remaining participants (n = 1 389), a sample was constructed using random selection. Of the 97 participants contacted, 80 (82.5%) participated.

This analysis is a part of a wider research on the trajectories of adults who were treated for childhood cancer, and on the subjective embedding of the illness into their lives (Dumas et al. 2015). In 2011, we did an exploratory qualitative study *with 17 adults,* using life history interviews and eliciting personal *narratives.* The analysis of these interviews provided the relevant categories to design a comprehensive semi-structured interview guide. This exploratory study also revealed a great variability in situations and contexts. The number of subsequent interviews was high (n = 63) in order to stratify analysis by different subgroups according to type of cancer and age at diagnosis.

Medical data concerning childhood cancer (type of cancer, year and age at diagnosis, type of treatment) were obtained from medical records. All other data came from the interviews. The interview guide was structured around the *health and social trajectories* of individuals. Besides the description of immediate and long-term effects of cancer or other unrelated diseases, participants were asked how they currently dealt with late effects of childhood cancer. In addition, the participants were invited to depict the larger familial and social context in which their health trajectory took form, as well as the extent to which they had incorporated the illness in their identity. To investigate the subjective meaning of childhood cancer for interviewees, and to explore the way cancer had been integrated in their personal history and identity, we asked about the *doing of cancer narratives,* i. e. how cancer had been evoked in the family, in particular with parents, and, over the life course, with friends, partners, children, and significant others.

Interviews lasted one hour and a quarter, on average. All were tape recorded and transcribed. We used an inductive approach in data analysis (Strauss and Corbin 1998). We followed the pattern coding approach suggested by Miles and Huberman (1994). Content analysis was computer-assisted with qualitative data analysis software (Nvivo). The study received approval from the national commission controlling data collection in France (CNIL) and from the Ethics Committee of the French National Institute of Medical Research and Health (INSERM). Informed consent to inclusion in the study was obtained from all participants. Initials and names have been changed for this article.

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3 Results

Participants (38 women, 42 men) came from socially diverse origins. They were 36 years old on average at the time of study (mean time elapsed since diagnosis: 30 years). At the time of interview, 11 persons did not know precisely the type of cancer they had or the treatment they underwent as children. Clinical characteristics of participants extracted from medical files (diagnosis, treatment, age at diagnosis and year of diagnosis) are presented in table 1. At the time of study, 69% of participants reported physical sequelae related to their childhood cancer; 19% of participants received economic compensation in relation to these sequelae. The majority of the adverse effects of treatments were cardiac and/or pulmonary diseases, functional limitations due to amputation, and/or severe musculoskeletal disorders. Sixteen persons had a recurrence or a second cancer – half of them during childhood or adolescence.

Table 1 Characteristics of participants (%)

Sex		Treatment	
Male	52.5	Chemotherapy	82.5
Female	47.5	Radiotherapy	57.5
Cancer diagnosis		Year of diagnosis	
Nephroblastoma	22.5	1970–1974	22.5
Lymphoma	22.5	1975–1979	28.8
Neuroblastoma	13.8	1980–1985	48.7
Soft tissue sarcoma	5.0	Age at diagnosis	
Bone sarcoma	8.7	Younger than 5 years old	41.2
Gonadal tumours	16.2	Between 5 and 9 years old	31.3
Retinoblastoma	2.5	Between 10 and 14 years old	23.7
Other	8.7	Between 15 and 18 years old	3.7

Interviewees (n = 80).

Different discursive patterns, reflecting contrasting gendered representations and attitudes concerning childhood cancer and ill-health, emerged from the inductive analysis. These contrasting attitudes were first perceptible through the account of the illness in childhood, which often turned out to be an "unspoken illness." Indeed, for half of the respondents, cancer had been a form of taboo within the familial sphere, during childhood and beyond. While women tended to disagree with their parents' attitudes, men tended to approve of them, and felt that they had been protected by the silence of their parents. These differences extended into adulthood, with gendered discursive patterns about ill-health: a passive attitude towards ill-health

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was more likely to be reported by men, who sometimes drew upon stereotypes of masculinity to legitimise their attitude.

