

Cancer – more than a disease

Changes and losses following treatment in primary bone sarcoma survivors

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Original papers

Fauske, L., Bruland, O. S., Grov, E. K., & Bondevik, H. (2015). Cured of primary bone cancer, but at what cost: a qualitative study of functional impairment and lost opportunities. *Sarcoma*, 484196.

Fauske, L., Bondevik, H., Bruland, O. S., & Ozakinci, G. (2015). Negative and positive consequences of cancer treatment experienced by long-term osteosarcoma survivors: a qualitative study. *Anticancer Research*, 35(11): 6081-6090.

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Abstract

This thesis explores how primary bone cancer (bone sarcoma) survivors experience the physical and psychosocial consequences of the condition several years after treatment.

Primary bone sarcoma is a rare form of cancer that can occur anywhere in the skeleton, with the incidence of the disease being higher among adolescents and young adults. There is often no obvious reason for the condition related to the environment or lifestyle of those affected by bone sarcoma. The treatment for primary bone cancer is complex, involving extensive surgery, chemotherapy and, in some cases, radiation therapy. The consequences of the disease and the associated treatment are often long-lasting and they may include reduced functional capacity, pain, fatigue, cognitive challenges, psychosocial challenges, as well as an altered appearance.

The empirical material in this thesis is based on interviews conducted with 18 Norwegian participants who had been treated for bone sarcomas in the hip/pelvis (n=10) or lower limb (n=8) between three and ten years previously. The participants were seven women and 11 men, and they were aged between 18 and 60 years. They had differing backgrounds in terms of demographics, education, employment and marital status. The participants were primarily asked about their experiences of the functional, practical, emotional and psychosocial consequences of cancer, as well as how their experiences of cancer had affected them as individuals, including with respect to their personal identities. The study has a phenomenological design and it is based on the participants' own experiences and everyday lives.

This thesis adopts a psychosocial and sociocultural perspective on health and illness. In order to understand how life is experienced in the wake of a serious cancer and the associated treatment, our aim was to draw an association between the biological concept of disease and the significance that the individual and society place on illness, as well as how it is interpreted and addressed in our particular culture. Both the understanding of health and notions of how good health can be achieved are of relevance to healthcare services. The central theoretical perspectives that underlie the analyses in this work are Fredrik Svenaeus's phenomenological approach to disease and Lennart Nordenfelt's holistic concept of health.

The findings of this study are presented in three papers, all of which address how the changes that resulted from their cancer and treatment have affected the participants. These papers are also separate works, each of which considers different aspects and contexts that the participants experienced when they had to reorient their lives after having cancer. The participants described the consequences, late effects and other challenges that have affected their daily lives practically, emotionally and psychosocially, as well as in terms of their future prospects and their identity. Several participants have had to adjust from leading a healthy and active life to experiencing a life with reduced function and new psychosocial challenges. Being cured of cancer comes at a price, and it is not guaranteed that former cancer patients will resume the same lives that they had prior to the onset of cancer. The practicalities of daily life may become more challenging due to decreased mobility, impaired strength and poor balance, while some bone sarcoma survivors struggle with fatigue and cognitive challenges. Another negative consequence of the treatment is an obviously altered body and a distinct change in appearance in terms of limping and the need to use mobility aids such as crutches and wheelchairs, as well as scars, hernia and deformed extremities. Hence, former patients' daily practical and social lives might be affected, including their participation in work, family life, friendships, sport and leisure time activities. For most participants, these changes resulted in them undertaking less physical activity, while for some the result was increased dependence on others, in addition to exclusion from social situations and other important life arenas. Their narratives thus compare to those expressed by people with various forms of disabilities. Many participants tried to hide their cancer history and the visible alterations to their bodies. They wanted to appear normal, healthy and attractive, no doubt due to the fact that deviations from cultural and social norms can be experienced as stigmatising and exclusionary.

Despite the negative consequences of having cancer and undergoing treatment for the disease, several participants expressed a greater appreciation for life as a result of their experiences. They consider themselves to have undergone personal growth and believe that they now feel more empathy for others. However, some participants noted a degree of ambivalence regarding how positive this change actually was. Most participants coped well with their cancer-related challenges, although a few still struggled to reorient themselves and find meaning in their altered daily lives.

For many participants, exposure to a serious form of cancer resulted in a need to reorient themselves in many areas of life. In addition to the practical difficulties and physical ailments, many bone sarcoma survivors must learn to relate to a new identity as a person with a disability. A more holistic approach to health and treatment than that encompassed by a purely biomedical perspective could be beneficial for such cancer survivors' rehabilitation. Those who struggle and find it difficult to reorient themselves in life after treatment, and who thus fail to find new dimensions of meaning in daily life, should be identified by healthcare services. By this means, they could be provided with help to cope with the new conditions and challenges they face and, hence, to move forward.

Sammendrag

Denne avhandlingen undersøker hvordan tidligere benkreftpasienter opplever fysiske og psykososiale følgetilstander flere år etter at behandling er avsluttet. Primær benkreft er en sjelden kreftform som kan oppstå alle steder i kroppen og rammer ofte unge. Det er oftest ingen opplagt årsak knyttet til miljø og livsstil hos dem som rammes av bensarkom.

Behandlingen er omfattende og innebærer kirurgi, kjemoterapi og i noen tilfeller strålebehandling. Følgetilstandene av sykdommen og behandlingene er ofte langvarige og innebærer blant annet nedsatt funksjon, smerter, fatigue, psykososiale utfordringer og et endret utseende.

Det empiriske materialet i denne avhandlingen tar utgangspunkt i intervjuer med 18 norske deltakere som er behandlet for bensarkom i hofte/bekken (n=10) eller underekstremitet (n=8) for 3-10 år siden. Deltakerne er 7 kvinner og 11 menn mellom 18 og 60 år som har ulike bakgrunn med tanke på demografi, utdanning, arbeid og sivil status. I hovedsak ble deltakerne spurt om hvordan de opplevde at kreften hadde medført funksjonelle, praktiske, emosjonelle og psykososiale konsekvenser i ettertid, samt om krefterfaringene hadde påvirket dem som person. Avhandlingen har et fenomenologisk design som tar utgangspunkt i deltakernes egne erfaringer og dagligliv.

Studien har et psykososialt og sosiokulturelt perspektiv på helse og sykdom. For å forstå hvordan hverdagen oppleves etter å ha gjennomgått alvorlig kreftsykdom ønsker vi å knytte det biologiske sykdomsbegrepet sammen med det meningsinnholdet som individ og samfunn legger i sykdom og hvordan dette tolkes og omsettes i kulturen. Hvordan vi forstår helse og hvordan god helse kan oppnås har betydning for hva helsevesenet skal befatte seg med. Sentrale teoretiske perspektiver som ligger til grunn for arbeidet og analysen er Svenaeus' fenomenologiske sykdomstilnærming og Nordenfelts helhetlige helsebegrep.

Funnene i denne studien er presentert i tre artikler som alle omhandler hvordan endringer som følge av kreftsykdommen og behandlingen har påvirket deltakerne. Samtidig er artiklene individuelle arbeider som tar for seg ulike aspekter og kontekster disse deltakerne opplever når de skal reorientere seg i livet etter alvorlig kreftsykdom. Deltakerne forteller om følgetilstander, senskader og andre utfordringer som påvirker det daglige livet, det praktiske så vel som det emosjonelle og psykososiale, deres fremtidsmuligheter og deres identitet. Flere

har gått fra en tilværelse som frisk og aktiv til et liv med nedsatt funksjonalitet og nye psykososiale utfordringer. Kurasjon har sin pris, det er ingen selvfølge for de tidligere pasientene å fortsette det samme livet som før kreften rammet dem. Det praktiske dagliglivet er blitt mer utfordrende med nedsatt mobilitet, styrke og dårlig balanse og noen sliter med fatigue og kognitive utfordringer. En annen negativ konsekvens av behandlingen er en tydelig endret kropp og et avvikende utseende i form av halting, bruk av hjelpemidler som krykker og rullestol, i tillegg til arr, brokk og deformert ben. Deres daglige praktiske og sosiale liv, deltakelse i arbeid, familieliv, vennskapsrelasjoner, sport og fritidsliv blir rammet. Dette medfører for de fleste nedsatt fysisk aktivitet, for noen økt avhengighet av andre, samt utestengelse fra sosiale situasjoner og viktige arenaer i livene deres. Deltakerne fortalte om erfaringer som likner på dem beskrevet av personer med ulike former for funksjonshemninger. Flere av deltakerne forsøkte å skjule kreftsykdommen og de synlige avvikene. De ønsket å fremstå som normale, friske og attraktive. Det å avvike fra de kulturelle og sosiale normene opplevdes av noen av deltakerne som stigmatiserende og ekskluderende.

Til tross for negative konsekvenser av sykdommen og kreftbehandlingen var det flere som fortalte at de satte mer pris på livet, de opplevde økt personlig vekst og følte mer empati for andre som en følge av erfaringene de hadde fått. En viss ambivalens til hvor positivt dette var, ble uttalt hos noen. De fleste mestret de kreftrelaterte utfordringene godt, mens et par fortsatt slet med å reorientere seg og finne mening i dagliglivet med de nye forutsetningene.

En kreftdiagnose kan medføre at man møter nye utfordringer på mange områder av livet. I tillegg til praktiske utfordringer og fysiske plager må mange forholde seg til en endret identitet på grunn av nedsatt funksjon. En mer helhetlig tilnærming til helse og behandling enn det som ligger i et rent biomedisinsk syn vil kunne komme pasientene til gode i rehabiliteringsøyemed. De som sliter og ikke klarer å reorientere seg etter behandlingen og finne nye meningsdimensjoner i dagliglivet bør få tilbud om oppfølging fra helsevesenet og få hjelp til å mestre og komme videre med de nye forutsetningene.

Preface

Some years ago, I completed my master's degree at the Department of Culture Studies, University of Oslo. The topic of my thesis was living with the sequelae following treatment for various cancers, as considered from a sociocultural perspective. Investigating this topic provided me with unique insights into the daily lives (lifeworld) of former cancer patients, as well as an understanding of how culture may affect illness and/or living with the challenges associated with serious disease. This research also made me aware of the considerable gap between the biomedical perspective on disease that health professionals typically adopt and the experiences of former cancer patients when they are cured, but left with long-term consequences of the cancer and its treatment. Thus, when I was asked to design and implement a qualitative PhD research project on bone cancer at the Norwegian Radium Hospital, Oslo University Hospital (NRH OUH), I realised that it would be an excellent opportunity to expand my research on the basis of the experience and knowledge I had acquired while at university. Based on my previous qualitative studies involving cancer survivors, I already had ideas regarding the psychosocial and sociocultural perspectives on cancer, and I was aware that these ideas would be of relevance to bone sarcoma survivors. I also took into account the fact that the participants in this study would, both socially and culturally, have much in common with those afflicted by other cancers, although there would be some specific challenges for this particular group. Patients with bone cancer in the hip/pelvic area, as well as those with cancer of the lower limb, undergo extensive treatment, often involving surgery, which might result in the development of numerous and extensive sequelae. My intention was to use the perspectives of the humanities to bring new knowledge to a field that has previously been largely studied by health professionals.

In terms of a sociocultural perspective on the phenomena of health and illness, I believe that one must go beyond physiological and psychological comprehension and look at these phenomena as also being conditioned by the historical, cultural and social context, which suggests that human behaviour is influenced and shaped by social and cultural contact and context. This applies to every sector of our daily lives, including how we communicate, understand, relate and cope with one another. In order to understand what it means to survive bone cancer and live with the consequences and challenges that result from the disease and its treatment, it is important that both the psychosocial and sociocultural approaches are considered, as well as medical perspectives on the sequelae of bone sarcomas. A sociocultural

and phenomenological approach that takes into account how culture affects sarcoma survivors' understanding of cancer, as well as how society views cancer and those who are affected by the disease, therefore has the potential to provide new knowledge. This knowledge is of importance in enabling healthcare professionals to obtain a comprehensive view of this particular patient group and thus better assist these survivors with the various challenges they may face.

The Scandinavian Sarcoma Group (SSG) has been involved in research on sarcomas in Scandinavia for decades. The NRH OUH plays a key role in this cooperation between Norway, Sweden and Finland. Several medical studies and some research surveys involving quantitative methods, including quality of life (QoL) studies in a bone sarcoma population in Scandinavia, have been performed. However, to the best of my knowledge no studies have yet been conducted in which qualitative methods have been applied. The papers in this thesis are therefore intended to bring new perspectives to this field, such that by using interviews we can convey the survivors' own perspectives and their unique and subjective experiences. This qualitative study is also intended to supplement previous research in the field in Scandinavia and to be complementary to the quantitative studies contained in Liv Hege Aksnes' PhD thesis, which is entitled *Health in Long-Term Survivors of Bone Sarcoma* (Aksnes, 2008). Qualitative research on cancer survivors provides important knowledge for healthcare providers. I thus decided to publish our findings in international medical journals aimed at physicians and other healthcare professionals, which of course influenced how I worked with the material, the types of theory I utilised, and how the research is presented in the three subsequent publications.

Based on the three papers, this dissertation aims to contextualise and discuss the overall research objective of the study, which is to broaden the understanding of the various physical, psychosocial and cultural challenges faced by bone sarcoma survivors following treatment by highlighting the participants' experiences and their lifeworld. Furthermore, I have attempted to put the three papers in context and illustrate how both theory and methodology were utilised.

I. Introduction

This chapter provides an overview of the literature and subjects that have been central to this study. First, it offers an overview of the medical field related to bone sarcomas and cancer survival. Next, it presents the main psychosocial and sociocultural theoretical perspectives that have been relevant to the analysis and discussion concerning the findings presented in papers I-III.

Primary bone sarcoma

Osteosarcoma, chondrosarcoma and Ewing's sarcoma are the most common primary bone cancers (Damron et al., 2007; Jawad et al., 2011), although they represent less than 0.2% of all newly diagnosed cancers (Hameed & Dorfman, 2011). While chondrosarcoma most commonly affects adults, osteosarcoma and Ewing's sarcoma are most frequent in children and adolescents (Damron et al., 2007; Dorfman & Czerniak, 1995; Eyre et al., 2009). There is most often no obvious reason for the cancer related to the environment and lifestyle of those affected by bone sarcoma (Eyre et al., 2009; Ottaviani & Jaffe, 2009). Surgery is the main treatment modality for cancer in general and for bone sarcomas in particular. The curative treatment of bone sarcomas in the hip/pelvic region and the lower limbs may require extensive surgery, often in combination with chemotherapy and, for some patients, radiotherapy (Hameed & Dorfman, 2011). The consequences of such radical surgery are often substantial (Bekkering et al., 2011; Ottaviani et al., 2009).

Since the late 1970s, the treatment of bone cancer has improved substantially (Aksnes et al., 2006; Damron et al., 2007). Previously, surgery was the main method of treatment for osteosarcoma, although it had a dismal survival rate of 15–20% due to micrometastases at the time of diagnosis (Bruland & Pihl, 1997; Malawer, 2011). Effective chemotherapeutic regimens and improvements in radiotherapy have now increased the survival rate dramatically. Indeed, the survival rate today has increased to 55–80% due to the use of effective treatment regimens, including neoadjuvant chemotherapy (Bacci et al., 2000; Bacci et al., 2004; Elomaa et al., 2000; Jawad et al., 2011). In the USA, from 1985 to 1998, the relative five-year survival rate was 53.9% for osteosarcoma, 75.2% for chondrosarcoma and 50.6% for Ewing's sarcoma (Damron et al., 2007). It used to be common to amputate in most instances of bone cancer in the lower extremities. However, we now have effective surgical techniques and prostheses that allow for limb-sparing surgery in the majority of cases. More

than 90% of patients with osteosarcoma in the lower extremities can now be radically operated on, thereby avoiding the amputation of the affected extremity (Bruland et al., 2009; Ottaviani et al., 2009). It can be challenging to establish a correct diagnosis of bone sarcomas at an early stage. Especially in patients with osteosarcoma and Ewing's sarcoma, there is often a substantial delay between the patient's initial consultation with a doctor due to his/her symptoms and when a firm diagnosis is established and treatment initiated. Unfortunately, late diagnosis may lead to an inferior prognosis and the need for greater intervention (Widhe & Widhe, 2000).

