

Changes in the Body Image of Bone Sarcoma Survivors Following Surgical Treatment—A Qualitative Study

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Background and Objectives: Among several long-term effects, people treated for cancer may experience an altered appearance. Our study aims to identify how visible body changes following surgical treatment affect the life and identity of primary bone sarcoma survivors 3–10 years after diagnosis. A qualitative, phenomenological, and hermeneutic design was applied.

Methods: Sarcoma survivors (n = 18) who were previously treated at Norwegian Radium Hospital, Oslo University Hospital, participated in the study. In-depth and semi-structured interviews were conducted and analyzed using inductive thematic analysis.

Results: The main finding of this study concerned how altered appearance after bone cancer treatment in the hip/pelvis or lower extremities affected the participants' self-esteem. Half of the participants expressed concerns about their visible differences, particularly those with functional impairment. They felt that it is important to hide the bodily signs of changes to appear as normal as possible, as well as attractive and healthy. They describe, with specific examples, how these changes influence their self-realization, especially their social life.

Conclusions: Healthcare providers who guide bone sarcoma survivors during follow-up should develop a comprehensive understanding of what it means to cope with a changed and challenging body.

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KEY WORDS: bone sarcoma; late effects; cancer survivors; body image; qualitative methods

INTRODUCTION

Dramatic improvements in treatment over the last few decades have led to cure being the most common outcome following a cancer diagnosis. However, for many patients, a cure does not mark the end of their cancer story. To recover from cancer does not necessarily mean that the person is finished with cancer; rather, they enter a new phase of life involving different experiences and conditions than previously experienced [1]. Among several long-term effects [2–3], people treated for cancer may experience an altered body, which, for some, has a significant psychosocial and emotional impact [4–6]. Previous qualitative research on the body image of cancer patients has focused on body disfigurement following the removal of the breast [5,7], hair loss and weight changes [7,8], and facial disfigurement resulting from head and neck cancer [9]. Among these studies, Rasmussen et al. [5] describe how cancer survivors tend to hide physical changes, for example, scars, mastectomies, altered appearances of hair, and weight gain, following cancer treatment because they feel that they will be avoided and/or viewed in specific ways by others. Costa et al. [10] highlight the prejudices and stigma associated with disfigurement after head and neck cancer and how survivors must construct new self-identities to accept and live with their new body images. Another qualitative study explored how female breast cancer survivors desired to reconcile with their changed body and reduce the discrepancy between their post- and pre-treatment (or ideal) bodies [7]. A systematic literature review concerning the body image of children and adolescents conducted by Fan and Eiser [11] found that adolescents seem to have more body image concerns than younger children and that males cope better than females with appearance changes. Despite the numerous late effects of bone sarcoma treatment [12–18] and the fact that many patients are left functionally impaired or disabled [19], body image is rarely studied in relation to this cancer.

Among the primary bone cancers, osteosarcoma, chondrosarcoma, and Ewing's sarcoma are the most common [20,21]. Whereas osteosarcoma and Ewing's sarcoma occur mainly in children and adolescents, chondrosarcoma most commonly affects adults [21–23]. The principle treatment for cancer in general and for bone sarcomas in particular is surgery. Curing bone sarcomas in the hip/pelvic region and the lower extremities may require extensive surgery, often in combination with chemotherapy and, for some patients, radiotherapy [24]. Bone sarcomas are rare, representing less than 0.2% of all new cancers [24], but the consequences of radical surgery are often considerable. Today, approximately 90% of patients with osteosarcoma in the lower extremities can be radically operated on using a limb-sparing procedure, thereby avoiding the amputation of the affected extremity [25,26]. The degree of anatomical disfigurement, bodily deviations, changed self-image, and stigmatization render body image studies involving bone sarcoma patients of general interest.

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Contemporary society seems to place increasing importance on appearance and looking good. Hence, exposure might prove distressing for many people, including those whose appearance deviates from that of dominant cultural norms. Negative self-perception and problems with social interaction are the most commonly reported challenges for people with a deviating body image [4]. An individual is often assessed and judged by the outward appearance. This judgment may result in stigmatization and exclusion from participation in different areas of life [4,27]. According to Rumsey et al. [28], concerns about visible differences are poorly addressed in current outpatient care.