3.1 An unspoken illness since childhood

The place of cancer in family interactions is a salient feature of the interviews. In fact, this place was a "non-place": more than half of the people we met reported a silence surrounding childhood cancer in the family, during childhood and after (42/80). This absence of communication about the illness was sometimes defined as a "taboo" by interviewees. This avoidance was so strong that eight people learned that they had had cancer in more or less accidental circumstances, not from their own parents, but from a third party.

Different reactions to this silence were expressed by the interviewees, with a clear sex-pattern.

3.1.1 An approved silence

Silence about childhood cancer was perceived by eleven interviewees as a way to protect them. This opinion, largely expressed by men (9/11) presented silence as an appropriate attitude. Silence during and after the disease was reported in a great variety of situations, and was not related to type of cancer or age at diagnosis. This silence was even reported by persons who were treated as adolescents in a cancer centre, as in the case of Denis, who learned from his medical oncologist, when he was 25 years old, that he had been treated for prostate cancer at the age of 15, and who stated that "[his] parents were right to be silent." Likewise Paul was treated at the age of 11 for osteosarcoma and also approved his parents' attitude, even though he remembered that he felt "lost" during the treatment period:

> *I was a little lost. I did not understand what I had, for a long time. I think that my mother knew, but the word was not pronounced. We could talk about plenty of things, but never about that. In my opinion… Well, finally, now I think that I was also protected from being anxious…* (Paul, 40 years old, had a bone tumour at age 11)

Sometimes, the word "cancer" had never been pronounced, as in the case of Antony, 45 years old, whose mother had never said the word "cancer" in the thirty years following the illness. Like others, he explained the attitude of his mother as a way of protecting him.

> *The word "cancer" was not really used when I was a child. It is only afterwards, that I realized… I told myself "Yes, it was simply a cancer" (…) Even when I became an adult, my mother never used the word "cancer" (…) It was her way of protecting me.* (Antony, 45 years old, had a bone cancer at age 14)

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This approval was counter-balanced by the opposite reaction of blaming.

3.1.2 A resented silence

Some participants (n = 14) did not approve of the silence about cancer and felt resentment towards their parents. In contrast, this view was dominant in women (9/14 were women). They blamed their parents for preferring technical terms that are meaningless for young children to that of "cancer." This led them to understand their history only belatedly, in a context they viewed as inappropriate. For instance Sabrina, treated when she was 5 years old, learned from her cousin when she was about 10 years old that she had had cancer. Instead of the word "cancer," her parents used the term "malignant tumour," which was meaningless for her.

> *It really disturbed me, to know nothing at all about it. I said to my parents: "Everybody knew about it except me!" That part, I did not like it so much.* (Sabrina, 37 years old, had a gonadal tumour at age 5)

Another woman, Nicole, who was treated when she was an 18-month old baby, revealed how she was systematically excluded by her mother from follow-up consultations. She discovered she had had cancer when, in her 20s, she received a letter from the cancer centre warning her about a risk of cardiac late effects related to the chemotherapy she received as a child. She did in fact have serious complications afterwards, and had to undergo a heart transplantation when she was 25. Her mother had died a few years after that; she had never discussed her medical history with her mother.

> *They did not really… tell me, they did not tell me in detail. In fact, when we were visiting the doctors, Mom would always say to me: "Stay in the waiting room, I'll see the doctor and after that, you can come in." My mother would listen to the doctor and, after that, I would come in. She did not want me to know… and I think that… Since my mom died… Well, I wish I knew more things. (…) I think they wanted to protect me but I like to know everything so… It is true that it is rather vague for me and… I think one day I will ask my father to tell me a bit more about my history…* (Nicole, 33 years old, had a soft tissue sarcoma at age 1)

Likewise, Sarah, who was treated for lymphoma at the age of 11, received chemotherapy for several months. She realized at the age of 14, listening to a radio show, that the hospital where she was treated was a cancer centre. She reported a very painful moment:

> *That lie hurt me… The fact that they did not talk about it, it hurt me… Afterwards, now, I understand, but at that precise moment, it was very, very hard to deal with…* (Sarah, 39 years old, had lymphoma at age 11)

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These contrasting reactions to the same parental attitude of avoidance echoed gendered health-related attitudes and behaviours in adulthood. Just as men and women tended to be opposed in terms of their judgment of their parent's attitudes, there was also a clear gender pattern in attitudes towards ill-health in adulthood.