Long-term consequences of cancer

Many cancer patients will complete their primary treatment and return, more or less, to the same level of health, function and well-being they enjoyed prior to their diagnosis (Macmillan Cancer Support, 2013). However, a significant proportion of cancer survivors may, following treatment, face a wide range of long-term consequences, both physical and psychosocial (Foster et al., 2009). The National Health Interview Survey (Hewitt & Rowland, 2002) and an analysis of these data in the United States (Hewitt et al., 2003), as well as several UK-based studies (Elliott et al., 2011; Treanor & Donnelly, 2016; Treanor et al., 2013) found that cancer survivors report poor general health in addition to having other chronic conditions, disabilities and limitations to their usual activities. Other studies have noted that the late effects of cancer involve fear of recurrence (Simard et al., 2013), sexuality and reproductive issues (Chapple et al., 2007; Dowswell et al., 2011; Kent et al., 2012; Klaeson et al., 2012; Lehmann et al., 2014), pain (Kaasa et al., 1999; Kurita & Sjogren, 2015), cardiac sequela (Aksnes et al., 2009), osteoporosis (Aksnes & Bruland, 2007), mental issues (Paredes et al., 2011), fatigue and cognitive challenges (Ahlberg et al., 2003; Knobel et al., 2003; Koornstra et al., 2014; Mitchell & Turton, 2011), an altered body image (Fan & Eiser, 2009; Pendley et al., 1997; Rasmussen et al., 2010), limitations in vocational life (Brown et al., 2003; Grunfeld & Cooper, 2012; Moskowitz et al., 2014; Rasmussen & Elverdam, 2008), as well as a negative impact on social life and sport and leisure activities (Curt, 2000; Lehmann et al., 2014). Such late effects can last for months or years after the patients have finished their cancer treatment, or they may only occur many years later (Macmillan Cancer Support, 2013; Treanor et al., 2013). Problems such as those mentioned above might affect people's lives more significantly than is generally recognised and they are often poorly dealt with by the healthcare system (Macmillan Cancer Support, 2013).

Fatigue is one of the most common late effects reported after cancer treatment and it affects many aspects of patients' and former patients' lives, including their physical condition, psychosocial condition and general well-being (Ahlberg et al., 2003; Curt, 2000; Koornstra et al., 2014; Stone & Minton, 2008). There is no universally accepted definition of cancer-related fatigue (CRF), although the National Comprehensive Cancer Network (NCCN) has defined it as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment, that is not proportional to recent activity and interferes with usual functioning."¹ Although both awareness of CRF and the number of studies on the issue have increased in recent years, a focus on fatigue has not yet become routine during clinical follow-up (Wang & Woodruff, 2015).

Long-term consequences of bone sarcoma

The surgical treatment of bone sarcomas in the hip/pelvic region is extensive and it often results in postoperative complications and late effects for the vast majority of patients (Han et al., 2010; Hoffmann et al., 2006; Zeifang et al., 2004). Most patients experience more than one complication following treatment, including infections, impaired wound healing, implant failure, loosening, a shorter leg, nerve injury (Han et al., 2010; Zeifang et al., 2004), and internal organ damage to the bowel or bladder (Han et al., 2010).

Previous studies of quality of life (QoL) among long-term survivors of lower extremity primary bone sarcoma have consistently reported lower QoL scores in terms of physical functioning, both compared to other cancer survivors and to individuals without cancer from a matched population (Aksnes et al., 2007; Barrera et al., 2012; Bekkering et al., 2010; Yonemoto et al., 2007a). In contrast, other quantitative studies concerning the education, employment, fertility and marital status of primary bone sarcoma survivors have revealed inconsistent results (Nagarajan et al., 2003; Yonemoto et al., 2007b; Yonemoto et al., 2003). Methodological differences have been emphasised as challenging in two systematic reviews on this subject and hence such differences may account for these inconsistent findings (Bekkering et al., 2012; Eiser & Grimer, 1999). Most of the studies cited above involve an evaluation of function among patients with lower extremity primary bone sarcoma following limb salvage procedures versus amputations. One difficulty of limb salvage surgery is that internal prostheses have only a limited life span. Prosthetic failure, including fractures

¹ National Comprehensive Cancer Network Inc. (2013); see www.nccn.org.

(Bekkering et al., 2011), and a high reoperation rate therefore remain challenging (Ottaviani et al., 2009). Extensive surgery also implies the removal of muscles, which may result in weakness associated with movement and balance problems. In addition, insufficient bending of the knee is a common result of surgery (Bekkering et al., 2012; Ottaviani et al., 2009). A systematic review article on survivors of extremity osteosarcoma emphasised that physical functioning is the best described domain, as well as one where treatment has a major impact. The psychological and social domains were less well described, although there is evidence that treatment has a variable impact on psychological status, social functioning and employment (Kwong et al., 2014).

The surgical sequelae, as well as the toxic effects of chemotherapy (Bacci et al., 2000), suggest that primary bone sarcoma survivors frequently experience considerable health challenges and disabilities as a long-lasting consequence of treatment (Aksnes et al., 2009). In a cross-sectional and descriptive study conducted by Paredes et al. (2011), 142 sarcoma patients reported on the anxiety and depression they experienced during different phases of their disease. During the follow-up phase, 21.3% presented with moderate to severe levels of anxiety, while 6.6% reported moderate to high levels of depression (Paredes et al., 2011). A systematic review and meta-analysis of QoL among paediatric, adolescent and young adult bone tumour survivors (Stokke et al., 2015) found that QoL improves over time, although an older age at the time of diagnosis and the female sex are both associated with poor QoL. The review concluded that it was difficult to detect trends in sarcoma patient outcomes because of diverging results.

Qualitative research on bone sarcomas that addresses the individual and long-term psychosocial effects of treatment is sparse. Despite this limited evidence, the treatment of bone cancer clearly has a profound impact on many survivors' life domains. An important qualitative study by Parsons et al. (2008) aimed to characterise the experiences of adolescent and young adult osteosarcoma survivors (n=14) in general, as well as in relation to resuming their vocational pursuits. They found that participants engaged in three types of 'work': illness work (i.e., when undergoing treatment and struggling with the consequences), identity work and vocational work. Importantly, the participants described an active process of 'identity work', or work that is characterised by 'becoming other' through self-reflection and effort (Parsons et al., 2008). One study reported that bone sarcoma treatment had an adverse impact on the work status of former patients, with 25% of participants (n=9) describing an

‘altered’ work status such as prolonged periods of disability or unemployment (Brown et al., 2003). A qualitative study concerning mothers’ views of children (n=12) with bone sarcomas showed that both the cancer and the treatment had a great impact on their children’s lives (Earle et al., 2005). The participants described how functional impairment caused a major disruption to their children’s everyday life, school, sport activities and social life. These studies show that moving from being healthy prior to having cancer to being functionally impaired following treatment is a transformation that has an extensive impact on survivors’ identities, daily lives and vocational lives. Another qualitative study stated that sacrectomy is a life-changing event for patients and their families because it has an effect on several of their life domains, including leisure activities, return to work, social interactions, family dynamics and sexual relationships (Davidge et al., 2010). A great deal of research on the sequelae of cancer and cancer treatment is focused on the time of diagnosis and the period of treatment. Much of this research is not relevant to the present study due to the decision to focus on long-term consequences. There have also been several qualitative studies on the late effects in children with bone sarcoma. Neither of these have been included in the present study since our participants are all aged over 18.

On being a cancer survivor

Diagnostic tools and treatment have improved significantly in recent decades and thus the majority of those diagnosed with cancer now survive the disease. In a population in which an increasing proportion of people are living longer, there will also be more people who are affected by cancer. This means that there will be many more people living with, and after, cancer. ‘Cancer survivor’ or ‘survivorship’ are commonly used terms. The term ‘survivorship’ was first adopted in the 1980s by an American physician who himself survived cancer and who believed that the term ‘cure’ did not adequately cover the long-term consequences that could result from cancer (Mullan, 1985). The term has now become widely accepted, especially in the USA. It is used by large organisations such as the National Cancer Society that work to improve cancer survivors’ conditions and rights. In other cultures, in different countries and in diverse healthcare systems, the use of the term varies (Khan et al., 2012). Macmillan Cancer Support, for example, does not use the term in its comprehensive document concerning those living with and beyond cancer (Macmillan Cancer Support, 2013). Instead, the consequences of cancer and its treatment are discussed. However, in cooperative projects involving the relatively recently established National Cancer Survivorship Initiative (NCSI) and the UK Government’s Department of Health, the term

‘survivor’ is central (Khan et al., 2012). Additionally, in Norway the term is used, albeit not widely. On the website of the Norwegian Cancer Society, for example, the term ‘survivor’ is not mentioned.² However, entering the term ‘cancer survivor’ into the Google search engine results in more than 13 million hits.

Surviving cancer (or cancer survival) has been defined in different ways. The two most common definitions are: (1) being cured of cancer after the completion of treatment; and (2) living with and beyond cancer. Hence, by using the latter definition, a person is already considered to be a cancer survivor from the time of diagnosis (Khan et al., 2012). The NCSI uses a broad definition: “those who are undergoing primary treatment, those who are in remission following treatment, those who are cured, and those with active or advanced disease” (Department of Health, 2010). Some even go so far as to use the word ‘co-survivors’ to refer to relatives who have been close to those with cancer.³ This is particularly true in the United States. While many choose to identify with the term, I suppose there are others who consider the term ‘cancer survivor’ to be stigmatising. This might be true for those who have been cured of cancer and who have then put the disease behind them. They feel and perceive themselves to be healthy, and they wish to be considered as such (Kaiser, 2008). The survivorship concept could also be perceived as problematic for those with metastases or terminal cancer, since they are living with cancer on a daily basis. ‘Chronically ill’ is another term used for those living with cancer or the negative consequences that result from the disease or its treatment (Feuerstein, 2007). This can also be a controversial concept, since it evokes those who have chronic diseases (Album & Westin, 2008; Norredam & Album, 2007), which often have a low status in both healthcare services and the community. Those living with cancer will be a growing group in the future, as new life-prolonging treatments can provide an extended life expectancy of months, years and even decades to those with unresectable cancer.⁴

In recent years, a large amount of research and information concerning living with cancer, its consequences and the late effects has become available. Cancer associations, especially in the USA and England (e.g., National Cancer Society and Macmillan Cancer Support), are involved in many activities. In addition to providing information about the possible

² <https://kreftforeningen.no/om-kreft/uhelbredelig-og-kronisk-kreft/>

³ <http://www.cancer.net/survivorship/about-cancer-survivorship>

⁴ <http://www.cancer.org/>

consequences and the late effects of the disease and its treatment, such associations focus on the actions that survivors themselves can take in order to prevent and manage their condition, as well as the support that they should request from healthcare services and society at large. A prerequisite here is that research has been conducted on the consequences and late effects associated with the various forms of cancer and the numerous available treatments, since there are considerable differences in the medical, psychosocial and sociocultural implications of the various cancer diagnoses. In particular, qualitative research on cancer survivors and the latter two categories (i.e., psychosocial and sociocultural implications) that investigates the patterns in our understandings and practices, as well as how they are associated with the practical situation, is essential.

The term ‘cancer survivor’ is, however, still challenging. Cancer consists of many diseases that are very different from each other. Those who live with, or who have survived cancer, will have many different perspectives, face a range of challenges, and require varying types of assistance. Using a standard definition and perception of someone who lives with the consequences and late effects of cancer may therefore preclude some cancer survivors from obtaining the specific assistance they need. On the other hand, those who are cured of their cancer and who want to move on with their lives may feel stigmatised by being labelled with something that they feel is behind them. Nevertheless, I have chosen to use this term in the three papers because it is an established concept in healthcare internationally and in everyday speech. In this study, the participants are considered to have been cured of cancer, although the term may be used differently in the papers to which I refer.

Physical changes and concerns

One potential consequence of bone sarcoma treatment is disability. In the scientific literature, disability is an umbrella term. Functional impairment is referred to as a possession of the individual based on an individual and disease-related understanding. The biomedical perspective defines functional impairment as a defect or a deviation that must be cured or eliminated for a person to be regarded as normal and healthy (Siebers, 2008). However, not all aspects of being a person with a disability are part of the medical understanding.

Therefore, it has been necessary to develop a social comprehension of the phenomenon. In the social model, the focus is not on impairment as an individual defect, but rather on the

interplay between subjective function and ambient requirements, social injustice and changes in the physical and social environment. As Toby Siebers (2008) stated:

“Unlike the medical approach, the emerging field of disability studies defines disability not as an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but significant changes in the social and built environment” (p. 3).

In this thesis, I utilise the social model when discussing disability.

Disability comprises an individual’s reduced function with limitations on activity on the one hand and limitations on participation in different arenas and in different life situations on the other (Siebers, 2008). An identity as a person with an impairment comprises how you perceive yourself, as well as how others look at you and treat you. Galvin (2005) emphasises that taking on an identity as a disabled person may be related to increased dependence on others, loss of identity as an employee, and losses related to both body image and sexuality. In a society grounded on being normal and healthy, a person with a disability could therefore be excluded from participating in certain situations or activities (Barton, 1998).

For obvious reasons related to illness or disability, there will always be someone who cannot find their place in the labour market. However, according to the social model, a lack of access to work due to architectural barriers and discriminatory attitudes is the most disabling characteristic of contemporary society, and it often has little to do with the ability and willingness to employ those with impaired function (Galvin, 2005). Research indicates that having a functional impairment after cancer may lead to exclusion from the labour market in general or from certain jobs in particular (Brown et al., 2003; Rougraff et al., 1994).

Employment is one of the most important factors for social integration and it contributes to defining people’s social status and personal identity (Jahoda, 1982). Being excluded from employment as a result of cancer can affect people’s everyday structure, a structure that is built around work and that gives richness and meaning to life. Furthermore, this could result in a reduced social life, in addition to a loss of identity (Rasmussen & Elverdam, 2008). The change from being employable to being totally or partially incapacitated can be a challenge in a country like Norway, where most of the adult population is in work and where being employed constitutes the central norm. Being an outsider can be difficult to reconcile. For

young people, the late effects of cancer could also have an impact on their education and employment opportunities in the future (Kent et al., 2012).

Research indicates that physical activity has a positive effect on cancer survivors' well-being and general health (Conn et al., 2006; Speck et al., 2010). In a society that is largely based on being a healthy person, an individual with a functional impairment or disability might be excluded from participating in certain activities (Barton 1998). Former bone sarcoma patients with current impaired function might experience changes in their physical activity that result in limitations to their social life (Davidge et al., 2010; Earle et al., 2005), which is similar to the experiences described by people with a disability (Galvin, 2005).

One may construct and interpret disability within the categories of either 'us' or 'the other', or one might assume a perspective on deviation and normality (Solvang, 2002). According to Goffman (1963, 2007), identities are relational and so make little sense without defining 'the others'. The 'other' can be someone who violates the prevailing cultural norm within a group or a society, or someone who is subject to social control (Goffman, 1963). All societies are based on rules, norms and common interpretative frameworks. Those seen to violate these dimensions or those who do not fit in will often be regarded as deviants on the basis of, for example, their spiritual beliefs, political affiliations or sexual orientation, or due to their lifestyle, physical abilities or appearance (Hylland Eriksen, 2006). Someone who is different, who clearly stands out, who represents the cultural and physiological other, is, according to linguist and sociologist Jan Grue (2010), someone who is noticed and talked about. Grue is a wheelchair user himself. While having a normal body and an ordinary appearance, as well as being employed and healthy, are all regarded as normal, deviating from the norm makes you a subject for others to glance at (Grue, 2014). A person with a deviating appearance or behaviour following cancer treatment can be such a cultural and physiological 'other' – an individual who after the completion of treatment is expected to return to society with an altered and impaired body and so becomes the subject of new assumptions.

Appearance changes and body image

Contemporary society seems to place a great deal of importance on appearance and looking good. In particular, the exposure of 'ideal' bodies, especially on social media, is growing. Glossy magazines about the body and fashion, as well as professional books about the body, gender and culture that critically analyse and discuss the phenomenon, illustrate that the body

is an instrument which says something about the culture we live in. It reflects the limits, norms and ideals that exist. The body, as an individual project, has become part of our everyday life and it is popularly believed that we are responsible for how we appear. The modern body is being shaped and built in line with cultural expectations, with ideals that leave little room for otherness (Skårderud, 2006; Skårderud & Isdahl, 1998; Shilling, 1993).

A deviant appearance can be considered to be a form of social disability. It affects the self-esteem and behaviour of those who have a body that deviates from the current norm (Rumsey & Harcourt, 2004). As a cancer survivor, it can be challenging to live with a body that diverges from the current ideals of being healthy, attractive, active and employable. Body satisfaction and appearance probably represent the major contributing factors to self-esteem, since they are important elements of how individuals perceive themselves (Tiggemann, 2011). An individual's experience of their visible difference and the disruption to their bodily identity are both influenced by prevailing cultural norms regarding how a normal and attractive body should appear (Eagly et al. 1991; Feingold, 1992; Toombs, 1995). In body image research, individuals with bodily deviations frequently report negative self-perception and they experience difficulties in forming relationships (Rumsey et al., 2004; Thompson & Kent, 2001). It is challenging to expose a visible difference to others, since such individuals might face negative reactions and encounter the feeling of discrimination (Rumsey et al., 2004; Thompson & Kent, 2001).

Following radical surgery, many cancer survivors experience an altered appearance, which can have a significant psychosocial and emotional impact (Lehmann et al., 2015; Burg, 2015; Lehmann et al., 2014; Rasmussen et al., 2010; Rumsey & Harcourt, 2004). For some, this might constitute a change in their social status from being a healthy, active and attractive individual to being a person with a visible difference, which is sometimes accompanied by a significant functional impairment. Such changes might contribute to an altered identity, which might be perceived as a loss and hence result in social challenges. The physical change is concerned with how that person is subjectively affected as an individual and how he is seen by others (Cash & Pruzinsky, 1990; Galvin, 2005).