For many cancer survivors, their disease is a biographical disruption and a serious life incident [29,30]. A cancer survivor is someone who is “living with or beyond cancer” [31]. Many survivors are cured of cancer. It is, however, not necessarily the case that an absence of disease is equivalent to enjoying good health [32]. Cancer survivors often experience the unavoidable consequences of treatment that involves significant changes and losses in their lives. Such effects might also influence their future and their self-identity [33]. The aim of medical treatment should thus be not only survival but also the restoration of survivors’ quality of life.

This study explores how visible body changes following surgical treatment affect the life and identity of primary bone sarcoma survivors 3–10 years after diagnosis. The aim is to provide insight for various healthcare providers to better guide sarcoma survivors’ following cancer treatment.

METHODS

Study Design

This study employs a qualitative methodology with a sociocultural and psychosocial perspective to explore bone cancer survivors’ experiences of their altered bodies. Thus, an explanatory design is used to identify the causes and reasons for experienced phenomena as the participants explain and talk about them. In line with this study’s methodological framework and research questions, we have adopted a broad phenomenological experience-based and hermeneutics interpretation-based approach on disease and illness. Phenomenological research aims to investigate individual human experiences (phenomena) as these manifest in daily life and specific situations [34–36]. Hermeneutics relates to methods for achieving understanding and interpreting phenomena in a comprehensible manner. Here, comprehension develops through the entire process and is based on the participant’s and researcher’s pre-understandings and on the historical and cultural context. This development of comprehension will affect the questions raised, the interview process and the analysis [37].

The material presented in this article constitutes part of a larger study exploring how cancer, its treatment, and its long-term consequences influence cancer survivors treated for bone sarcomas in the hip/pelvic region or the lower extremities. A core theme emerging from this study is that cancer survivors experience a visibly changed body following surgery.

Participants and Recruitment

We interviewed former bone sarcoma patients who had been treated at Norwegian Radium Hospital, Oslo University Hospital (NRH OUS). Potential participants were identified from the prospective clinical sarcoma database (Med Insight) at NRH OUS, which treats approximately 80% of bone sarcoma patients in Norway [38]. Of the 20 eligible patients contacted, 18 agreed to participate.

Eleven men and seven women, aged 18–60 years (Table I), who had been treated for bone sarcoma in their hip/pelvis region or lower extremities, participated in this study. The participants’ quotes are identified by participant ID and gender. For instance, P1M indicates male participant number 1, while P5F indicates female participant number 5. The participants represent a range of ages and have diverse

TABLE I. Demographic and Clinical Data

	Group I—hip/pelvis	Group II—lower extremity
	Numbers	Numbers
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	

backgrounds. They all write and speak Norwegian. All were treated with surgery (Table II). Fourteen participants received chemotherapy, and two received additional radiotherapy. One participant subsequently had an amputation with a hemipelvectomy because of chronic infection. All participants were diagnosed between 2002 and 2009 (Table I) and were followed-up at the oncological or orthopedic surgical outpatient clinic at NRH OUS. None experienced a relapse of the disease for at least 3 and up to a maximum of 10 years following primary diagnosis. Initial contact with the participants was established by the treating physician at NRH OUS. The first author then provided further details regarding the project before the participants provided informed consent. The interviews were conducted face-to-face by the first author in connection with a routine clinical follow-up appointment that occurred at NRH OUS during 2012–2013.

Procedure

This research is anchored in the fundamentals of the Helsinki declarations. Permission to conduct the interviews and to collect and store sensitive data was obtained from both our Institutional Review Board and the Regional Committee for Medical Research Ethics, REK South East, Approval Number 2012/918. All information was stored confidentially. The analyses were conducted on anonymized transcripts.