3.2 Attitudes towards ill-health in adulthood

Attitudes concerning childhood cancer and ill-health during adulthood were classified into two categories, a passive and an active one.

Participants were classified in the active category if they had: 1) looked for information about their cancer; 2) if cancer had been positively integrated into their identity; 3) if they worried about possible late effects; 4) if they said they took care of their health. Participants were classified in the passive category if 1) they had never looked for information about their medical history; or 2) they had distanced themselves from their history of cancer, trying to forget it; or 3) if they said they did not pay attention to their health, e. g. if they smoked or avoided medical appointments. While the active attitude category was composed of 15 men and 21 women, men were dominant in the category displaying a passive attitude towards health (22 men and 6 women).

3.2.1 An active attitude

An example of displaying an active attitude was provided by Carole. Like several other women, her concern about her medical history emerged when she was planning to have a child. She wondered if her childhood cancer was a genetic disease, and if the treatment she had received as a child could have an impact on the health of her offspring.

> *I really obtained information when I got pregnant, in 2008, when I was wondering about the possible consequences of the fact that I have only one kidney, and related to the treatments I had when I was a child, if that could have an impact on the baby. So I called someone from the paediatric department of the hospital, who sent me my medical file, and who told me that there was no problem for my pregnancy.* (Carole, 32 years old, had Wilm's tumour at age 1)

Several men also displayed proactive attitudes about their health. Ben, who was 29 years old at time of interview, was among the youngest persons we met. He was treated for Neuroblastoma when he was only a few months old. He reported how, a few years earlier, he had learned the name of his cancer by searching in his medical record and by questioning his parents.

> Interviewer: *"When did you understand what had happened to you when you were a child, that you had cancer?"*

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> Ben: *"Well, the word cancer, that was kind of late, because this was not a word that was used… For instance I learned about the word 'Neuroblastoma' late, very late, when I was about 20 years old. Before that, I did not want to remember it… We did not talk about it that much… I was the one who looked in my health record. I was the one who interrogated my parents. I was the one to… (unfinished). It was not so long ago… Four, five years ago. Previously I could not give a name to it…"* (Ben, 29 years old, had Neuroblastoma when he was 6 months old)

3.2.2 A passive attitude

A passive and fatalist attitude towards ill-health was displayed even in the context of severe and chronic disease. For instance Patrick, a 28 year old accounting officer in the insurance sector, who had a cardiac disease because of the treatment he received 25 years earlier, demonstrated masculine stereotypes while explaining his smoking habit:

> *My parents think I am frail. Each time I go out, they say to me: "Don't drink too much, don't smoke too much." I don't have the feeling I smoke too much, I smoke only three, four cigarettes a day. I know this is not good. My aunt died of it… But for me it is a pleasure, I don't want to miss that pleasure because of… my childhood. So each time it gets on their nerves when I say: "I have already had cancer once. I will not have a second one. Anyway, I am invincible."* (Patrick, 28 years old, had neuroblastoma at age 3)

At times, the passive attitude was associated with approving the parental taboo about cancer; but it could also be performed together with enactment of gender stereotypes. Joel was treated for osteosarcoma at age 8, and underwent amputation at age 11. He has had a life-threatening respiratory disease since adolescence because of recurrence of cancer in the lung at age 16. Employed as a technician, he was registered as a disabled worker at the time of the interview. He recalled that, during his adolescence, "it [cancer] was not a complete taboo, but we did not talk about it at dinner." He enacted masculine traits of resistance in explaining his avoidance of medical appointments.

> *I have to feel extremely bad to go and see a doctor… Meanwhile, nothing really important happens to me! The day I will spit five litres of blood I will go and see a doctor!* (Joel, 44 years old, had osteosarcoma at age 8)

Many of those who exhibited masculine stereotypes with respect to health also suggested that they distanced themselves from cancer (12 men and 2 women reported such an attitude of distancing). This was the case for Lionel, a musician who was treated in 1982 for lymphoma and who has lived with HIV and HVC – both contracted at the hospital – ever since. While portraying himself as a survivor – saying

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"yes, I have the feeling that I am a survivor, and I am quite proud of it," he acted as if cancer had "never happened."