Previous qualitative research on the body image of cancer patients has mainly concentrated on an altered body following the removal of a breast (Brunet et al., 2013; Denford et al., 2011; Rasmussen et al., 2010), gaining weight and hair loss (Brunet et al., 2013; Larouche & Chin-

Peuckert, 2006), as well as disfigurement due to head and neck cancer (Fingeret et al., 2015; Konradsen et al., 2012). Among these, Rasmussen et al. (2010) described how cancer survivors tend to hide the physical changes, including scars, mastectomy, different looking hair and weight gain, in their body following cancer treatment because they feel that they will be avoided and/or viewed in specific ways. Costa et al. (2014) highlighted the prejudices and stigma associated with disfigurement due to head and neck cancer, as well as how survivors have to construct a new identity for themselves in order to accept and live with their new body image. Another qualitative study explored how female breast cancer survivors typically want to reconcile with their changed body and reduce the discrepancy between their post- and pre-treatment (or ideal) bodies (Brunet et al., 2013). One review study showed that adolescent males cope better than adolescent females with appearance changes in general following cancer treatment (Fan & Eiser, 2009). Despite many former bone sarcoma patients being young and likely to experience bodily changes after surgery, I cannot find any studies that explore how an altered appearance impacts their lives and identities.

Impotence as a result of neural damage can also occur in pelvic bone sarcoma survivors (Han et al., 2010). However, it is not customary to talk about impotence as part of appearance change. In a situation where one should have sexual interactions with others, this is an impairment that will be visible. Whereas in the past it was more common to mention impotence in connection with marriage and fertility, there is now, in both the media and academic literature, an increasing focus on men's sexuality and masculinity. There has been a shift in views on masculinity from the previous focus on men's reproductive capacity and qualities as a husband, to today's masculinity discourse wherein impotence is as much a social and cultural construction as a bodily affliction (McLaren, 2007). Erectile dysfunction no longer has to be a visible deviation for some of those affected. Drugs like Viagra mean that it is now possible for some men to hide their impotence and outwardly retain their masculinity.

With healthcare currently firmly rooted in a biological approach to disease and the body, it is difficult to see, as well as to explain in a reliable way, that a person's subjective, emotional and relational world strongly affects their health and self-image. Further, concerns about visible differences are poorly addressed in current outpatient care (Rumsey & Harcourt, 2004).

Perceived as being 'other'

Diseases and injuries can result in a wide range of changes to a person's life, as well as leading to challenges that might affect their interactions with others. Such challenges include impairments that are made obvious, for example, through limping or the use of walking aids. People who have a prosthesis or an amputated limb, and those who use crutches or a wheelchair, all have bodies that are quite different from the ideals that dominate in Western culture. Being disabled or visibly different means that a person deviates from what is perceived as normal, which may be stigmatising (Goffman, 1963; Murphy, 1987; Toombs, 1995). According to Paul Hunt (1966), a leading activist during the early years of the disability movement in Britain, it is common to perceive people with disabilities as being more dependent on others and perhaps even less intelligent. As indicated above, stigma in general terms means that a person is thought of as being 'other'. This can lead to many negative effects for those who are stigmatised. They can face prejudice and discrimination, and they are often victims of stereotyping (Goffman, 1963; Hunt, 1966; Murphy, 1987).

The Canadian-American sociologist Erving Goffman (1963), who is especially known for his work on stigma, argues that the notion of normality or the normal human has its origin in medicine's view of what a human being is and what normality and deviation represent. He adds that people are assessed and judged based on how they appear to others (Goffman, 1963). The 'stigma' phenomenon refers to how, one way or another, an individual differs from what is perceived as normal. This difference can either be physical (i.e., bodily deviations), mental (i.e., lack of concentration), or social (i.e., if one has, for example, an ethnicity or religion that violates the current norm). Goffman (1963) believes that this conception of normality provides people with a basic pictorial world in which they build their self-perception.

However, recent research suggests that the extent to which a visible difference results in a social disability actually involves a complex interplay between social and individual factors. Social control may affect those who have a body that deviates from what is considered beautiful and ideal in their culture (Goffman, 1963). Perceived stigma depends on both the situation and the person. It may also change over time. Goffman (1963) emphasises that people with a physical impairment or a difference in appearance do not experience negative attention and stigmatisation all the time and in all situations. In fact, the stigmatising conditions may be dependent on the situation and the context (Goffman, 1963).

Deviating from current norms regarding outer appearance or behaviour may cause embarrassment for both the person concerned and others. Fear, prejudice and hostility may all be attitudes that stigmatised people experience from others. The stigma may be innate as a form of physical damage, it may be related to an accident or illness, or it may be related to identity. It is not unusual for a stigmatised person to react to the situation with shame (Goffman, 1963). Shame is a non-rational response to bodily changes that may manifest in many ways. According to Sartre (1943, 1993, p. 33), shame is the experience of 'being-for-the-Other'. Shame is about being divested or revealed, whereby aspects of ourselves that we wish to hide are made visible to others. It may involve a loss of dignity and honour. Recent research shows that the concept of shame has changed in contemporary times. While shame was traditionally associated with family, relatives, traditions and sexuality, the contemporary notion of shame centres on identity, coping and self-image (Skårderud 2001; Frønes 2001; Wyller, 2001). The feeling of shame that many people experience due to having an illness often involves a visible change. In particular, a protracted illness that results in altered functionality and mental impairment might be deemed shameful. This may in turn decrease ill people's level of activity, affect their employment and income, and make them dependent on care for short or longer periods (Gulbrandsen, 2006). The reality of illness leading to the aesthetic consequences of an altered body image and visibly impaired functionality is not uncommon. A body that is changed as a result of disease can be experienced as being so deviant that it may affect a person's identity in a particularly negative way. This stigma may have consequences in terms of how that person presents themselves and their body to others in social interactions (Goffman, 1963; Nettleton & Watson, 1998). A better understanding of the various issues related to shame and guilt is important in health-related work, although the issue is all too often overlooked, despite the good faith of all those involved (Schei, 2006).

Identity changes and reorientation in life

From a psychosocial and sociocultural perspective, serious disease can be understood as a biographical disruption and a serious incident in a person's life (Bury, 1982; Sontag, 2002; Svenaeus, 2000, 2005). Not only are there disruptions to the ill person's biography at the time of diagnosis and during treatment, but also when any long-term consequences of that treatment are experienced (Frank, 1995). A patient is hence a person for whom illness has broken into their daily life and altered their life experiences. Their previous life story is

disrupted, as is their identity (Bury, 1982; Drew, 2007; Frank, 1995; Svenaeus, 2005). Serious disease may lead to a disruption in their expected life trajectory and biography, which leads to the need to create new narratives and reconstructed identities (Bury, 1982; Frank, 1995). This may influence both how they see themselves and how they perceive others to see them. This experience of otherness can lead to a sense of standing out from what is perceived as normal in a negative way, as well as to a reduced social life (Bury, 1982).

Even if Heidegger did not, according to Svenaeus (2005), conceptualise the phenomenology of disease, he did describe how people who have been struck by disease are thrown into a world of homelessness due to ceasing normal daily activities and entering into the world of illness. A depletion of meaning occurs that creates anxiety for ill people who are thrown into an unknown world. It is not only the body that is broken, but also a pattern of meanings. An ill person exists as a foreigner in the world – a world that offers resistance and acts as a source of frustration and suffering (Svenaeus, 2005). Illness also has a structure and a meaning in itself. Svenaeus (2001) states that illness is a certain way to “be in the world” (p. 62). Unlike when we are healthy and in a world of everyday proverbial chores that are well known to us, a serious illness forces us to interrupt our daily chores and thus be thrown into an unknown world of illness where we feel homeless. This homelessness or alienation makes our horizon of understanding shrink so that everything is driven back to our ailments. The world is no longer a home, but something alien, a source of resistance, which has been dislocated (Svenaeus, 2005).

With reference to Heidegger, Svenaeus (2005) emphasises that disease and the sequelae of disease are not just a deviation from health and normality that interferes with the meaningfulness of our lives. Heidegger was concerned with the role played by both the body and language in these processes. The body is not only lived, but also experienced in the sense that Heidegger believed it to create meaning. He spoke about illness and the consequences of disease as a lived and meaningful experience, with our feelings being an essential part of this experience (Svenaeus, 2005). Being cured of cancer is not the same as being healthy or returning to the normal life you had before the cancer struck. The late effects of cancer and the associated treatment also represent a break from one’s previous life and the opportunities that existed prior to the cancer diagnosis. For many, it is about entering a new phase of life that is governed by different conditions and terms than before (Drew, 2007).

Sociologist Sarah Drew's (2003) qualitative work on childhood and adolescence states that being a cancer survivor means taking part in a social process involving the complex negotiation of identity issues, future planning and future health concerns. It reflects a consciousness that requires a complex process of self-reconstruction and biographical revision in order to cope with the unpredictable situation of being in a new world following the cancer experience (Drew, 2003). In their qualitative study of former bone cancer patients, Parsons et al. (2008) note that such a serious diagnosis causes serious disruptions and changes in cancer survivors' lives. Their participants expressed changes in their health, identity changes and changes in their vocational life. They further emphasised that having been a bone cancer patient meant having to break away from the life they had before the cancer struck, a life characterised by being healthy and employable, and become accustomed to a new identity. This change in identity involves moving from being healthy to being ill and, furthermore, to being disabled and perhaps unable to work. It presupposes hard work and reflection, which are essential to getting back on track with life.

After having been affected by a serious disease and its consequences, people might have to reorient their life and construct some sort of new identity using their affected body as the starting point. This might help cancer survivors to create new meaning in their life, both in terms of understanding themselves and recognising new limitations (Bury, 1982; Frank, 1995; Svenaeus, 2005).

Experiences of positive growth following cancer

Previous research on people's reactions following traumatic events has mainly focused on the negative consequences. However, research in the field over the last 15–20 years has shown that this is too narrow a description of the situation of people who have experienced severe losses (Calhoun & Tedeschi, 2013; Morris et al., 2005). In retrospect, major emotional stresses can also lead to positive changes; hence, a more holistic view of post-traumatic adaptation and research on post-traumatic growth (PTG) have increased significantly in recent years (Calhoun & Tedeschi, 2013). The term was coined by psychologists Richard G. Tedeschi and Lawrence G. Calhoun at the University of North Carolina mid-nineties (Calhoun & Tedeschi 1995). PTG is described as the positive consequences that emerge through the processing of a traumatic experience and that lead to growth and personal development (Calhoun & Tedeschi, 2013). It is not concerned with any positive aspects of

having experienced a trauma, but rather with the paradox that such an experience, despite the major negative consequences and losses involved, can provide fertile ground for personal growth and change. Calhoun and Tedeschi (2013) summarise the positive change and growth after having encountered major challenges as follows:

“Common elements of the experience include a changed sense of self, a change in experience of one’s relationship, and a changed philosophy of life. The change in self-perception may include an increased sense of vulnerability, but also an increased experience of oneself as capable of surviving suffering and of dealing with subsequent major problems in life. Positive changes in relationships can include a deepening of relationships with important others, a greater sense of compassion and sympathy of others who suffer, and a greater freedom of truthfully expressing oneself to others. Finally, some people report a greater appreciation for life, a changed sense in priorities, and meaningful changes in religious, spiritual or existential elements of their lives” (p. 13).

Positive change and personal growth following cancer have also been documented by both quantitative (Thornton, 2002) and qualitative research methodologies (Barskova & Oesterreich, 2009; Helgeson et al., 2006). Among cancer survivors, higher levels of personal growth, both with an increasing time from diagnosis and a younger age (Cordova et al., 2001; Danhauer et al., 2013; Searset et al., 2003), have been found. Thornton’s (2002) review of benefit finding in the cancer experience reports that a ‘substantial proportion’ of previous cancer patients link positive changes in terms of their life perspective, relation to others and relation to self with their cancer and illness experiences. In some studies, the majority of adolescent cancer survivors report personal growth (Barakat et al., 2006), including long-term survivors of osteosarcoma (Yonemoto et al., 2009). In one study, however, PTG was significantly lower among adolescent and young adult survivors of bone sarcoma than among other cancer survivors (Arpawong et al., 2013). Evidence suggests that psychological resilience may be present among adolescent and young adult survivors who have been treated for bone tumours in the lower extremities (Teallet et al., 2013). A comprehensive review of the PTG research from 1960 to 2004 (Stanton et al., 2006) that combined the word ‘cancer’ with ‘benefit finding’, ‘post-traumatic growth’ and ‘positive change’ revealed that the related research is extensive, albeit conceptually and methodologically weak. However, there has been a distinct shift from focusing on the negative consequences of cancer and its treatment to also looking at cancer as an opportunity for positive change and growth (Stanton et al., 2006).

The cultural context is essential to how illness is experienced by an individual and how it is perceived by society. Research indicates that different societies perceive and handle positive growth differently (Calhoun & Tedeschi, 2013; Shakespeare-Finch & Copping, 2007). It is argued that people in the United States grasp the positive aspects of tough and traumatic experiences to a greater extent than those from other cultures (McMillen, 2004), especially with regards to religiosity, spirituality and sympathy (Shakespeare-Finch & Copping, 2006). However, not everyone agrees that cancer is something good and that it leads to positive growth. In her bestselling book, *Bright-Sided*, Barbra Ehrenreich critically challenges pink ribbon culture and the way in which cancer has been embraced in the United States, where cancer might seemingly be regarded as a gift rather than an illness (Ehrenreich, 2009). Ehrenreich clearly states that her breast cancer never did her any good.

Some even question whether cancer survivors, based on the long-term course of their disease, their vulnerability and the uncertainty related to the disease, actually belong in the post-traumatic growth category. A recent review compiled the latest studies of PTG in cancer survivors and contrasted the real but also illusory nature of PTG and its adaptive value (Sumalla et al., 2009). This paper explains why cancer may be different from other traumas and why PTG may interact differently with the ecology of circumstances.

On the basis that Calhoun and Tedeschi (2013) themselves use stories told by cancer patients and their families as examples in their books, I have chosen not to discuss whether or not cancer can actually result in PTG, but have instead opted to see whether the participants in my study conveyed any positive experiences. Another question that it is natural to ask in this context concerns the value that post-traumatic growth really has (Calhoun & Tedeschi, 2006). Positive change following traumatic events will always come at the cost of something. Is the growth really worth the loss of this ‘something’? Yet, it remains legitimate to talk about positive change and personal growth, despite claims that the price one has to pay in this regard is high.

II. Study perspective and research aims

This thesis explores how former primary bone sarcoma patients experience the physical and psychosocial consequences of the disease several years after treatment. A sociocultural perspective on health and illness is adopted. In order to understand how life is experienced in the wake of a serious cancer diagnosis and the resultant treatment, our aim was to draw an association between the biological concept of illness and the significance that the individual and society place on disease and illness, as well as how it is interpreted and addressed in our particular culture.

The following research questions were therefore formulated:

1. How does functional impairment as a result of bone sarcoma treatment in the hip/pelvic region impact former patients' daily life, ideas about future and sense of identity?
2. How do cancer and its treatment influence the life of long-term survivors of osteosarcoma in a lower extremity?
3. How do changes in body image following surgical treatment affect the daily life, self-esteem and identity of long-term bone sarcoma survivors?

III. Theoretical context

This chapter provides an overview of the theoretical context in relation to health, illness and culture that is applied when I describe, analyse and discuss the findings of this study. A reflection on how I understand health and the concepts of disease and illness, as well as how culture affects how we perceive and consider illness and those who suffer, has been of major importance to this project. This reflection has significantly influenced the findings, analyses and discussion contained in this study.

Concepts of health

There is no unambiguous answer to the question of what good health actually is. How we understand health and how health can be achieved are significant in terms of what we anticipate our healthcare system to need to deal with. While various health models exist, the two models I want to briefly present here are the biomedical health model, which is based on traditional medicine, and the holistic health model, which arises from the World Health Organization's (WHO's) definition of health.

Within the biomedical health model, health is defined as the absence of disease (Boorse, 1977). Disease is here understood as any deviations from healthy and so from the norm. Following the biomedical approach, disease is an organic process that affects the body and is objectively observable. The doctor's job is to fight disease and repair the body. This is a disease model that could be described as reductionistic and hence criticised for being too narrow. Such a model focuses on cure and survival, but it says nothing about the more existential, relational and contextual aspects of life, as well as the quality of life of those who survive. Cancer treatments are prerequisites for cure, but they are not sufficient. For those affected by cancer, the actual life they are living, their relationships and their social environment are all important.