The interviews lasted 67 min on average (ranging from 30 min to 104 min) and were audiotaped and then transcribed verbatim by the first author (8) and a medical secretary at OUS NRH (10). Field notes were written following each interview to document observations made by the interviewer. The complete interview guide comprised the following topics: how the participants experienced their cancer diagnosis and

TABLE II. Surgical Interventions

Surgery treatment	Numbers
Hip transposition, (1 amputation with hemipelvectomy)	3
Saddle prosthesis	1
Fibula-graft reconstruction	4
Only tumor resection without reconstruction	1
Autograft microvascular reconstruction	1
Tibia prostheses	4
Femur prostheses	4
Urostomy and colostomy	1

treatment; functional, practical, psychosocial, emotional, and vocational consequences of the disease and treatment; and whether the cancer experience had changed the patient as a person. In this paper, we focus on patients' experiences related to body image and how it influences their current lives. The interview guide was designed to allow the participants to narrate their entire cancer story chronologically. Many patients expressed that they appreciated the opportunity to share their stories, and some patients said that this was the first time they had told their stories. The interview guide was, however, loosely followed, allowing participants to strongly influence the depth of the interview. In this approach, structure and meaning are produced jointly by the participant and the researcher. As such, certain interpretations emerged during the interview from both sides, thereby enabling the confirmation or rejection of the interviewer's perceptions of what the participants expressed [37].

Data Analysis

The participants' accounts underwent thematic analysis [39] by hand by the first and last authors. The analysis was completed in stages and followed an inductive strategy within a contextualized framework. First, the transcribed interviews were read to gain an overall impression and identify preliminary themes. Second, the entire data set was coded in detail and organized into themes, and concepts were then developed. The themes were reflected on in accordance with the study's objectives and compared with existing literature and theory on the interaction between cancer and cancer survivors' life experiences [39].

RESULTS

All participants disclosed a story about a body and an appearance that changed because of surgery (Table III). Two main themes were identified during the analysis: hiding or exposing bodily deviations. Half of the participants reported trying to hide deviations in various ways. Their attempts at concealment were based on participants either no longer feeling attractive or not wanting to be perceived as a sick or disabled person but instead seen as the person they feel like. The decision to expose a deviant body depends on the situation and the context.

Hiding Bodily Deviations

Not wanting to be "different". The majority of participants in this study developed a limp following cancer treatment. Some use a crutch, a

cane or a wheelchair to facilitate improved mobility. These assists could be regarded as visible signs of deviation. Several younger and older participants alike expressed their awareness of their limping and attempted to limp less in social situations than when they are alone. A few participants from the hip/pelvic group stated that the reason they wanted to limp less was to avoid appearing different from others, though some male participants stated that they attempted to walk upright to not strain their body. Three female participants highlighted that they used crutches or a cane for assistance not simply to support their balance and compensate for their weak muscle tone, but also to reduce their limp, effectively making the impairment less visible. The crutches help to create a smoother walk, which, in the participants' opinion, draws less attention from others in social situations. P6F expressed how it has been very difficult to accept having to limp and that she felt her daughter was embarrassed by having a mother who is visibly disabled. Her daughter's embarrassment is the reason she decided to use crutches. In contrast, some other participants found limping to be unproblematic.

P7F stated that she has tried to hide the cancer and her visible difference from most people since she was diagnosed. She has one short leg, and thus, her shoe requires a special sole. She opted not to use special shoes in social situations and uses ordinary shoes instead to appear as normal as possible. She uses crutches for stability, with the additional purpose of looking normal while walking. She states that she never wanted to focus on illness or deviations. The most important objective for her is to not "look different." For P7F, the ability to appear attractive, healthy, and normal is of considerable significance, as she feels these ways of appearing are characteristic of young people. Today, she feels a sense of irony and jokes when people ask her about her scars and her limping: "Now, when people ask me why I limp, I tell them that I was bitten by a shark." She stresses that because people believe her, she sticks to that explanation. Cancer is not a topic for social discussion for her.