> *I never asked my parents about what happened, I never looked for information… I acted like nothing had ever happened… Maybe I could have asked. For a very, very long time, I pretended it had never happened.* (Lionel, 40 years old, had lymphoma at age 10)

Participants who distanced themselves from cancer often reported that they did not pay attention to their health. Both these attitudes were mainly reported by men (12/14). Christian, a 33-year-old programmer, who was treated for Wilm's tumour at age 3, reported that "up to now, [he had] tried to forget, to live a normal life." A cardiac examination and follow-up was offered to Christian, in the same way as to many of the former patients who received anthracyclines, a chemotherapy which can seriously damage the heart function. He declined because he did not want to discover that he might have late effects related to childhood cancer.

> *It seems that the medications that were used back in the days when I was treated, they were kind of… experimental. They gave me one which is bad for the heart. I was supposed to do tests to check that, and I did not go because I did not want to find out I had late effects related to it.* (Christian, 33 years old, had a Wilm's tumour at age 3)

In the end, this passive attitude results in a lack of information about one's own medical history, possibly resulting in gendered vulnerabilities. At time of interview, 11 persons (14% of interviewees) did not know the type of cancer they had as children, or the type of treatments they received. Of these 11 persons, 7 were men.

4 Discussion

This study aimed to investigate health-related behaviours in adults who had a life-threatening illness during childhood or adolescence and who have had an increased health risk ever since. The accounts of participants reflected firstly the perceived lack of communication about childhood cancer. The medical context, in the 70s and 80s, was different from that of today. At that time, barely 30% of children with cancer survived the disease. An important finding was that reactions to this perceived lack of communication followed a gender pattern, with women unsatisfied and wanting to know more about their history, and men satisfied with the situation but enclosed in a passive position. Beyond this gender difference, the life course approach used in this study highlights the role of the parents' management of the illness, their difficulties in evoking the illness with their child and thus in providing their child with sufficient useful information to take care of their health adequately

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as adults. Indeed, whether they were men or women, the participants' lack of knowledge about medical history originated in the parental reaction to the illness during cancer treatment and beyond, revealing a long-lasting familial construction of a health-related vulnerability.

Secondly, discourses provided insight into the intensity of masculine normative values and attitudes in this particular health context. A passive and fatalist attitude was mainly displayed by men. Avoidance of medical follow-up was also mostly reported by men, and was sometimes associated with a performance of masculine stereotypes. Our findings reflect the results of other qualitative studies, in which enacting masculine traits has been found to deter help-seeking behaviours such as reporting symptoms, and to be associated with reluctance to consult doctors, in the context of prostate cancer (Cameron and Bernardes 1998; Chapple and Ziebland 2002) or myocardial infarction (White and Johnson 2000). Some authors argue that the embarrassing nature of the symptoms of prostate cancer contributes in a unique way to reluctance to seek medical help (Chapple and Ziebland 2002), and therefore that disease does not constitute an adequate point of comparison. White and Johnson (2000) describe men's decision making in help seeking prior to admission to a coronary care unit with chest pain. These men sought assistance at a point beyond that which would have been logically expected by the clinical team. A feature of the men's experiences was that, although they had suffered intense pain prior to admission, they had ignored their feelings of ill-health because of masculine feelings of invincibility. Further light is shed on the role of masculine stereotypes in health-related attitudes by a study based on focus groups with 55 men from different social backgrounds, ages and health contexts (O'Brien et al. 2005). In this study, authors found "a widespread endorsement of a hegemonic view that men should be reluctant to seek help" (O'Brien et al. 2005, 503). However, such views were dominant in younger men who stressed the need to be obviously injured, seriously ill or pressured before they would consider seeking medical care. One of the interviewees of the study made by O'Brien et al., who was young and in good health, stated that "you have to be bed-ridden or half dead before you'll go to the doctor" because "that's what being a man is" (O'Brien et al. 2005, 508). In contrast, the authors report accounts of greater willingness to consult in older men in their 50's or over who have had prostate cancer or cardiac disease. The authors conclude that seeking help is perceived as a behaviour challenging the conventional norms of masculinity amongst young men "who adhered to a model of masculinity that men who had experienced serious illness had been forced to question" (O'Brien et al. 2005, 514). The authors thus introduce the idea of a "hierarchy of threats" to masculinity: in their study, in which men who have had prostate cancer or cardiac disease attribute a higher priority to the preservation of their health than to the preservation of their masculinity. In contrast, the accounts provided here by childhood cancer survivors indicate that the dominant model of invulnerable masculinity may still be prevalent,