The health concept espoused by the WHO is far more comprehensive and inclusive than that of the biomedical approach. The WHO proclaimed its definition of health in 1946: "Health is a state of physical, mental and social well-being and not merely the absence of disease or infirmity."⁵ Here, the WHO has established a holistic perspective on health that broadens its medical, social and political role. The WHO's definition of health has faced much criticism,

⁵ http://www.who.int/governance/eb/who_constitution_en.pdf

since it not only defines health as involving the absence of disease, but also includes happiness and well-being. The Swedish philosopher Lennart Nordenfelt opposes the biomedical model wherein health is seen as solely the absence of disease, although he has also criticised the WHO for its holistic and idealistic definition. Nordenfelt (1993, 2007) claims that both definition are too narrow to define the concept of health, which is inherently extensive and complex. He instead promotes his own articular-holistic health concept (Nordenfelt, 1993, 2007), which stresses that health must be linked to action and function.

The individual's ability to cope and his/her opportunities to achieve vital goals are more important than whether an individual is defined as healthy or ill (Nordenfelt, 1993). In addition to being able to maintain vital goals and everyday activity, I interpret that his concept of health involves one's ability to receive an education and to work, to have an active and social life, and to have the opportunity to form close relationships and establish a family. He points out that it is not necessarily an either/or issue. Both health and disease can be present simultaneously (Nordenfelt, 1993, 2007). This may be of particular relevance to both those who have survived cancer and those who have a disability.

According to the German philosopher Hans-Georg Gadamer (1996), health is a way of being in the world, one that is concerned with being in a meaningful relationship with others. He emphasises that one cannot only divide health into somatic and psychological issues, but that health is a part of a being's completeness (a whole of being) where we find our own well-being in the world in which we live. He characterises health as a natural equilibrium where disease will disrupt this balance. He points out that good medical art simply involves helping patients and others who are in contact with the healthcare system to restore that balance. Gadamer (1996) warns that modern medicine's unilateral focus on science and technology can interfere with seeing the whole person, including one's health challenges and opportunities.

It is, however, not necessarily true that the absence of disease is the same as having good health and a meaningful life (Nordenfelt, 1993, 2007). For those who have been cured of cancer and who are living with the consequences of the disease and its treatment, a holistic view of health on the part of healthcare providers may be crucial to how they are met and handled by the healthcare system.

Perspectives on disease

What exactly a disease is, and what the terms ‘disease’, ‘illness’ and ‘sickness’ entail, have been discussed for decades. Indeed, there is still no consensus on how these terms should be defined and understood (Hofmann, 2002). The terms and their distinctions are well known in academic traditions such as medical anthropology, medical sociology and medical philosophy. Yet, in everyday talk, they are not equally unambiguous. The first person to apply this triad was Andrew Twaddle in 1967 (Twaddle & Nordenfelt, 1994). These three terms, which can be associated with both diagnosis and treatment, as well as with patients’ suffering and sick role, are relevant to health professionals, patients and society, and they provide different answers to the question of what illness is. At the same time, the various terms relate dissimilarly to some actors (Hofmann, 2002; Hofmann, 2008). Hence, in this thesis I have made a clear distinction between the perspectives of ‘disease’ and ‘illness’.

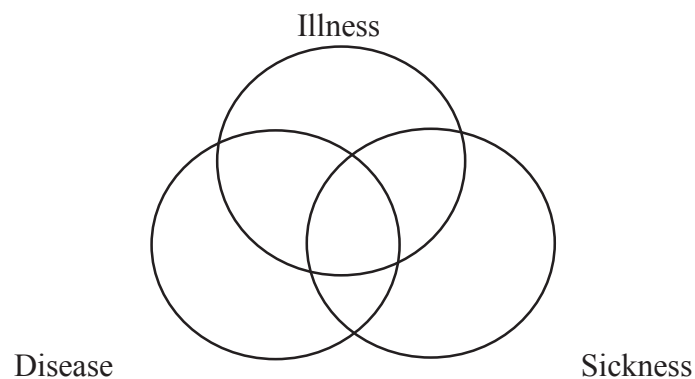
As stated by Eisenberg (1977), “patients suffer ‘illnesses’; physicians diagnose and treat ‘diseases’.” He acknowledges that illness and disease are synonymous, but he makes it clear that there is a semantic distinction between the two:

“illnesses are *experiences* of disvalued changes in states of being and in social function; disease, in the scientific paradigm of modern medicine, are *abnormalities* in the *structure of function* of body organs and systems” (Eisenberg, 1977, p. 11).

Illness applies to the patient’s personal experience with a disease, with the causes, diagnosis, treatment and consequences (Eisenberg, 1977, Kleinmann, 1988). On the other hand, disease is based on a medical-scientific approach concerned with locating and classifying in order to diagnose, treat and alleviate based on the objective symptoms and signs (Hofmann, 2008). A patient’s suffering (illness) is often derived from disease, although it may also be the designation of symptoms prior to diagnosis, diffuse and undiagnosed pain, distress or suffering, or illness without disease (Eisenberg, 1977). The last perspective, sickness, is concerned with being perceived as ill in a social and cultural context. It is what gives you rights, access to healthcare, social security, as well as an exemption from duties. Sickness gives you legitimacy and the excuse of being ill, which also contributes to shaping our attitudes toward disease and ill people in society (Hofmann, 2008). It should be noted that ‘malady’ is a fourth designation that refers to all three of the perspectives mentioned above (Mukherjee, 2010).

Figure 1 shows how the three perspectives overlap with each other, although they can still be understood from different perspectives and within different traditions (Hofmann, 2008). When there is a lack of concurrence between the various actors' understanding of these concepts, it may lead to considerable challenges in terms of communicating and understanding what disease and illness are, as well as how the actors should relate to each other. It could also affect the kind of treatment the patient receives and the type of economic rights that are available.

Fig. 1



Being ill and having a serious disease not only affects a part of the body or an organ, but also impacts the individual's social, intellectual and emotional needs (Eisenberg, 1977; Kleinman, 1988; Svenaeus, 2005). Illness and disease also have linguistic and cultural dimensions. The way we speak and write about disease and illness will influence our attitudes and experiences (Gadamer, 2004, 2012; Svenaeus, 2005). Furthermore, the attitudes and perceptions related to the illness within a particular society will influence how former cancer patients experience their illness and their life as a cancer patient or a cancer survivor with physical and psychosocial challenges.

The three dimensions (i.e., the biological-physiological, the experience-based-phenomenological, and the linguistic-cultural) are not separate concepts, but rather they can serve as complementary approaches to understanding disease, which is of course a multidimensional phenomenon (Svenaeus, 2005). The three perspectives are hence all

necessary for a complete description of the phenomenon. Indeed, Sveaneus (2005) states that a complete separation of these three dimensions is not feasible:

“They are entwined in different ways. One way to understand the differences between the three layers that give disease/illness meaning, is to say that biology gives the cause relationship explanations to the actual disease, whereas phenomenology provides an understanding of the experience of the illness, and the language links biology and the perception of illness to the culture” (Sveaneus, 2005, p. 34).

However important and detailed the physician’s diagnosis and treatment are, they cannot provide a complete understanding of the patient’s situation. The phenomenological perspective is based on interpersonal encounters within the people’s meaningful lifeworld and not on his/her biology. First and foremost, the patient is an ill person for whom illness has broken into life and changed his/her life experience (Frank, 1995; Helman, 2007; Sveaneus, 2005). The current study will focus on the point of intersection between our understanding of experienced illness and the linguistic-cultural perspective regarding cancer in particular.

Culture and illness

As mentioned above, our culture affects the way we perceive and consider illness. On one hand, our traditions, experiences, values, employment and economic situation all contribute to our perceptions of health and illness. On the other hand, interest groups, patient organisations, political movements and the pharmaceutical industry are all powerful forces that shape our perceptions (Helman, 2007, 2008; Lupton, 2012). Adopting a sociocultural perspective on illness involves exploring the relationship that exists between biological processes and the disease itself, as well as the meaning placed on this relationship by individuals and society in general (Ingstad, 2007). As stated above, illness is, on the whole, the patient’s or the survivor’s own perspective, although it also plays a role in the meaning of disease and how this meaning is communicated to society. It is in this arena of experiencing and witnessing disease that the hidden dimensions of illness can be found. First, there may be suspicion regarding the seriousness of the patient’s ailments, while second, there is the grief that is experienced due to the loss of life’s possibilities, a lack of energy, and all the other negative experiences associated with being ill (Kleinman, 1988).

Our culture can modify and shape illness in a variety of ways. Interpretation patterns, beliefs, attitudes, norms, language, values and symbols are all examples of cultural phenomena that have been shaped and changed by the interactions between humans and the influences of sociocultural forces (Grimen & Ingstad, 2006). Both the patient's role and the roles of the other actors involved in illness and health vary within and between different societies and cultures, and these roles have also evolved and been modified throughout history (Lie, 2007). The ways in which we interpret symptoms, as well as the cultural ballast we carry with us, relate to our previous experiences and, in particular, to the responses that we receive from our own specific environments when we are ill. How we present our symptoms and how we react in our encounters with healthcare services and the public are also culturally determined (Ingstad, 2007). We learn from our cultures how we are expected to withstand and cope with illness, as well as obtaining guidance about the meaning to be found in suffering. We relate to illness, pain, causal relationships and forms of treatment in different ways:

“People's experience of illness is determined by social and cultural categories. The 'characters' we express being ill, are socially and culturally learnt. The patient presents a change in his behaviour that the environment then can interpret as illness. These ways of communicating illness, are learnt in the same ways as we are taught to communicate social roles or identities” (Alver & Selberg, 1992, p.113, my translation).

It is not just the illness experiences of patients that are influenced by their cultures. The perspectives and attitudes of physicians towards illness are also affected by the cultural and social aspects of norms, values, economy and technology. At the same time, physicians' views on various diseases have an impact on society's discussions about health, as well as on how different groups of patients are treated in the healthcare system and perceived in society. A survey of physicians and medical students demonstrated that medical specialties, as well as diseases, are ranked by prestige (Album & Westin, 2008). Oncology and cancer are at the higher end of the scale, while chronic diseases and mental illnesses are the furthest down, with fibromyalgia being right at the bottom (Album & Westin, 2008). Furthermore, a literature review on the prestige ranking of diseases and medical specialties demonstrated that organs in the top half of the body, as well as conditions affecting the young and middle-aged male, were prioritised (Norredam & Album, 2007). Moreover, active, highly specialised medicine, advanced surgical treatments, and treatments requiring advanced technology ranked the highest. Incurable cancer is one of the diseases that ranked low, since, in general,

incurable diseases ranked low (Norredam & Album, 2007). A cancer patient is therefore someone who has travelled in the first class carriage through the healthcare system until, that is, their cancer treatment is completed. How does it feel then, when, due to the various consequences of the disease and its treatment, the cancer survivor ends up grouped with those with chronic illnesses, those with diffuse and incurable ailments?

IV. Methodology and research process

In line with the study's overall objectives, research questions and psychosocial and sociocultural perspective, I have adopted a qualitative design grounded on a phenomenological and interpretative approach, with interview forming the basis for data collection. Conducting qualitative research involves being concerned with how something is experienced, appears, is done, or is expressed. It may be related to describing, understanding and interpreting or deconstructing phenomena that exist in human experiences, as well as the meaning that the individual places on experiences, and actions at an individual or collective level, either specifically or abstractly (Brinkmann & Tanggaard, 2015). As Kvale & Brinkmann (2009) note, a qualitative orientation primarily emphasises that:

“the process and phenomenon of the world are described before theorized, understood before explained, and seen as concrete qualities before abstract quantities. The qualitative stance involves focusing on the cultural, everyday, and situated aspects of human thinking, learning, knowing, acting, and ways of understanding ourselves as persons, and it is opposed to ‘technified’ approaches to the study of human lives” (p. 31).

To get close to the participants' experiences and their lifeworld, as well as to grasp the meaning of their experiences prior to scientific explanations, has been the overall aim of this research. I have aimed to describe and understand the experiences and challenges of persons living with late effects following bone cancer treatment as the participants themselves perceive and describe them. Kvale & Brinkmann (2009) perceive the research interview in this context to be a professional conversation. By conducting interviews, I will gain access to different people's experiences of phenomena in their lifeworld; that is, the world they experience in everyday life and from a first person perspective (Tanggaard & Brinkmann, 2015a).

In this chapter, I will begin with a brief introduction to interpretive phenomenology in qualitative research. Then, I will describe and reflect on the research process, how I have collected data, coded and analysed the material, and the ethical considerations that have arisen during the process, as well as discussing the choice of method and quality criteria that are central to this study.

Interpretative phenomenology

According to Edmund Husserl,⁶ the German philosopher considered to be the founder of phenomenology, the ambition of phenomenology is to study phenomena as they appear by themselves. Effectively, one should try to understand the world and phenomena by studying how they are presented to the subjects in their lifeworld (Svenaesus, 2005). The term ‘lifeworld’ is central to phenomenology. It refers to the meaning pattern that constitutes the background of our conscious actions, and it is concerned with the specific reality that we can experience and are familiar with by acting. We sense and feel in relation to the world we live in, as it reveals itself to us in our consciousness. An individual’s consciousness is perceived as intentional, meaning that it is directed against something different from itself. It is this pre-scientific experience (i.e., the lifeworld) that should be the basis for describing phenomena (Svenaesus, 2001). According to Swedish philosopher Svenaesus (2002), Husserl’s philosophy is based on:

“A detailed description (the philosophical method) of various experiences of the world, where in the consciousness take diverse forms and have different contents, may find basic structures which are unchangeable, meaning structures which do not vary from person to person without that they constitute a meaning pattern which the world is molded in, for example, spatial, temporal and logical relationships” (p. 540, my translation).

Heidegger⁷ also demonstrated his starting point in specific human experiences when he developed phenomenology as research into human existence (i.e., being-in-the-world) in his major work *Being and Time* (Svenaesus, 2002).⁸ Svenaesus (2002) points out that the human historical and cultural world of phenomena such as feelings, actions, language and communication is of crucial importance to how the structure of our meaningful world is constructed.

When describing lifeworld structures in phenomenology, it is vital to obtain and visualise the meaning that exists implicitly in everyday life (Svenaesus, 2001). In this study, I attempt to describe and understand the phenomena that one takes for granted in everyday life, but that influence how the world is perceived. By using a phenomenological approach in contrast to,

⁶Edmund Husserl (1859–1938) (Moran & Mooney, 2002).

⁷ (Heidegger, 1962; Heidegger, 2007).

⁸ I have chosen not to deeply explore the original texts of Husserl and Heidegger, but instead to refer to others who apply these within the healthcare and medical field.

for example, discourse analysis, the interview can act as a medium that expresses human experience that is preferably situated outside the interview interaction (Tanggaard & Brinkmann, 2015a).

In what is referred to as medical phenomenology, one seeks to describe and understand social and cultural phenomena in health and medicine on the basis of the actor's perspective, as well as to describe the world as it is experienced by the individual themselves (Gadamer, 1996, 2004; Svenaeus, 2005). Svenaeus (2005) divides medical phenomenology into three meanings, all of which are relevant to my study. First, people in an everyday sense provide detailed descriptions of situations and experiences about living with illness, as well as about how to meet the ill. Second, medical phenomenology is a qualitative method for studying empirical data in order to gain insight and describe personal experiences. Finally, it also involves a philosophical theory wherein one tries to answer general questions regarding the nature of health, human beings, or disease and illness (Svenaeus, 2002). In this project, the aim was to situate participants' experiences in a context where they were asked some general questions about how the nature of their illness and their suffering can best be understood.

A criticism that several commenters have raised against phenomenology is that a purely descriptive approach is not sufficient to understand meaningful phenomena, since we all interpret what we feel and experience differently. An interpretative shift in phenomenology has therefore become common in qualitative research, where the purpose of interpretation is to achieve a universal and valid understanding of what a text or action means (Jacobsen et al., 2015; Svenaeus, 2005). While the subject of classic hermeneutics was originally text, in recent years it has been expanded to include the interpretation of discourse and action, particularly meaningful action (Kvale & Brinkmann, 2009). In hermeneutics, comprehension develops through the entire process of understanding, and it is based on both the participant's and the researcher's pre-understanding phase, as well as the historical and cultural context (Gadamer, 2004; Kvale & Brinkmann, 2009).

The researcher's intentions and pre-understanding are fundamental in hermeneutics. The components that make up a particular researcher's pre-understanding may include language and concepts, their own personal experiences and their beliefs (Gadamer, 2004; Kvale & Brinkmann, 2009). An important element of qualitative research concerns the researcher's pre-understanding and prejudice, both when interpreting a text and meeting a participant

(Gadamer, 1996, 2004). Hence, in hermeneutics it is essential to determine how the researcher's pre-understanding and prejudice affect the entire research process, from the choice of design and research questions in an interview situation to how the data material is encoded, interpreted and presented. This determination should be both transparent and reflective in order to ensure the credibility and integrity of the research (Kvale & Brinkmann, 2009). This issue will be expanded on later in this thesis when I discuss my role and perspective regarding this project.