Don't feel attractive anymore. Several of the participants have scars, while others have hernias or visible deformities, such as skinnier legs or skin discoloration, resulting from the surgery. Several participants expressed that they try to hide these deviations or disfigurements in social settings. They do not want special treatment or attention based on their changed appearance, or status as a cancer patient. Many participants commented that they feel less attractive after treatment. One of the participants mentioned that she is no longer proud of her body. Other participants even reported that they felt ugly because of their scars and deformities and that they were struggling to accept them. Several participants disclosed that they no longer used dressing

TABLE III. Key Findings Extracted From the Individual Stories

Participant number and gender	P1M	P2M	P3M	P4M	P5F	P6F	P7F	P8M	P9M	P10M	P11M	P12M	P13F	P14F	P15F	P16M	P17M	P18F
Age	>35	<35	<35	<35	>35	>35	<35	<35	>35	<35	>35	<35	>35	<35	>35	<35	<35	>35
Localization	H/P	H/P	H/P	H/P	H/P	H/P	H/P	H/P	H/P	H/P	LE	LE	LE	LE	LE	LE	LE	LE
Consequences																		
Limping	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X		X
Crutches/cane			X		X	X	X		X	X								
Wheelchair									X	X								
Amputation									X									
Stomas										X								
Erectile dysfunction	X			X					X	X								
Hernia	X				X	X				X								
Scars	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Thinner leg		X									X	X	X	X	X	X	X	X
Shorter leg				X			X	X										
Discoloration													X					
Avoid undressing at the beach			X		X		X			X	X				X		X	

Participants are identified by participant number and gender. For instance, P1M indicates male participant number 1, while P5F indicates female participant number 5. H/P represents localization in hip/pelvis, and LE indicates localization in a lower extremity.

rooms and saunas. P3M prefers not to dress among strangers. He is afraid that someone will find him disgusting or feel uncomfortable around him. He does not want to take off his clothes at the beach for the same reasons, and he stated that he was unsure if he would ever be able to do so again. He stressed that taking off his clothes is more difficult in certain situations, particularly in intimate situations: *"I feel, in all reality, very ugly when I am naked. I had girlfriends who say that they like me regardless, but I don't really believe them because they might just say that because they don't want me to be hurt or something like that. [...] I am more daring now but still afraid. Afraid that they will reject me because of my ugly scars."* The vulnerability and fear of being rejected are so strong in this patient's case that he is unsure if he should believe others' positive reactions.

Another finding was that not all participants who hid the consequences of their cancer treatment felt that the scars were problematic. When something is experienced as worse than the scars, hiding the scars becomes less important. Some individuals who had surgery on the bone sarcoma in their hip/pelvic region also developed a hernia in the same area because of the treatment. *"The scars are not the worst thing,"* P5F explained, *"the hernia is."* She was clear about being uncomfortable with undressing in front of strangers: *"The scars are not too bad. The problem is the thing that protrudes from my hip/pelvic region [hernia]. [...] I don't have a pelvic bone, as it was removed in the front, and they moved a muscle from the stomach down to my hip/pelvic area. Now I feel that my abdomen has caved in and that it sticks out when I am not wearing something tight."* She explained that she does not feel particularly attractive anymore. She further noted that her disfigure is located in an intimate area that she would not particularly want to expose.

Being seen for who you really are. P10M highlighted that the main problem is not his diminished ability to move around or the fact of being disabled, but others' attitudes towards him when he uses a wheelchair. The wheelchair is the main factor that mediates how people treat him, and this fact influences his self-esteem. When using the wheelchair, he does not feel that he is seen for who he really is, a resourceful person with much to offer. He can use crutches but only for short distances; otherwise, moving becomes too painful and exhausting. Therefore, he depends on the wheelchair in his day-to-day life. In his experience, the wheelchair is the biggest problem among all the deviations he has encountered following his cancer treatment. P10M's experiences entail everything from people choosing to walk on the other side of the street when they see him because they do not know how to deal with a person in a wheelchair to people regarding him as an invalid because he uses a wheelchair: *"Alarmingly many people have a theory that if you're in a wheelchair, you must be brain damaged."* He noted that he encounters these attitudes too frequently. He emphasized that he has often been both frustrated and hurt when encountering such prejudiced attitudes but that, unfortunately, he does not have the energy to fight people's perceptions.