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and that the hierarchy of threats may still prioritise masculine ideals over health even in men who have been in bad health since childhood. One important point is that these masculine traits were spontaneously enacted by men *without being asked about it specifically,* since the scope of our study did not initially cover gendered health-related attitudes. This means that help-seeking behaviours, which include a wide range of manifestations, may have lacked the more sophisticated treatment that their full exploration merited. However, participants' accounts emphasized not only gendered *discourses* about health, but also stressed gendered *practices:* ignorance about one's own medical history, reluctance to seek medical care, and delay in physical examination for cardiac or respiratory diseases consequential to childhood cancer.

As Courtenay emphasizes, "by dismissing their health care needs, men are constructing gender" (Courtenay 2000, 1389). Because gender stereotypes are rooted in power relationships (Pyke 1996), Courtenay argues that men use health beliefs and behaviours to demonstrate dominant masculine ideals that clearly establish them as men:

> *[In] Exhibiting or enacting hegemonic ideals through health behaviours men reinforce strongly held cultural beliefs that men are more powerful and less vulnerable than women; that men's bodies are structurally more efficient than and superior to women's bodies; that asking for help and caring for one's health are feminine; and that the most powerful men among men are those for whom health and safety are irrelevant.* (Courtenay 2000, 1389)

Masculinities are multiple and socially located in both time and place, varying within persons and across situations and contexts (Connell 1995). Conformism to hegemonic masculinity, defined as the socially valued and idealised form of masculinity at a given place and time (Connell 1995), was enacted by some participants and was used to legitimise a reluctance to undergo medical surveillance. Paradoxically, adherence to hegemonic masculinity norms such as being strong, invincible and independent turned men into passive objects of care. A remarkable proportion of these men, irrespective of their social background, did not know the type of cancer they had as children or the treatments they had received, which is a major obstacle to prevention of late effects. This lack of control over information about their own history has the potential to put them at risk. Excess mortality related to childhood cancer treatment (in particular in relation to cardiovascular diseases and cancer) begins at age 40 (Tukenova et al. 2010a; 2010b). The standardised mortality ratio for cardiovascular mortality is 8 fold higher for survivors of childhood cancer as compared to the general population of the same age and gender (Tukenova et al. 2010b). Prevention strategies are possible, including medication reducing the risk of developing severe cardiac disease, and screening for cancer, possibly resulting in early detection and better prognosis (Mulder et al. 2013; Yeh et al. 2014). Not everyone needs regular medical surveillance; nonetheless, prevention of late effects

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following cancer treatment presupposes a knowledge of at least the kind of therapy received during childhood.

However, not all men lacked interest in their medical history and their health. Our data also highlighted the diversity of experiences and practices within both sexes. While some women also displayed passive and fatalistic values about health, some men contested masculine norms, showing the limits of an essentialist concept of gender. In their study of help seeking for cardiac symptoms, Galdas et al. (2010) also demonstrated that while some individuals explicitly positioned their behaviour during the cardiac event as stereotypical of their gender, some behaviours that might be stereotypically considered as masculine or feminine practices were shared by both male and female participants. These results remind us that gender is not always central in the doing of health. Obviously, gender interacts with social class, culture, or ethnicity; other life events that occur over the life course may interfere with perceptions and representations of health so that, at different times and settings, individuals may hierarchise their priorities differently. More research on health attitudes and practices over the life course in different social and health contexts could make a substantial contribution to this issue.

5 Conclusion

These narratives provide insight into the gender construction of ill-health over the life course in a specific health context. Participants' accounts illustrate the construction of a health-related vulnerability caused by a lack of communication about the medical history of the child in the family, during childhood and after. The findings extend the literature on gender stereotypes and provide an example of the intensity of masculine stereotypes concerning ill-health in men who have experienced lifelong illness or health risk. A passive attitude towards health, mostly reported by men, is likely to account for the formation of gendered vulnerabilities, especially in this population of individuals with an increased risk of developing chronic diseases.

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Christian Reutlinger

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