Another essential aspect of hermeneutics is the notion that meaningful phenomena are understandable within a context. In fact, it is the context in which they occur that gives a specific meaning and basis for understanding (Gilje & Grimen, 1993; Kvale & Brinkmann, 2009). There are numerous challenges for researchers when it comes to understanding and interpretation. According to the double hermeneutic theory, scientists have to deal with a reality that is already interpreted by the actors themselves. This means that I must use theoretical concepts to reconstruct the actors' interpretations and go beyond their own understanding. Interpretation is to a large extent based on the researcher's experience, assessment and judgment, and it will therefore always be uncertain and auditable in the context of new information (Gilje & Grimen, 1993).

In sum, inspired by interpretative phenomenology and a hermeneutical orientation, the aim of this study is to describe and interpret the participants' experiences of returning to and functioning in society after being cured of bone cancer. My intention is to link the biomedical aspect of cancer to the former patients' experience and the linguistic and sociocultural context the participants live in. Those who are interviewed make meaning by sharing their experiences and interpretations of their own lifeworld in terms of what it means to be ill or disabled (Toombs, 1995).

Participants and recruitment

This study is based on experiences expressed in the narratives of 18 former bone sarcoma patients who were treated at the NRH OUH. The participants were identified from the prospective clinical sarcoma database (Med Insight) at the NRH OUH. Approximately 80% of bone sarcoma patients in Norway are treated at the NRH OUH (Berner et al., 2014).

The inclusion criteria for participation in this study were that participants should have been diagnosed with bone sarcoma of the hip/pelvic regions or lower limb three to ten years ago. Additionally, they had to present as being cured of the cancer at the time of selection. Both genders were represented and all participants were aged between 18 and 60 at the time of interview. As many bone sarcoma patients are young, some participants had of course been diagnosed while they were still in their early teens. This might have affected both their cancer experience and their perspectives on future possibilities, thereby potentially leading to a different overall impact than that experienced by middle-aged persons. The participants came from diverse backgrounds. People with known mental illness were excluded from the study. All those who participated had to be able to both speak and write Norwegian. After searching through the sarcoma database, it was found that only 20 former patients met the inclusion criteria. Initial contact with the potential participants was made by telephone by the treating physician at the NRH OUH, who also informed them about the project. Eighteen of those contacted agreed to receive further information about the project. Subsequently, all 18 were contacted by me with further details about the study and appointments were made to interview them. Written information about the study and consent forms were also sent to all participants.

All participants were diagnosed with bone sarcoma between 2002 and 2009 (from Paper III, Table 1), and all of them were undergoing follow-up at the oncological or orthopaedic surgical outpatient clinic at the NRH OUH. They were all treated with surgery (from Paper III, Table 2). Fourteen participants received chemotherapy, while two received additional radiotherapy. One participant subsequently underwent an amputation with a hemipelvectomy due to chronic infection. None experienced a relapse of the disease for at least three, and up to a maximum of ten, years following primary diagnosis.

Table 1 – Demographic and clinical data

| | Group 1 Hip/Pelvis | Group 2 Lower extremity |
|--------------------------|-------------------------------|------------------------------------|
| | Number | Number |
| Gender | | |
| Female | 3 | 4 |
| Male | 7 | 4 |
| Age | | |
| 18–25 | 3 | 3 |
| 26–35 | 3 | 1 |
| 36–50 | 2 | 4 |
| 51–60 | 2 | |
| Diagnosis | | |
| Osteosarcoma | 2 | 8 |
| Ewing’s sarcoma | 5 | |
| Chondrosarcoma | 3 | |
| Time of diagnosis | | |
| 3–5 years ago | 5 | 3 |
| 6–10 years ago | 5 | 5 |
| Treatment | | |
| Surgery | 10 | 8 |
| Chemotherapy | 7 | 7 |
| Radiation | 2 | |
| Amputation | 1 | |

Table 2 – Surgical interventions

| Surgery treatment | Number |
|--|---------------|
| Hip transposition (1 with later amputation and hemipelvectomy) | 3 |
| Saddle prosthesis | 1 |
| Fibula-graft reconstruction | 4 |
| Only tumour resection without reconstruction | 1 |
| Autograft microvascular reconstruction | 1 |
| Tibia prostheses | 4 |
| Femur prostheses | 4 |
| Colostomy and urostomy | 1 |

Data collection

All data were collected through in-depth interviews conducted face-to-face following a routine clinical appointment at the NRH OUH during 2012 and 2013. Sixteen interviews took place in my office. Mobility issues meant that two participants had to be interviewed in an office at the outpatient clinic. One participant brought his wife with him to the interview. Before the interviews started, I thoroughly informed the participants about the project. The

participants were shown the journals where the study's results were intended to be published and they were given an example of a qualitative paper on bone sarcomas. My role as a PhD student was explained, as was the research process. I informed all participants that I was not a health professional, but that I had a background in humanities and had previously interviewed cancer survivors. The participants were thoroughly prepared regarding how the interviews should proceed and they were informed of what the interviews' content would be. They were also made aware that they could limit what they were willing to talk about in terms of both their cancer and their lives, and that they were free to stop the interviews at any time. Finally, I promised to keep them informed throughout the PhD process by providing information about the project's development once or twice a year. They will be offered a copy of the thesis, as well as information about the disputation. I obtained a signed declaration of consent from every participant before the interviews started.

The interviews lasted for an average of 67 minutes (ranging from 30 minutes to 104 minutes) and they were all audiotaped. Field notes were made following each interview in order to document my observations and reflections. All interviews were conducted by me, although the principal supervisor was also present for one interview. The complete interview guide, which is available in the appendix to this thesis, comprised the following topics: (1) how the participants experienced their cancer diagnosis and treatment; (2) the functional, practical, psychosocial, emotional and vocational consequences of the disease and its treatment; and (3) whether they felt the cancer experience had changed them as a person. After the first three interviews, I went through the transcripts and interview guides with the study's supervisors and adjusted the order of the questions. It was decided that the interview guide should appear less detailed so that I was able to be more flexible during interactions with the participants. The interview guide was designed to allow the participants to chronologically narrate their entire cancer story. Many participants expressed that they appreciated the opportunity to share their stories. The interview guide was, however, only loosely followed, so as to allow the participants to strongly influence the depth of the interviews.

During the interviews, I began each topic with open-ended questions, while the follow-up questions were often more detailed and specific. On several occasions, I asked participants to elaborate on what they had said in order to guarantee that their meaning had been correctly understood. Unlike the more established forms of empathic and consensus seeking interviews, I maintained an active style where appropriate and confronted participants with some of their

own statements (Kvale & Brinkmann, 2009). Through such an approach, each interview becomes an interpretative and active process whereby structure and meaning are jointly produced by the participant and the researcher. As such, certain interpretations emerged on both sides during the interviews, thereby enabling the confirmation or rejection of the interviewer's perceptions of what the participants had expressed (Kvale & Brinkmann, 2009). How active I was able to be during the interviews depended on the participants. In some cases, I had to proceed cautiously. In contrast, some of the younger men in particular were surprisingly open and interested in discussing their experiences. To the greatest extent possible, I also tried to meta-communicate about how the conversation and interaction worked. Following the interviews, when the recorder had been turned off, many of the participants talked even more freely. Some brought up how they could get help with cancer-related ailments, while others expanded their story with topics that had not been covered in the interviews. This information was not transcribed, although some of it was written in my field notes, which were then used to enhance comprehension of the data.

The interviews were transcribed verbatim to an appropriate level of detail by me (n=8) and a medical secretary at the NRH OUH (n=10). The transcripts have been checked against the tape recordings to ensure that the text is accurate. In line with the phenomenological tradition, the interview is a medium with which to explore human experience and so it does not equal an end in itself. In the transcripts, the pauses or repetitive "eeeh" sounds that many sentences started with were not noted. This approach was chosen because I did not consider such statements and sounds to be beneficial information. The content of the statements and the participants' experiences formed the main basis of the subsequent analysis.

Data analysis

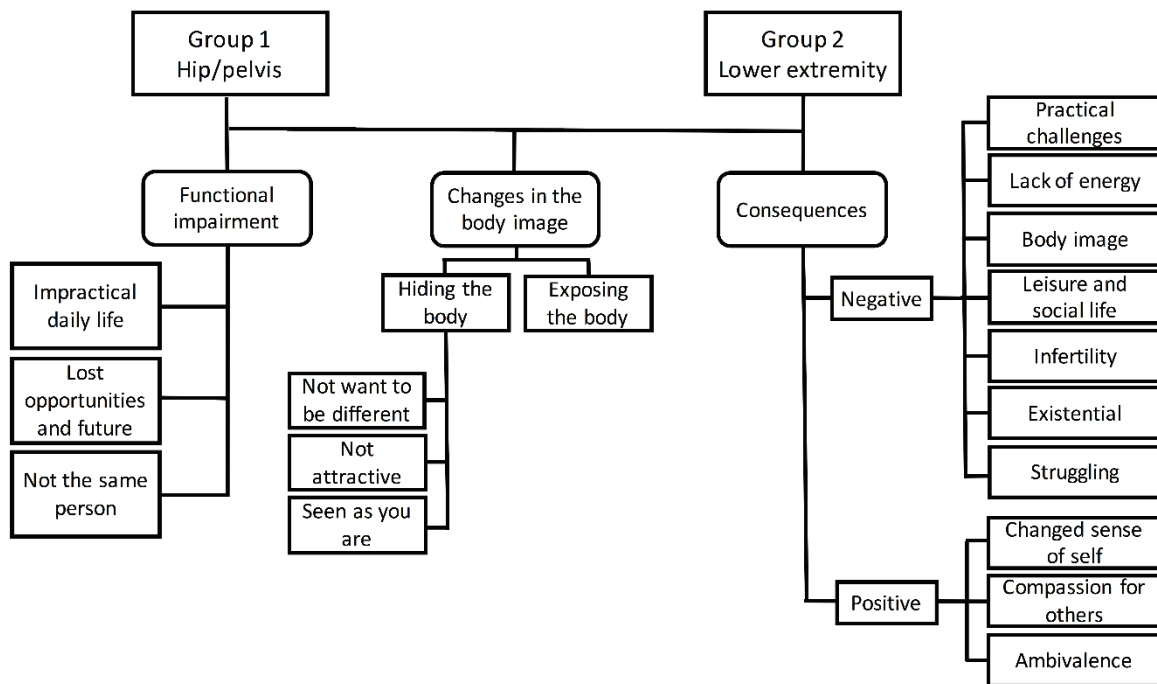
Thematic analysis is a method that has been widely used across the social, behavioural and more applied sciences, including clinical practice, health and education (Braun & Clarke, 2006). The purpose of the method is to identify patterns of meaning across a dataset that provide an answer to the research question being addressed. Patterns are identified through a rigorous process of data familiarisation, data coding, and theme development and revision. One of the advantages of thematic analysis is that it is theoretically flexible (Braun & Clarke, 2013). It can hence be used within different frameworks and to answer quite different types of research questions. Thematic analysis particularly suits questions related to people's

experiences, views and perceptions. As the current research project involves a large and comprehensive dataset, inductive thematic analysis is the method that was considered to best provide the necessary possibilities and flexibility.

The participants' accounts underwent an inductive thematic analysis (Braun & Clarke, 2006). The transcribed interviews were read to obtain a general overview of what they included and to identify the preliminary theme. This was subsequently put aside and the results were not taken into account when coding the material at the next stage. In this thesis, I coded all the material inductively by hand. In a thematic analysis, the two most common ways to code a dataset are: (1) to code what the participants say, which is an inductive coding wherein the coder must not draw on theory and must avoid his/her personal interpretations, and (2) to code what the participants are talking about, which is a form of variable thinking (Tjora, 2012) wherein the coder considers the empirical data as being comprised of themes that can be sorted and influenced by existing theory (Braun & Clarke, 2006). The main criticism of the latter approach is that it often reproduces existing research or the coder's own views (Tjora, 2012). I thus chose the first approach. The entire dataset in this study was coded in detail and the coding process was thorough, inclusive and extensive (Braun & Clarke). The coding therefore reflected what the participants actually said, rather than what they talked about (Tjora, 2012).

At most, a single interview in this study could generate up to 200 codes, since the participants related their entire cancer history from the time of diagnosis until the present day. The study's focus was on the participants' current experiences and challenges some three to ten years after their diagnosis. Therefore, some of the encoded material was not appropriate for the subsequent analysis. However, it did provide an overall picture that was valuable when attempting to understand their situation. I also felt strongly that it was meaningful for the participants to narrate their whole cancer story. All codes were further divided into 25 sub-themes. These were presented and discussed with the co-authors. The themes that were relevant to the period three to ten years after diagnosis and that were in line with the research questions were then further developed into three concepts (Fig. 2), which in turn formed the basis for the three papers.

Fig. 2



Paper I was based on data from Group 1 (hip/pelvis sarcoma), while Paper II stemmed from the interviews with Group 2 (lower extremity sarcoma). In Paper III, the participants were from both groups. Here, data related to the participants' views on body image were extracted from the transcribed material and coded inductively. After the material was coded and divided into themes and concepts, quotations that illustrated the experiences expressed by one or more participants were identified. These were commented on and then put into a code context in order to aid in understanding and highlight whether the particular experience was experienced by one participant or several.

In an interview, the language is oral, sometimes so much so that it does not do the participant's meaning justice. For ethical reasons, some repetitions were removed and some words and phrases within the quotes were adapted to a written form without modifying the content and meaning. Throughout the whole analysis process, I often returned to the original data to check the transcript and quotes, as well as to ensure that the meaning had not been lost during interpretation or translation. Finally, the themes were reflected upon in accordance with the study's objectives. They were compared with the existing literature and theory (Braun & Clarke 2006). The themes mentioned by several participants, which could also be linked to both theory and literature, were disability, stigma, appearance change, reorienting,

and post-traumatic growth, as well as the dichotomies of normal/deviant, healthy/ill and active/inactive.

Ethical considerations

Ethical questions can emerge during any part of the research process, including design, generating data, analysis and reporting. In qualitative research and research on humans, informed consent is of particular importance, as are confidentiality, consequences and the researcher's role. These dimensions should all be carefully considered (Brinkmann, 2015). The question of whether it is ethically acceptable to interview individual adults who have previously had bone cancer about their lives may therefore arise during the present study. However, I believe that such an act is justified, so long as the interviews are conducted in accordance with all relevant ethical guidelines and the project is intended to improve cancer survivors' lives and their relationships with healthcare providers. By adopting psychosocial and sociocultural perspectives, it might be possible to generate new knowledge that provides greater insight and understanding of the challenges that bone sarcoma survivors struggle with. The aim of the present study is to benefit both former patients and healthcare professionals.

The unique aspect of qualitative research is that, when generating data, researchers are engaged in a close encounter with the participants. In this study, each participant's attending physician first contacted them, informed them about the project and asked if they would like to participate. The doctors had the medical records of their former patients, but I did not have access to such information. It could of course still be questioned whether a person has a real choice when the attending physician is asking him/her to participate. Once the participants had responded positively, I sent them information about the project and suggested a meeting. All participants signed an informed consent form prior to the interviews. I felt that it was important to spend sufficient time helping the participants to understand the essential aspects of qualitative research (i.e., what the project involved, openness and confidentiality, and what rights they had).

During interviews, researchers have a great responsibility in terms of balancing proximity and distance, knowing how far to go, and reading the participant so that they do not overstep boundaries. In an extensive interview about a participant's lifeworld, the researcher should be aware that the participant might talk about subjects he/she has never shared with another

person before, and that this may alter self-understanding (Kvale & Brinkmann, 2009). In several interviews, I found that the participants stated it was the first time they had ever talked about private and intimate topics related to their cancer experience, and for some it was the first time they had shared their comprehensive cancer story. Many expressed that they appreciated this research project. In a few cases, the attending physician received feedback that the interview experience was regarded as useful for reflecting upon their own situation. It was necessary to ask intimate and very private questions during the interviews. In a few cases, there were topics that I clearly perceived the participant did not want to go into. These topics were therefore only superficially touched on or else omitted. Fortunately, I never experienced asking the questions and conducting the interviews to be difficult or unpleasant. In fact, there were many moving encounters and touching stories.

Confidentiality in terms of anonymity is essential for both the project and the participants (Kvale & Brinkmann, 2009). The recordings were only listened to by me and one medical secretary during the transcription process. The supervisors and co-authors of this thesis received transcripts for review and analysis after they were de-identified, meaning that the names of the participants, their families, friends, and physicians, names of places, dialect and other information that could identify the participants were removed or altered. All data that could identify individual participants were separated and stored securely. In accordance with the guidelines of the Regional Committee for Medical Research Ethics, such data will be deleted following the project's completion in 2016. This research is anchored in the fundamentals of the Declaration of Helsinki. Permission to conduct the interviews and to collect and store sensitive data was obtained from both the Institutional Review Board and the Regional Committee for Medical Research Ethics (REK South East Approval Number 2012/918).