Some participants indicated that they chose not to show their scars and deformities because they do not want to be identified as a cancer survivor. P11M would prefer that people regard him as the person he is today, that is, a healthy and normal individual: *"I want to be as normal as I can be. I'm wearing long trousers in the summertime to cover the scar [...] By doing this, I am first and foremost (participant's name) and not a former cancer patient."* Similar to many of the other participants, he conceals the effects of surgery with clothes.

Some of the men revealed that they had problems with erectile dysfunction resulting from cancer treatment. This is a visible deviation that is exposed during intimate interactions. They expressed that they are open about their disease but that the impotence issues are relatively difficult to discuss. P4M is one of the youngest participants to suffer treatment-related impotence. He explained that, for a young man who is just beginning his life as an adult, becoming impotent was very difficult. However, he disclosed that with the assistance of a potency pill

(sildenafil), he was able to regain sexual function and that his impotence is not visible during intimate situations. To him, bodily deviations matter only when people know about them. Consequently, he hides the pill and has not mentioned his impotence to anyone, including girlfriends.

Exposing Bodily Deviations

The scope of the deviations experienced by some participants is so large that the only way for participants to deal with their bodily changes is by getting to know their "new" bodies. P10M is a young male at the beginning of his adult life. Scars, stomas, and obesity all contribute to his new appearance as a cancer survivor. The changes in his appearance are so extreme that for him, it was a matter of becoming reacquainted with, and accepting, the person he sees in the mirror: *"I have in many ways spent time getting to know myself again. For example, daring to be naked in front of the mirror. One has to become familiar with one's body shape again. Getting to know what has changed, getting to know all the scars, and daring to show them a little bit."* Furthermore, he stressed that being brave enough to appear unclothed before others has been a process. He showed his body to good friends first to see how they reacted. He said that most of the time, he receives normal responses, which give him confidence. P10M further reported that the deviations from how he looked before the treatment were not the only matters of concern. Similar to other participants, he also talked about concerns regarding how one might experience deviating from the norm or, alternatively, what is considered normal in a given setting. He expressed that it is not easy to appear without clothes among strangers. He indicated that he can accept his obesity on the beach, though he chooses to hide the stomas. Nevertheless, when he is among other cancer survivors, he does not experience the same feelings. In such a setting, the treatment-related deviations are considered normal, although his obesity might be regarded as a more substantial problem. He explained that the circumstances and the norms within that particular context determine his willingness to expose his undressed body to others.

Many participants who undress at the beach are aware of the gazes of others around them, but whether people are bothered and whether the participants notice the stares depend on several factors. P16M, who has a deformed leg, feels comfortable with being different and with the fact that people tend to stare at him. In contrast, P6F found it difficult when people stared at her while she undressed at the beach, though the difficulties she experienced did not stop her from doing so: *"The thing I noticed was how the adults stared at me. The children approached me and asked me what happened, and I said that I had an operation. That was totally fine, and they did not stare at all. How the adults were staring at me, on the other hand, was something that really caught my attention."* Some people choose to undress at the beach despite drawing stares. Others choose to remain clothed or avoid beach life altogether to avoid experiencing others' stares. Notably, some participants commented that it was actually more difficult to undress in their local surroundings among familiar people. They stated that they would prefer to remain clothed in their neighborhood but said that in places where nobody knew them, for example, when on vacation, they felt more at ease being seen in a bikini or in swimming trunks. We did not find any discrepancy in body image experiences between participants aged less than 35 and those older than 35.

DISCUSSION

The main finding of this study concerned how altered appearance after cancer treatment affected the self-esteem of the participants. The survivors describe with specific examples how their altered appearance influences their self-realization, particularly their social life.

All the participants experienced appearance changes following their surgical treatment. Half of them expressed concerns about their visible

differences and considered it important to hide the bodily signs of changes. Despite their functional impairments or bodily deviations, appearing as normal as possible, as well as attractive and healthy, seems to be highly important to the participants. Their opinion regarding the appropriateness of exposing their changed appearance is situation dependent. Both the cultural and social norms and the context are crucial.