The analysis in a qualitative project is not limited to the analytical phase alone, but instead takes place continuously throughout the entire research process from generating any data to selecting theory (Kvale & Brinkmann, 2009). When reading empirical data, it was important for me to consider how I had understood and used participants' statements, as well as to be conscious of not including too much of my interpretation of their statements. As previously mentioned, in order to be loyal to the participants when translating from oral language into text, I attempted to keep the quotes as accurate as possible in terms of content and meaning (Brinkmann, 2015). In particular, because there are very few bone cancer patients nationwide

and because the environment is therefore small and transparent, it was important to ensure participants' anonymity in the published papers. The only demographic and medical data provided concerning the participants are their gender and approximate age (i.e. > or ≤35 years), and if they had cancer in the hip/pelvis or lower extremity. In the tables contained in Papers I to III, the findings are presented and related to the participants, but it should not be possible to identify individual participants since only such limited demographic data are mentioned. The aim throughout this study has been to handle all statements made by the participants in an ethical way in the papers. By following a descriptive approach in line with a phenomenological orientation, I have thus tried to stay true to their stories.

The participants in this study have survived a serious form of cancer and comprehensive treatment. Many of the topics discussed were very private and even intimate. It has therefore been essential to uphold all necessary ethical considerations during all parts of the process. On the other hand, the subject under discussion was not controversial. Ultimately, it appears that such research should not be detrimental to those individuals or groups involved (Brinkmann, 2015).

Reflexivity

Reflexivity is a term applied in qualitative research to describe a process or an interplay between the researcher and the researcher's work (Braun & Clarke, 2013). In qualitative research, the researcher influences and shapes the process, both personally and professionally. It is therefore particularly important to reflect on the researcher's own role and how his/her own values, experiences, interests, political sympathies, aims and social identities have influenced and formed the work. This includes the study's design, the researcher's own role in interactions with the participants, the researcher's pre-understanding, theoretical perspectives, and the analysis of the empirical data (Braun & Clarke, 2013; Brinkmann, 2015). Here, my background in humanities and culture studies has influenced several choices made during the research process. A sociocultural approach to health and illness means that a qualitative design is a sound choice. The aim of studying bone sarcoma survivors' lifeworld in view of the society and the culture in which they live has also impacted the choice of literature and theory being mainly taken from the fields of psychology, anthropology, sociology and philosophy. Additionally, articles from medical and health journals were found to be relevant. My background has also affected the questions raised in the interviews, which words were used, and how the statements of the participants were perceived and interpreted. Further, my

previous experience of interviewing cancer survivors has been of great value in the current research process.

When dealing with comprehensive empirical data, questions always arise regarding what to include and what to exclude when proceeding further with the analysis following coding. Based on the phenomenological method, only certain elements of the participants' stories are presented in the papers. I have attempted to be very open-minded during the inductive coding, although my own standpoint, my pre-understanding and the aim of the research all likely influenced the choice of themes, concepts, quotes and theory further along in the process. The use of a different qualitative method, for example, a narrative method, with this empirical data would also have influenced the process and results. The results would be quite different due to the differing research question if someone with a health professional background and knowledge of health-related theory were to have analysed the data and published a paper based on the gathered material. The fact that I am not a health professional is highly likely to have had an impact on my interactions with participants during the interviews. They knew that I was not one of the therapists they had met previously or would meet in the future. This knowledge may have positively affected participants' openness regarding several aspects of their lives. It might also have made it easier for the participants to be critical about the experiences they have had with the healthcare system.

In terms of my experiences and attitudes towards the phenomenon under study, I have not had cancer myself and no close family/friends of mine have a history of cancer. However, I felt sufficiently familiar with the field to follow the participants in their history of cancer, to be able to raise questions, and to play an active role in the interviews. With regards to my religious, moral and political attitudes, I do not believe that such attitudes have significantly affected the research study. Lastly, I feel that maintaining the necessary distance during the interviews and analysis has not been difficult (Brinkmann, 2015).

Discussion of the methods

In quantitative research, criteria such as validity and reliability are important when assessing the research, but this is disputed in qualitative research. In the latter, the majority of researchers are convinced that these terms are poorly suited to evaluating qualitative research, which should instead be assessed based on criteria that better recognise the research goals and

ambitions (Braun & Clarke, 2013; Tanggaard & Brinkmann, 2015b). Tanggaard and Brinkmann (2015b) emphasise that it is particularly important to consider quality criteria relating to the study's transparency, credibility and the extent of the methodological reflection. In the following, I will first reflect on the methodological choices and then later discuss the quality criteria, including coherence, consistency, accuracy and transparency.

Methodological reflections

According to Braun and Clarke (2013), the triangulation of methods could improve the quality of qualitative research. This implies that certain phenomena are best studied from multiple and diverging perspectives, or by using different methods to address the research questions. In this study, only former patients who have been affected by bone cancer were interviewed, although it would be interesting to interview their spouse/family members and/or healthcare professionals working in the sarcoma department in order to illuminate the phenomenon from various standpoints. Interviews with relatives might have added to the study by providing an outside perspective that could have situated the bone sarcoma survivor's lifeworld and his/her experiences in a broader context.

I initially also considered the usefulness of conducting two interviews with each participant, but concluded that it would be inappropriate since all the participants were in a stable situation three to ten years following diagnosis. A second interview would only be useful if carried out several years later, which would not be compatible with the three-year timeframe given for a PhD.

Another option, albeit one that I did not consider, was to first write a review article. In retrospect, such an article could have been advantageous. The main purpose here would then have been to provide an overview of the published qualitative and quantitative research on bone sarcoma patients and survivors. Although I undertook an extensive literature review in Papers I to III and this summary, a review article could have been a good starting point for the subsequent qualitative research. Mixed methods, such as combining qualitative and quantitative methods, is another approach that is becoming increasingly common, although it was not considered as part of this study.

By using other qualitative methods, for example, a narrative analysis, in one of the papers, it might have been possible to gain a deeper understanding of individuals' perceptions of the

consequences of having had bone sarcoma. Human lives consist of narratives intended to organise and explain impressions and experiences, as well as conveying them in order to create meaning and context in a complex world (Riessman, 2008). Serious illness implies that people need narratives to understand the situation and the circumstances, so that others may acquire an understanding of how the lives of cancer survivors and functionally impaired persons are experienced. This is essential to the identity work that many former cancer patients must live through. The stories are individual, but they arise within the cultural context in which people live (Frank, 1995). To a greater extent, narrative analysis relates to the participant's entire story, unlike phenomenology, which relates to the phenomena present in a dataset. Here, the participant's story is torn apart and it is not unproblematic to determine what to include and what to exclude. A narrative analytical method was considered at the start of the present work, but I decided to instead use interpretive phenomenology throughout the study.

There are several reasons why I chose not to use triangulation. The triangulation of methods is laborious and complex. In addition, it would have been challenging because it represents different concepts of knowledge, perceptions of reality and research strategies. It is also difficult to maintain the necessary stringency and system within such a study (Frederiksen, 2015). On the basis of the research questions, the sociocultural perspective and the limited time available, I concluded that following a qualitative interview method according to a phenomenological hermeneutic approach would be adequate. In retrospect, however, I recognise that triangulation would have broadened the learning outcomes of this study.

Member checking is a way to assess the quality of the data and the analytical process (Braun & Clarke, 2013). This implies that participants take part in the process by reading through the transcripts and/or participating in the analysis. The objections against such a way of working while completing a PhD are many. In this study, it would be both time consuming and practically challenging to communicate with all 18 participants about innumerable details along the way. Another difficult factor associated with member checking concerns the researcher's position of power. What if the participants express doubts or criticism about the credibility of the analysis? Additionally, when should the process stop (Braun & Clarke, 2013)? The limited time available was the determining factor in not conducting member checking in this study. However, it is acknowledged that involving participants in the research process currently appears rather frequently as a criterion when applying for research grants.

Based on the research questions and the inclusion criteria, it was decided to focus on the period three to ten years after the participants were diagnosed. The data therefore contains, in addition to what is included in the papers, stories about how they remembered being diagnosed, their encounters with the healthcare system and their experiences during treatment. Furthermore, the data says something about how they obtained information about the disease and its treatment, and if they had contact with the Cancer Society and/or other cancer survivors. In addition, the data contains information about the participants' sexuality, relationships with their family, friends and colleagues during treatment, how open they have been about the disease, and how they experienced the patient role. Here, there exists a lot of data that would have been interesting to further explore. In retrospect, it would have saved time to not code that part of the interviews involving the time from diagnosis to the completion of treatment. On the other hand, no one knows in advance what will be found in a dataset. To be open-minded and to exhibit as little bias as possible during encoding is in accordance with a phenomenological anchoring (Jacobsen et al., 2015).

Writing scientific papers aimed at a medical professional audience was a new experience for me. In that sense, working with just one method provided tranquillity and it was an opportunity to really delve into this subject. On the other hand, it was challenging to write three papers based on one dataset and, within the same methodological framework, to pick out and focus on certain phenomena while staying true to the participants and their experiences. It has therefore been important to maintain the 'common thread' running through the three papers, which all reveal that several participants have been left with a functional impairment and bodily changes following cancer treatment, as well as what this implies for them individually and culturally.

Quality criteria

Here, I want to briefly reflect on some key quality criteria in qualitative research. *Coherence* is concerned with the connection between research questions, literature selection, methodology, theory, analysis and conclusions (Tanggaard & Brinkmann, 2015b). The reason why a qualitative interview method and interpretative phenomenology were selected as a result of the research questions and the sociocultural perspective has been previously explained. Thematic analysis is highly flexible and it is well suited to managing the comprehensive volume of qualitative data found in this study. The inductive coding and in-

depth analysis of the data have ensured that the most important experiences and challenges are drawn from the participants' stories in their own words. In my opinion, both the theoretical approach and the literature are in line with the chosen methodology, perspectives and results, as are the conclusions of this study.

The other two quality indicators that are important in qualitative research are *consistency* and *accuracy*. Consistency should be maintained throughout the study in terms of the theoretical concepts and the researcher should consistently apply the given scientific perspective. Furthermore, all concepts, theories and methods should be precisely defined and applied (Braun & Clarke, 2013; Tanggaard & Brinkmann, 2015b). This doctoral thesis has been a process in which awareness, knowledge and understanding have evolved along the way. In retrospect, I could have been more consistent and accurate regarding the relevant concepts throughout the whole process. In this summary, I have attempted to improve on this.

In both the quantitative and experimental research traditions it should be possible to repeat studies and obtain similar results, while in qualitative research it is more appropriate to talk about *transparency* and *credibility* (Braun & Clarke, 2013; Tanggaard & Brinkmann, 2015b). It has been important throughout this study for me to justify the choices, the procedures and the methods, as well as the implementation of the study, so that transparency is achieved in both the papers and the summary. Among other things, I have shown in Papers I to III the number of participants who expressed a particular phenomenon during the interviews. This was not done because it was believed that the numbers, as such, would be more representative, but rather because openness concerning how many participants had articulated a given phenomenon would provide the study with greater credibility. This is not a common approach in my academic discipline, but given the target audience of the publications, it was deemed to be of interest. The question of trustworthiness (Tanggaard & Brinkmann, 2015b) was taken into account during all stages of the process according to the character of a phenomenological study.

Although the participants in this study represent the majority of those former bone sarcoma patients in Norway who fulfilled the inclusion criteria, the actual number of participants (n=18) is low. It is not relevant to talk about representativity as one does in quantitative research involving larger cohorts. On the other hand, although qualitative research does not aim at representation or generalisation, it is an ambition of phenomenology that by studying a

given phenomenon, one should, on a descriptive and qualitative basis, raise awareness about general aspects of the human experience (Jacobsen et al., 2015).

V. Results

The findings of this research have been published in three interrelated papers, all of which are concerned with late consequences following the treatment of patients diagnosed with primary bone sarcoma in the hip/pelvis or lower limbs. Each publication is also a ‘stand-alone’ paper, each addressing different aspects as expressed by the 18 (10 + 8) participants during the stage when they reorient themselves in their new lives following cancer and the related treatment. The study participants all described how their functional impairment and altered appearance have affected the practicalities of everyday life, their future prospects and their own identities. This chapter summarises the participants’ experiences, as well as the key findings presented in the three papers.

Paper I

Fauske, L., Bruland, O. S., Grov, E. K., & Bondevik, H. (2015). Cured of primary bone cancer, but at what cost: a qualitative study of functional impairment and lost opportunities. *Sarcoma*, 484196.

The empirical material in this paper consists of interviews with ten, mostly young, participants who had been treated for primary bone sarcoma in the hip/pelvis between three and ten years previously, and who are now considered to be cured of cancer. The purpose of this study was to explore how the functional impairment resulting from their treatment had affected the daily lives of these former sarcoma patients. The paper provides insights into how major surgery involving a vital body area and, for the majority of participants, the consequences of oncological treatment create challenges in everyday life, including working life, leisure time, social life and relationships. We identified three main themes: *the impracticalities of daily life; lost opportunities and an altered future; and I am no longer the person I once was.*

Our findings confirm that having cancer represents a serious incident in life and a rupture in one’s personal narrative that often requires reorientation according to a new set of conditions. As elucidated in several of the phenomenological-hermeneutic treatises of Fredrik Sveaneus (2005), serious illness can result in existence itself being seemingly turned upside down, so that the patients feel they have been thrown into an unknown world in which they do not feel at home. Our findings demonstrated that participants who were previously healthy and active

now experience impaired movement, and several of them are dependent on sticks, crutches, or a wheelchair in order to get about. As expected, pain, fatigue and stoma were experienced as challenging and exhausting. Several participants considered their situation to be comparable with being disabled. In addition, the participants related that they experienced alterations in their understanding of their own identity, that they met constraints in everyday life, and that they felt excluded from arenas and situations that were of importance to them. According to Toby Siebers (2008), these are all conditions that are described in modern disability theory. Our analyses indicated that remaining in employment was important to the participants. Those who were unable to resume work due to the late effects of bone sarcoma treatment commented that this significantly affected both their identity and their social life. They were also concerned about their future careers, since they believed a disabled employee would not be attractive to a potential employer.

Another domain that was emphasised by the participants was reduced or complete exclusion from physical activities as a result of functional impairment. The participants felt that they were not only deprived of important hobbies, but that the deprivation also impacted on their social lives. Some of the men mentioned that they felt less masculine now that they were no longer as strong and fit as they were prior to having cancer. The change from being healthy and active to being regarded as disabled, both by oneself and by others, may affect how one considers oneself and how one is perceived by society. Several participants commented that deviations from current cultural and social norms were particularly problematic. One participant emphasised that the greatest burden was being a victim of the stereotype that persons with a disability are dependent on others and less intelligent than non-disabled people. However, most participants said that they had adapted to their 'new normal', despite the significant changes and various losses. The study also highlighted that a successful reorientation depends on achieving sufficient recovery, both physically and psychosocially, following treatment.

Paper II

Fauske, L., Bondevik, H., Bruland, O. S., & Ozakinci, G. (2015). Negative and positive consequences of cancer treatment experienced by long-term osteosarcoma survivors: a qualitative study. *Anticancer Research*, 35(11), 6081-6090.

The aim of this study was to investigate how former patients treated for osteosarcoma in the lower extremity with limb-sparing surgery experienced the long-term consequences of the cancer treatment some three to ten years after diagnosis. Eight participants, half of whom were adolescents or young adults, were interviewed about the practical, emotional and psychosocial challenges that they currently had to cope with, as well as regarding whether and how the cancer had affected them and changed them as a person. Negative consequences such as impaired mobility, fatigue, a reduction in activity levels, less social participation, fertility concerns, and an altered appearance were among the topics identified in the analyses of the interviews. In addition, half the participants noted that their cancer experiences had resulted in positive changes and personal development.

Our findings show that the negative consequences of cancer treatment affected the participants' work life, time spent with their children, social life, leisure time activities, possibilities for having children, and, not least, their visions of the future. In addition to reduced capacities, the surgery also led to alterations in appearance. Moving from the status of being healthy and active prior to the cancer, they, like the participants in Paper 1, had to reorient themselves with an identity of being partially disabled. The analyses showed that exclusion from important life arenas could result in limitations to one's social life, as well as affecting future opportunities in terms of employment and family.

Finally, the participants were asked whether the cancer had affected and changed them as a person. Several participants used this question as an opportunity to describe how their experience of cancer and the subsequent conditions had also influenced them in a positive way. In line with the theory of post-traumatic growth proposed by Calhoun and Tedeschi (2013), half the participants emphasised that they were now more appreciative of life, had grown as people, had become stronger and more mature, and had become more compassionate regarding the situations of others. Nevertheless, some participants mentioned that they felt a certain ambivalence towards this positive growth. Although they appreciated their positive experiences, they would rather not have had the cancer. Most of the participants expressed that they did not feel any guilt about having developed cancer and, therefore, they had not changed their lifestyles. There was also no widespread fear of recurrence.

The majority of participants in this study felt that the cancer had caused them losses and, in some respects, changed their lives, although they had adapted to their new lives and coped

with their changed circumstances well. Only one participant spoke about still struggling to reorient himself in life. He found it difficult to become involved in meaningful activities, and he had not yet become accustomed to his new life and his altered identity.

Paper III

Fauske, L., Lorem, G., Grov, E. K., & Bondevik, H. (2016). Changes in the body image of bone sarcoma survivors following surgical treatment – a qualitative study. *Journal of Surgical Oncology*, 113(2): 229-234.

In this paper, we explored how former bone sarcoma patients experienced their changed appearance as a result of surgical treatment, as well as how they experienced their daily life, their self-esteem and their identity in interactions with others. The empirical material consisted of interviews with 18 participants (those in Papers I and II), many of them young, who had previously been treated for primary bone cancer in the hip/pelvis (n=10) or lower limb (n=8). The paper emphasises the challenges that the participants highlighted as being associated with having obvious physical differences and disabilities, as well as those that impact upon their interactions with others in a society characterised by high expectations and demands for a normal, healthy and attractive appearance.

Two themes were identified in the analyses: the need to hide the bodily signs of change, and what it is like to differ in appearance from current cultural norms. The three main reasons participants gave for concealing their visible difference were: (1) not wanting to stand out as deviant; (2) the feeling of not being attractive; and (3) the importance of one's appearance being consistent with one's self-identity. In line with the theory put forward by Nichola Rumsey and Diana Harcourt (2004) that appearance is one of the main factors that affect self-identity, the participants stated that having a visibly different appearance is challenging, since it affects how one perceives oneself, as well as how others perceive you.

The analyses showed that walking with a limp, scars, hernias and using a wheelchair are all visible deviations from the norm that many participants found to be problematic in social and interpersonal situations. Half the participants chose to hide their deviations whenever possible. In line with Goffman's (1963) theory of stigma, the material in this paper demonstrates that they wanted to avoid drawing attention to an altered appearance and to not provoke negative reactions from others. For example, a crutch was used by two participants

both as an aid for walking steadily and as a means of hiding a limp. Some participants said that they considered themselves to be less attractive than they were prior to having cancer. They found that it took a while to become familiar with their new body and to dare expose it in the company of others. Undressing at the beach, for example, results in one being exposed to other people's gaze. While some participants thought this was tolerable, others felt uncomfortable with being stared at. Several participants commented that the particular situation and surroundings were decisive regarding whether or not they undressed in different social contexts.

In summary, we concluded that the change in social status from being healthy to being a person with reduced function and an altered appearance involves a change in identity that can be demanding. The participants noted that they wanted to be perceived as they now think of themselves, and not as a former cancer patient or a person with a disability. The need to appear normal, healthy and attractive was important for many of them. Hiding their body by various means was part of this strategy.

In these three papers, we conclude that it is important for bone cancer survivors to overcome the challenges associated with both the disease and its treatment, as well as to cope with a changed identity and a different set of value dimensions under a new set of conditions. We argue that it is vitally important for healthcare professionals to have a more holistic view of health, in addition to an understanding of each individual person's specific situation. By gaining a greater understanding of the importance that the various consequences associated with bone sarcomas have for the individual, as well as the different challenges that they face, it should be possible to provide appropriate and adequate assistance to those who struggle to reorient themselves following cancer treatment. As many of those affected by bone cancer are young, it is particularly important to pay attention to the challenges associated with their future life expectations.

VI. Discussion

The main research question that underlies this thesis concerns how former bone sarcoma patients experience and perceive the consequences of their disease and treatment three to ten years after diagnosis. The study has focused on (1) how impaired function impacts the daily life, future and identity of those treated for bone sarcoma of the hip/pelvis, (2) the negative and positive consequences experienced by those who have previously suffered from osteosarcoma in the lower extremities, and (3) how visible changes due to surgical treatment affect the self-esteem and identity of participants from both groups. The findings of Papers I to III will be discussed in this chapter and placed into a broader psychosocial and sociocultural context that may be of interest to healthcare providers.

Initially, the discussion will be structured according to the study's main findings, how culture influences the experience and understanding of being a bone sarcoma survivor, the linguistic-cultural dimension that influences those who have disabilities, as well as the challenges and opportunities faced by young bone sarcoma survivors. Finally, I will consider what it means to apply a holistic perspective to sarcoma survivors during the entire period they are followed in our healthcare system.

Physical and psychosocial challenges

Looking at the findings of the three papers as a whole, it seems that this study can be divided into two major dimensions, both of which are significant to the healthcare field: the participants' physical and mental challenges, as well as their psychosocial and cultural challenges. Although they are not two separate phenomena, the division serves to foster better understanding and facilitate good interactions between healthcare providers and bone sarcoma survivors.

The health-related challenges experienced by many participants in this study include impaired mobility, pain, fatigue, stoma and sexual problems. In several cases, the challenges experienced are clearly related to the cancer treatment. For many of those who have been affected by cancer, it can be difficult to determine which ailments are related to the disease and which are not. For young people in particular, who do not have experience of how the body acts in adulthood, the psychosocial challenges following cancer treatment can be complex and more intertwined with the life one lives and the environment one lives in. In this

study, the participants expressed a number of psychosocial challenges, including anxiety about standing out due to a visible difference, challenges related to education and employment, a changed identity, an impaired social life, being excluded from activities, and a fear of being unable to have children or engage in intimate relations. All these challenges may result in exclusion from various situations and contexts, as well as lost opportunities in the future. Based on the current study, four challenges related to the clinical follow-up of former sarcoma patients emerge. First, it may be difficult for healthcare providers to capture what the cancer survivor is struggling with and hence needs help with. Second, it may be hard for former sarcoma patients to both know and express what they need help with. Third, it can be difficult to know exactly what survivors should expect from the healthcare system. Finally, it can prove hard for former cancer patients to determine what circumstances they could prevent and/or influence.

When discussing the findings of this study, it is essential to keep in mind that it is not concerned with the representativeness of issues among those who have had bone sarcoma, but rather with describing important and current phenomena that emerged during the interviews with participants.

Groups 1 and 2 – differences and similarities

Papers I and II are based on two different groups of participants. Group 1 comprises those who had bone sarcoma in the hip/pelvic region, while Group 2 is made up of those who had osteosarcoma in the lower limb. I will briefly describe what is different and what is similar between the groups based on the entire dataset. Those who have had bone sarcoma in the hip/pelvis (Paper I) require extensive surgery, which often has complex consequences that may involve internal organs. Indeed, the consequence of the disease and its treatment could be urostomy, colostomy and neurological sequelae. Impotence and infertility may also occur after surgery. One participant who experienced protracted infections and problems with wound healing following surgery had to have his leg amputated up to the hip joint as a result of chronic infection. Large scars were present and in some cases hernia was a result of surgical treatment, although these consequences are often not visible when wearing ordinary clothes. Pain was common. Many participants need crutches today and two are dependent on a wheelchair. The participants in Group 2 have had bone cancer in an extremity, either the femur or lower leg (Paper II). They have all undergone advanced limb-sparing surgery with

an inserted prosthesis, although the surgery did not affect any other organs or functions than the actual leg. These participants face many of the same daily practical challenges related to mobility as those in Group 1, but they rarely use crutches and they are less troubled by pain. In Paper I (Group 1), the focus is on functional impairment, which is discussed and related to everyday life, future and identity, while in Paper II (Group 2), the focus is on the negative and positive consequences that participants expressed during the interviews. The latter provides a more comprehensive picture of the experiences of participants in Group 2.

Positive growth was not a defined issue in the interview guide for either group. It was, however, something that several participants brought up themselves when I asked if the cancer had affected or changed them as a person. Positive growth is as much present in Group 1 as in Group 2, although the research question for Group 2 was more open and so allowed for a wider focus. There are several publications concerning positive growth following cancer, particularly with an increasing time from diagnosis and a diagnosis at a younger age (Cordova et al., 2001; Danhauer et al., 2013). This is in line with our results. This study does not search for an explanation regarding the reasons why some participants experience positive growth and others do not. In phenomenological research, one should primarily describe and try to understand. We know from the positive growth theory that a person's personality plays a role (Calhoun & Tedeschi, 2006). Yet, how internal and external factors influence whether or not sarcoma survivors experience positive growth would be an interesting area of study. As mentioned above, there were some differences between the two groups, but they presented several common experiences of being a bone cancer survivor.

Bone sarcoma – function and culture

In this study, both during the interviews and in the process of analysis, I realised that many of the participants talked relatively little about cancer and the fear of recurrence. They were most concerned about their function and future life. One explanation for this may be that years had passed since they were diagnosed. Additionally, a cultural influence may play a role. A relevant question in this regard concerns how the culture of a particular society affects how we look at cancer and how it influences peoples' experience of living with a cancer diagnosis and its consequences. We know that bone cancer is very rare. Hence, there has been very little focus on this type of cancer in the public health discourse. Instead, the focus is on more common cancers, for example, breast cancer and prostate cancer. Most people do not associate hips, thighs and legs with cancer. In addition, we know that bone cancer is seldom

related to one's previous lifestyle (Eyre et al., 2009; Ottaviani & Jaffe, 2009). We also know that if there is no metastasis at the time of diagnosis, the prognosis for bone cancer is good (Berner et al., 2014; Damron et al., 2007). Some participants highlighted that physicians at the Radium Hospital clearly conveyed this fact. This study illustrates that developing bone cancer in the hip/pelvis or lower limb implies that survivors are highly concerned about function, both practically and emotionally. In many ways, this can be compared to the key concern of victims of traffic accidents and sports injuries.

How one copes with and communicates about illness is culturally learned, similar to how we learn to communicate other social roles and identities (Alver & Selberg, 1992). Those diagnosed with breast cancer will be influenced by the discourses present in society about this specific type of cancer. These discourses include the symbols associated with breast cancer, for example, the 'pink ribbon culture', the norms and values that exist, as well as the roles that are presented in the media and on social media. However, the participants in this study had fewer cultural pegs on which to hang their specific diagnosis, or role models to identify with, aside from the more general considerations of cancer, which are naturally wide and diverging. In contrast to the breast, which is related to many cultural and symbolic associations (Yalom & Lie, 1999), the lower limb is more related to function. A sociocultural perspective on this would involve looking at the relationships that exist between the medical process and the disease itself, as well as the meaning placed on these by both individuals and society (Ingstad, 2007; Kleinman, 1988). The participants' attitude towards the way they coped with their cancer is very much concerned with mobility and rehabilitation, and less with cultural dimensions such as fear, lifestyle, guilt and shame. This may be explained on the basis that the biological dimension is strongly present in bone sarcoma, while the cultural performances and expectations in connection with this particular form of cancer are less distinct.

In addition to function being important for former bone sarcoma patients, we see that cultural norms also affect participants' attitudes and their perception of what is healthy, normal and attractive. One participant who has a knee prosthesis expressed that she lost a lot when she could no longer take part in many of the sports and recreational activities she previously enjoyed. She misses being able to be an instructor, to exercise and go skiing with others. Meanwhile, she compares herself with another woman who has undergone something similar, but who had her leg amputated. The other woman can participate in many more activities than her and she is still an instructor. Yet, the participant would never exchange her knee

replacement for an amputated leg. She prefers to have her own leg. I interpret this as meaning that to have a 'culturally' intact leg in everyday life is better than having good function during sport.

If having bone cancer itself is not a phenomenon that is influenced greatly by culture, having an altered appearance following cancer treatment certainly has a cultural dimension (Rumsey et al., 2004). All the participants in this study have bodily deviations following their cancer treatment. The fact that half of them choose to hide these visible differences may be part of the stigma that those with bodily deviations and disabilities experience as a result of Western cultural norms.

Disability – attitudes and language

As emerges in the interviews with participants in this study, there are several challenges associated with being disabled and having a deviating appearance. As mentioned previously, half of the participants detail several different attempts to hide the bodily deviations caused by the disease and its treatment in order to avoid standing out or being stigmatised. They want to look healthy, normal and attractive. How they perceive themselves and the physical changes that cancer has inflicted on them is influenced by the attitudes and prejudices they face in society. The same factors also affect how others perceive them. This may influence their social life, work life and identity. I will now briefly mention attitudes that are present in Western society concerning those who deviate from cultural norms with regards to function and appearance.

One participant in this study stated that it is not the disability itself, but rather the fact that he is dependent on a wheelchair that is the problem. He may well live with this problem even though it can be demanding. The biggest challenge he faces as a wheelchair user is that people do not see him as he is, but rather he experiences being seen and judged as someone who is less worthy, less intelligent, and who other people do not turn to. He feels that people avoid and ignore him when he is sitting in a wheelchair. Therefore, he sometimes attempts to use crutches, despite it being very exhausting. He finds it hurtful that people judge him based on his appearance and that they do not see the resourceful young man who has a great deal to contribute in many areas. These are well known phenomena that have been widely discussed in disability research (Galvin, 2005; Hunt, 1966; Siebers, 2008).

As mentioned previously, the meaning of disease/illness can be divided into three dimensions. The medical-physiological dimension, which often prevails in healthcare, the experience-based phenomenological aspect, which concerns the patient's or survivor's perspective, and the linguistic-cultural dimension, where we are all part of the cultural patterns and hence are influenced by cultural considerations. The popular perception and view of an ill person or a person with a disability has changed considerably over the past few decades, which is evident in both actions and language. This has been thoroughly studied in the professional literature, for example, in disease-illness discussions (Hofmann, 2002), medicalisation debates (Illich, 1974) and not least in modern disability theory, which can be referred to as a social shift in the disability research. In the latter, disability is currently not defined as an individual trait, but rather as a relationship or situation that may arise in an individual's interactions with the community (Siebers, 2008).

How we talk about phenomena and one another, and which words we use, affect our thoughts and attitudes. The words we use when discussing persons with disabilities have changed over time. In the Western world, in recent years there has been clear recognition of the importance of using words that do not discriminate against or stigmatise vulnerable groups (Siebers, 2008). It was, therefore, surprising to note some of the words I found on Thesaurus.com⁹ when I searched for 'disabled'. Here are some of the descriptions I found: 'weakened', 'helpless', 'incapable', 'out-of-action', 'confined', 'hamstrung', 'wrecked' and 'powerless'. The related antonyms are: 'firm', 'strong', 'healthy' and 'able'. Most of these words are loaded with negative meaning and they are not consistent with current attitudes towards disability as promoted through contemporary scientific literature and disabled people's own organisations. The use of negative and discriminatory words affects people's feelings, thoughts and attitudes regarding how one views those with disabilities and how we talk about and treat them. In addition, we shape people's views of themselves when we characterise them in negative or positive terms. As several authors have pointed out, the greatest challenge facing many people with disabilities is society's attitude and the way in which they are described (Galvin, 2005; Hunt, 1966), not the disability itself. By continuing to describe people with a disability using negatively loaded words, we are adding to the burden they are already struggling with. As Paul Hunt (1966) underlines, there is no such thing as a disabled person, only people with disabilities.

⁹ <http://www.thesaurus.com/browse/disabled>

One point that Aimee Mullin¹⁰ highlights in her sobering TED Talk, ‘The opportunity of adversity’, is that language seems to lag behind the medical and technological changes that have taken place in recent years. Laser surgery for visual impairments and knee and hip replacements provide those with disabilities with far better function and more opportunities today than they had a few years ago. In addition, social network platforms allow people to self-identify so they can align with global groups of their own choosing. Clearly, physical and social conditions have changed, while language lingers. Through being conscious of our attitudes and vocabulary, we will be able to reduce or avoid the stigmatisation of people with disabilities or those who have a different appearance. By focusing on opportunities rather than obstacles, by treating the wholeness of a person, and by acknowledging their potential, one will increasingly be able to include those who have physical challenges in both the workplace and social situations.

Challenges and opportunities faced by young bone sarcoma survivors

The majority of those who develop bone sarcoma are young or young adults (Damron et al., 2007). Although many of the findings of this study are congruent among both adolescents and adults, the young experience other needs and challenges than adult cancer survivors, particularly in terms of education, work, social life, identity and having a family. They are also in both a secession and an establishment phase, although when they are cancer patients and when they return to everyday life once cured, they may find that impaired function and psychosocial factors leave them more dependent on others. In general, many young people and adolescents lack the necessary life experience and coping strategies to deal with major changes such as a cancer diagnosis and its consequences. Therefore, it is especially important for this group that healthcare providers are aware of the challenges and opportunities such cancer survivors face when they meet them during clinical follow-up in the years after treatment is completed.

In this study, some of the adolescents commented that they have late effects that impact their education. Fatigue, difficulty concentrating and physical challenges cause them to struggle more than before they had cancer, and this also affects their social life. Several of them were not aware that late effects are common and to be expected following what they had been

¹⁰ Aimee Mullins (born July 20, 1976, in Allentown, Pennsylvania) is an American athlete, actress and fashion model who first became famous for her athletic accomplishments. She was born with a medical condition that resulted in the amputation of both her lower legs. https://en.wikipedia.org/wiki/Aimee_Mullins

through. Not everyone was aware that it is possible to get help and assistance at school so that learning and progress are manageable. For some, impaired function and fatigue also reduced their opportunities in terms of a future vocational life, and they expressed concerns about whether they are no longer attractive as an employee.