Extensive surgery in the hip-pelvic region or the lower extremities could result in a person becoming disabled and, thus, differing from what is deemed normal because of having to use a wheelchair or crutches or walking with a limp. Additionally, scars and deformities engender a deviating appearance that others notice, and as a result, those affected may hide themselves when they are in social situations. For survivors of serious cancer, one may assume that the side effects in terms of an altered appearance would be a small price to pay for being alive. However, that assumption is not necessarily true. An individual's experience of their changed appearance and the disruption to their bodily identity are both influenced by cultural norms concerning how a normal and attractive body should appear [40,41]. Body satisfaction and appearance likely represent the major contributing factors to self-esteem, given their important role in shaping how individuals feel about themselves [42]. In body image research, individuals with a visible difference may experience problems in their social life [4,43]. It is challenging to expose a deviating appearance to others because doing so might result in negative reactions from others and discrimination.

The change in social status from being a healthy individual to being a person with a functional impairment or disability constitutes an altered identity, which might be perceived as a loss and, thus, cause social challenges. These changed perceptions result from how a person sees themselves and how others treat them [44,45]. Becoming disabled actually involves creating a sort of new identity. The shift in identity and future possibilities is clearly articulated by Robert F. Murphy [46], a professor of anthropology, in his book *The Body Silent*, after he is diagnosed with a tumor in his spinal cord in adulthood:

“From the time my tumor was first diagnosed through my entry into wheelchair life, I had an increasing apprehension that I had lost much more than the full use of my legs. I had also lost a part of myself. It was not just that people acted differently toward me, which they did, but rather that I felt differently towards myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence” (p.85).

People who limp or use crutches, a cane, or a wheelchair have bodies that differ noticeably from that of the Western cultural ideal [27,41]. This may be stigmatizing [47]. A stigma generally means that a person is perceived as being “other.” This perception of otherness can beget many negative effects for those affected, who may face prejudice and discrimination and be stereotyped [4,27] because a person's appearance is critical to how other people perceive them. As participant P10M noted in this study, he is easily overlooked when he uses his wheelchair. It is common to perceive people with disabilities as being more dependent on others and less intelligent [47]. Their new identity as functionally impaired or disabled because of surgery [19], in addition to their young age, might differentiate our participants from many other cancer survivors.

When a participant avoids undressing in public or when they cover their bodily deviations with clothes, they do so because they do not want to expose their differences. They want to avoid being stared at. The latter desire echoes other research on cancer survivors [5,7]. However, recent research suggests that the extent to which a visible difference results in a social disability involves a complex interplay

between social and individual factors. A stigma based on a visible or experienced deviation is a common reason people experience shame [27].

It is important to mention that people with a physical impairment or a deviating appearance do not experience negative attention and stigmatization in all situations. In fact, the stigmatizing conditions may be context dependent [27]. In this study, the participants emphasized this dependency when they commented that the reactions of others depend, for example, on whether they use crutches or a wheelchair and that they perceive a difference between exposing bodily deviations in their home area versus in places where no one knows them.

The small sample size limits the generalizability of this study. Nevertheless, these narratives are rich and full of nuanced examples. In qualitative research, we do not seek representative data but rather aim to illumine the phenomena that participants experience from their own perspectives. In subsequent research, it would be interesting to determine why many bone sarcoma survivors experience appearance concerns in this wide variety of reported ways.

CONCLUSION

A more holistic view of health and treatments compared with the traditional biomedical approach could provide measures that are better oriented towards health protection and rehabilitation. To better guide bone cancer survivors, we first must understand patients' individual experiences. A sociocultural and psychosocial perspective on health may provide a more robust comprehension of what it means to be a cancer survivor who experiences concerns with one's appearance. Healthcare providers who guide bone sarcoma survivors during follow-up should develop a comprehensive understanding of what it means to cope with a changed and challenging body.

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