Unlike adults who have had cancer, who have already determined their preferences in the labour market and who might have a job to return to, many adolescents with disabilities lack a network of contacts and work experience (Gjertsen, 2013). It is interesting to consider the findings of this study in relation to a survey on living conditions conducted by the Directorate for Children, Youth and Family Affairs (BUFDIR).¹¹ The survey indicates that the general level of employment in Norway in 2015 was 74%, while for people with disabilities it was only 43%. In addition to those with disabilities who were already in employment in 2015, some 87,000 disabled persons who did not have a job wished to gain employment. According to the Central Bureau of Statistics (BUFDIR, 2016), in Norway one is defined as employed when one works at least one hour a week, which is a fairly broad definition. In addition, the survey shows that the rate of employment for people with disabilities increases with educational attainment and that education hence proves far more gainful for this group than for people without disabilities. This implies that for young and adolescent bone sarcoma survivors, supervision and assistance in completing their education is vitally important. As students, they must be helped to complete a programme of study that can provide opportunities for future employment.

Our study emphasised that many of the participants are also excluded from sport and physical activities, which are important arenas for social participation. The BUFDIR living conditions survey shows that fewer people with disabilities participate in sport and outdoor activities than those without disabilities. This may be due to health challenges and the lack of suitable arenas (Elnan, 2010). On the other hand, there is no difference in the level of participation of those with or without a disability when it comes to participation in clubs, associations and organisations (BUFDIR, 2016). The participants in our study indicated that exclusion from sport and outdoor activities was a great loss that also impacted their social life. They stated that they had lost the identity they previously had as physically active and sporty. Focusing on

¹¹ http://www.bufdir.no/Statistikk_og_analyse/Nedsatt_funksjonsevne/

opportunities for participation in physical and social activities is therefore an important aspect of facilitating a meaningful life for those with functional impairment.

Erectile dysfunction, uncertainty about fertility and the impact this has on both social and emotional life were other topics the young participants brought up. These can be difficult topics to talk about when one is in contact with the healthcare system, both because they are taboo areas and because many people lack the necessary words to explain themselves, which means that they often refrain from discussing important issues (Chapple et al., 2007; Gulbrandsen, 2006). It can also be difficult for them to see sexual problems in conjunction with, and as a result of, cancer treatment many years after diagnosis. The inability to have children is something that might impact one's ability to get a partner and start a family, which may have a profound effect on the young. In particular, one participant stressed that this was the most difficult challenge he faced, not the wheelchair, fatigue and stomas, but rather the infertility. It is important that healthcare providers are aware of these challenges, particularly among adolescents, and that health professionals take the initiative to talk about them and help to find solutions.

Education, employment and physical activity are all important arenas for social participation, and hence exclusion from them could affect bone sarcoma survivors' social life and their overall quality of life. Several of the adolescents commented about having a reduced social life as a result of being excluded from activities due to decreased functionality and a lack of the energy necessary to be active and social. In sum, along with the dimensions of love and relationships, these factors affect several aspects of daily life, not to mention affecting and creating uncertainty about the future. For different reasons, many of these negative consequences of cancer treatment are not brought up when that treatment is completed, although the challenges are present on patients' return to everyday life as cured and 'healthy' individuals.

Treating the wholeness of a person

Many people with cancer experience travelling 'first class' through the healthcare system at the time of being diagnosed and throughout treatment (Album & Westin, 2008). Bone sarcoma patients who are affected in the hip/pelvis and lower limb are perhaps in a unique position when their treatment also involves advanced and innovative surgery. But what

happens when you are cured? What is the situation when you are no longer a cancer patient, when you are considered healthy, but when you have many physical and mental ailments as a result of the treatment, as well as a number of psychosocial challenges? Does one then receive continued attention from healthcare professionals regarding the ailments and challenges that one experiences? Former sarcoma patients have the advantage that, since it is such a rare form of cancer, they are followed up for ten years at the NRH OUH, often by the same physician, and not at the local hospital or by a GP as other groups often are. However, research indicates that continuing healthcare and follow-up clinics do not necessarily focus on the late effects of cancer such as fatigue, cognitive ailments and pain (Wang & Woodruff, 2015), as well as on concerns about visible differences (Rumsey et al., 2004).

During their treatment, cancer patients have the status of being ill. They mobilise and receive understanding and support from both healthcare professionals and their family and friends. In the period following treatment, when one is declared cured but is still struggling with fatigue, physical or mental ailments and challenges, one loses the acceptance and understanding associated with being ill. One might end up categorised as chronic or counted among those with diffuse symptoms. According to Norredam and Album (2007), these are among the groups with the lowest status in the healthcare system. Several participants touched precisely upon this fact in the interviews, namely that they wished they had received better follow-up care after having completed treatment. For some, they had a long way to go before they regained the energy and health necessary to live a life that resembled what they had prior to the cancer. We also know that a few participants are still struggling in different situations and arenas, and that it will take time for them to deal with numerous everyday dimensions and reconcile themselves to their new life. It is therefore important that the challenges and opportunities that exist beyond clinical medical findings receive attention in the outpatient clinics held for those who are cured of bone cancer.

A more comprehensive view of health, rather than simply a focus on medical conditions and sequelae following cancer treatment, may provide bone sarcoma survivors with opportunities to seek help and to facilitate and cope with subjective challenges. A holistic view of health (Nordenfelt, 1993, 2007) implies that one should focus on activity and function with regards to opportunities to study, work and have the social and relational life one needs in order to be a whole person. It is not about being characterised as healthy or ill, but rather it is concerned with leading a decent life with the prerequisites you have. It is clear that many of the

challenges these survivors are struggling with cannot be entirely managed by the healthcare system, but rather they are something the individuals must deal with themselves. However, healthcare providers could attend to and address bone sarcoma survivors' critical needs (e.g., pain management, sexuality problems), refer them to an appropriate professional (i.e., social worker, nutritionist, sexologist, psychologist) and inform them about advocacy groups or peer groups. This is in line with the recommendations of a recent publication (Kwong et al., 2014). In many cases, it is sufficient to provide knowledge and offer advice about what can be done by the cancer survivors themselves. The importance of being seen, the ability to talk about your challenges and, most of all, being told that those challenges are normal and can be handled could be of great value to the affected person. However, in the end, most of the challenges in life have to be managed by the individuals themselves.

VII. Conclusions

The aim of this study has been to broaden the understanding of the various physical, emotional, psychosocial and cultural challenges faced by bone sarcoma survivors following treatment. It expands current knowledge about the consequences of treatment and deals with the cost survivors must pay for a cure. This relates to both impaired function and changed appearance in the years following treatment. The study is based on participants' lifeworld, their first-person experiences of being a cancer survivor. To the best of our knowledge, there has been no previous qualitative research in the phenomenological hermeneutic tradition on sarcoma survivors with a sociocultural perspective.

In the three papers, we have concentrated on how impaired function has affected participants' daily life, future and identity following the treatment of hip/pelvis bone sarcomas (Paper I), the negative and positive consequences following treatment of the lower extremity in osteosarcoma survivors (Paper II), and how bodily deviations following surgery affect bone cancer survivors from both groups (Paper III). On this basis, the findings of the study encompass three dimensions. First, the participants' physical and mental challenges. Second, the psychosocial challenges that the participants face. Finally, the cultural challenges they face as cancer survivors. Based on these findings, the following conclusions are drawn:

The physical and mental consequences following bone sarcoma treatment:

- Impaired mobility, limping, poor balance, decreased muscle strength, pain and a shortened leg, which may all lead to daily activities being experienced as painful, challenging or impossible.
- Reduced energy and cognitive challenges.
- Fear of recurrence and depression are present in relatively few survivors.
- Bodily deviations, scars, hernia and thin legs.

The psychosocial consequences following bone sarcoma treatment:

- The physical and mental health challenges mentioned above may result in exclusion from different situations and arenas one had access to before the cancer struck. Many survivors experience this as a loss. For example, a loss of the opportunity to participate fully or partially in employment, education, social situations and

relationships, as well as in sport and physical activities. This has particularly severe implications for young people.

- Scars, hernia, limping, wheelchair use and thinner or shortened legs cause many former bone sarcoma patients to hide their bodily deviations with clothing, or to avoid social venues where they feel that they stand out. Hiding their visible differences is a strategy used to appear healthy, normal and attractive.
- Not being able to do what was possible prior to the cancer, or not being seen as the person they really are, can affect the self-esteem and identity of sarcoma survivors.
- Positive growth following cancer treatment, such as a changed sense of life and self, as well as increased compassion for others, is something several sarcoma survivors reported, especially the young. However, a certain ambivalence was experienced regarding the value of the knowledge and experience they had acquired.

How culture may affect bone sarcoma survivors:

- Survivors have relatively few cultural pegs on which to hang their cancer experiences. Deviating from the cultural norms of being healthy, normal and attractive may affect how they perceive themselves and how they feel they are seen by others.
- Impaired function and a changed appearance following cancer could make you stand out due to not being able to meet the expectations of being healthy, attractive, employable or sporty. This may cause a person to become stigmatised or experience stigmatisation in interactions with others.
- Cultural norms and the context may affect the need to hide the fact that one has had cancer and been left with visible deviations following treatment.
- Attitudes towards, and how one talks about, those who have a disability or a different appearance affect both how they see themselves and how they are perceived in society. A positive and inclusive attitude that provides everyone with opportunities in various arenas and in different situations will be of great value for those who are struggling with physical impairments and lost opportunities.

VIII. Implications for healthcare providers

Former bone sarcoma patients at the NRH OUH attend regular outpatient follow-up clinics for at least ten years. A more holistic view of health, with increased knowledge on the part of healthcare professionals about the challenges and opportunities survivors face, could help bone cancer survivors to fulfil vital goals, even if they are living with disabilities and the late effects of cancer treatment. This could be crucial for both their present and future life.

Furthermore, health professionals' recognition of the psychosocial and sociocultural challenges faced by sarcoma survivors during follow-up might present an opportunity for dialogue that could provide them with the necessary assistance in terms of healthcare, as well as understanding and knowledge of how they can cope with and prepare for a better life. A simple approach to this might involve asking the survivors about fatigue, cognitive problems, sexuality and infertility, pain, physical activity, work, school/studies and social life,¹² as well as initiating contact with a cancer coordinator, peers or the Cancer Society (Kreftforeningen). This could easily be done by filling out a short form prior to the consultation wherein they simply tick off what they want to discuss with their doctor. This may facilitate dialogue concerning issues affecting health and quality of life that the survivors, for various reasons, hesitate to bring up themselves. The present work has clearly shown that a few survivors struggle with their new conditions following bone cancer treatment. These individuals must be given extra attention and support to progress in their practical, emotional, social and relational life.

¹² An interactive and electronic system, CHOICE (requires a tablet), is available to register the patients' experiences during their stay in hospital (Ruland et al., 2010). It has not been tested in any of the out-patient clinics at the NRH OUH.

IX. Further research

Moving towards the end of this thesis, I will briefly mention four areas for future study in the field of bone cancer survivors.

First, several of the participants, especially the adolescents, experienced personal and positive growth as a result of their illness. Why do some people experience positive growth, while others do not? What is it in the personality of cancer survivors or in their environment that creates this difference? How can knowledge about positive growth help those who are struggling to cope with life and reorient themselves after cancer treatment?

Second, one issue that is not included in this study concerns how bone sarcoma survivors relate to the Cancer Society, advocacy groups and other cancer survivor services that are not part of the traditional healthcare system. Who makes use of these opportunities and how are they experienced by those taking part? How may this affect cancer survivors' coping ability?

Third, several participants in this study struggled with psychosocial late effects following bone sarcoma treatment. To what extent is this captured by the healthcare system? How can we improve communication with healthcare providers so that former cancer patients receive a more comprehensive follow-up? How can this be implemented?

Fourth, individual blogs written by cancer patients and survivors are common. The blogs allow users to communicate with each other and share understanding with people who are facing the same challenges and tribulations. Additionally, cancer societies, advocacy groups, hospitals and universities have their own blogs that are dedicated to telling the stories of cancer survivors. A text or discourse analysis of such blogs might broaden the understanding of how being a sarcoma survivor is experienced.

X. References

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Appendices

Appendix 1: Forespørsel om deltakelse

Til deg som har hatt bensarkom

Forespørsel om deltakelse i forskningsprosjektet:

Hvordan opplever og håndterer tidligere kreftpasienter med bensarkom følgetilstander av sykdommen og behandlingen?

Hensikten med studien

Dette er et spørsmål til deg om å delta i en forskningsstudie hvor vi ønsker å lære mer om hvordan tidligere pasienter med bensarkom i bekken-/hofteregionen eller benet har opplevd og håndtert sykdommen og senskader som kan ha oppstått. Vi trenger mer kunnskap om funksjonsnedsettelse, deltakelse i arbeidslivet og hvordan kreftsykdommen kan ha påvirket selvbildet.

Studiet er en del av et doktorgradsprosjekt ved Radiumhospitalet og Universitet i Oslo (UiO). Stipendiat Lena Fauske, som tidligere har skrevet masteroppgave om senskader av kreft vil stå for gjennomføringen av intervjuet. Veiledere er Ellen Karine Grov (UiO), Hilde Bondevik (UiO) og overlege Øyvind Bruland UiO/Radiumhospitalet.

Hva innebærer studien?

Studien innebærer at du blir intervjuet om hvordan du har opplevd kreftsykdommen og eventuelle senskader – hvilke utfordringer du har hatt og hvordan sykdommen har påvirket livet ditt. Det vil være en samtale mellom deg og intervjuer som vil vare i ca en til halvannen time. Det er utarbeidet en mal for intervjuet, men det er dine opplevelser, tanker og erfaringer som er viktige. Det er du som bestemmer hvor personlig og privat du ønsker å være. Det er også opptil deg å bestemme hvor lenge vi kan holde på, og om du trenger pause eller om du vil avbryte samtalen. Vi vet at det kan være utfordrende å samtale om personlige erfaringer, men det kan også oppleves meningsfullt og gi nye tanker og innsikt om nåværende situasjon.

Det bes om tillatelse til å ta opp samtalen på lydbånd. Opptaket skal kun brukes i denne studien. All informasjon vil lagres og behandles konfidensielt. Personopplysninger vil bli anonymisert; det vil si at alle opplysninger vil bli behandlet uten navn og andre gjenkjennelige data. En kode knytter navnet ditt til informasjonen fra lydopptaket og kun stipendiaten, Lena Fauske har tilgang til navnelisten og kan slik sett finne tilbake. Alle lydopptakene vil bli slettet når prosjektet er avsluttet i desember 2016. Det vil ikke være mulig å identifisere noen av deltakerne når resultatene fra studien publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din behandling. Da vil lydopptaket bli slettet umiddelbart. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte stipendiat Lena Fauske.

Dersom du ønsker å delta og muntlig har sagt ja til legen, undertegner du samtykkeerklæringen på siste side. Den kan postlegges i vedlagte frankerte svarkonvolutt, leveres legen ved kontroll eller tas med til intervjuet. Samtykkeerklæringen må være undertegnet før intervjuet kan gjennomføres. Informasjonsskrivet kan du beholde. Har du sagt ja til å delta i studien, vil du bli kontaktet av Lena Fauske på telefon innen en uke for å gjøre avtale om tid og sted, som fortrinnsvis vil være på Radiumhospitalet i forbindelse med en kontrolltime.

Hvis du ønsker mer informasjon om studien før du samtykker kan du kontakte Lena Fauske. Studien er godkjent av Regional komité for medisinsk forskningsetikk.

Dersom du har spørsmål kan du kontakte Lena Fauske på telefon 22 78 12 03 / mobil 913 45 672 eller e-post lenfau@ous-hf.no

Med vennlig hilsen

Lena Fauske
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Appendix 2: Samtykkeerklæring

Samtykke til deltakelse i studien:

Hvordan opplever og håndterer tidligere kreftpasienter med bensarkom
følgetilstander av sykdommen og behandlingen?

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Lena Fauske, stipendiat)

Appendix 3: Intervjuguide

Opplevelse av kreftsykdommen

- Tanker om kreft før du ble syk
- Diagnosen
- Møtet med helsevesenet
- Informasjon om sykdommen
- Kontakt med andre kreftsyke/pasientforeninger

Hvordan kreftsykdommen har påvirket og/eller forandret livet

- Smerter
- Funksjonsnedsettelse
- Fatigue
- Kognitive symptomer
- Mentale symptomer
- Endret kroppsilde
- Det praktiske livet
- Fysisk aktivitet
- Livstil – kosthold, trening, fritid

Sosial interaksjon –hvordan har omgivelsene taklet din kreftsykdom og følgetilstander

- Ektefelle/samboer
- Barn
- Venner
- Sosiale liv før og nå
- Kolleger
- Åpenhet

Opplevelse og mestring av arbeidet etter kreftsykdommen

- Sykmeldt
- Arbeidsutfordringer
- Arbeidsgiver
- Tilrettelegging
- Kollegaer
- Hvordan er arbeidslivet i dag

Hva er den største forskjellen i livet ditt før og etter du fikk kreft?

Hvordan har kreftsykdommen endret deg som person?

