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Body Image and Cancer

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1. Introduction

Human beings have always been interested in their appearance. Most of us make active efforts to influence the way we look: we exercise, we lose or put on weight, we use make-up and dye our hair, we dress in certain ways, and some of us even have surgery to change parts of the body with which we are dissatisfied. Changes in appearance are sometimes desired, and sometimes not. According to Giddens, the body is easily changeable and reflects our identity (Giddens 1991). Individuals therefore have the ability to change their bodies, if they so wish. The healthy body symbolises a healthy society, while the sick or imperfect body represents a sick society. In advertising, good-looking models are often used, as it is expected that this will cause us to buy the product they are advertising (Rumsey N. & Harcourt D. 2005). Visual appearance is sometimes also linked with inner values. Most societies have their own traditional links; in Western society, for example, red hair is associated with a hot temper, and a link has been found between appearance and the chance of being convicted in court through false consensus (Miyake & Zuckerman 1993). Stereotypical conceptions of links between visual appearance and a person's inner qualities have also been experienced by patients (Rumsey N. 2003). Plough Hansen has, for example, described how women with chemotherapy-induced hair loss experienced this as a loss of womanhood, associated with sickness and death, and therefore used wigs and make-up to control and minimize the effects of the changed appearance (Hansen H.P. 2007). Jutel and Buetow argue that outer appearance and a tendency to focus on first impressions may imply a tendency for health care professionals to use this as an indicator of health, with the risk that this could harm medical practice (Jutel & Buetow 2007). However, although there is an emphasis on visual appearance in our society, such norms as "true beauty comes from within", "do not judge a book by its cover" or "beauty lies in the eye of the beholder" are often more acceptable. People do not generally wish to be regarded as being overly concerned about their appearance, or as someone who judges others on their appearance. This makes it difficult for patients to talk about issues of appearance. It might therefore also seem a contradiction that many smokers continue to smoke rather than risk gaining an extra five kilos, even though the health risk from smoking is many times greater than that of a small amount of extra weight. Similarly, young amateur bodybuilders risk taking anabolic steroids in order to increase their muscle mass, even though this affects their bodies in many ways, and may involve the risk of impotence. In a study of patients attending a cancer rehabilitation centre, it was found that the lack of communication about appearance was experienced as a socially-accepted norm, supported by the taboo on speaking out about cancer (Rasmussen, Hansen, & Elverdam 2009).

Visual appearance affects first impressions when two people meet. In addition, another determinant is how those impressions are understood and socially returned. It has for example been shown that people who undergo facial changes experience social encounters in ways that are different from others, with behaviour or rules of social conduct that differ from the norm, e.g. greater standing distance (Rumsey N., Bull R., & Gahagan D. 1982), staring and comments, or differences expressed in "silent language" such as body movements and gestures (Macgregor F.C. 1990). This is an example of how reactions are determined, not only by the actual physically changed appearance, but also by social interaction between people. In patients who have undergone a changed appearance after surgery for head, neck or eye cancer, this was described in their first year post-operatively as "interactional integration" (Konradsen H. 2010). The integration of disfigurement was affected not only by the attitudes of the patients themselves, but equally by their social interaction with the surrounding society, also described as the movement from becoming disfigured, to being a disfigured person, to becoming a person with a disfigurement.

One of the first philosophers to talk about the body was Plato, who lived from 427 - 347 BC. He regarded the body and mind as two separate entities, and this dualistic view of body and mind still underlies much of our health care today. Others have criticised this approach. The anthropologists Scheper-Huges and Lock (Scheper-Hughes & Lock 1987), for example, view the body on three levels: the individual body, the social body and the political body. According to them, society socialises us and our bodies, and our bodies therefore represent our ability to live up to these norms. This puts a great deal of pressure on those who fall ill.

In the early 1990s, Bob Price developed the "Body Image Care Model" (Price 1990). This model focuses on how we experience our bodies, and our reaction to how others regard us. The model describes our body image as influenced by three dimensions: body ideal, body reality and body appearance (Figure 1)

Subsequently, other people have developed other models. Professor Robert Newell, for example, has developed the "fear-avoidance model" (Newell 1999). His model can help to evaluate body image-related concerns and provide possible suggestions for intervention. (Figure 2).

In healthcare research, the use of the concept of body image began in the nineteen-sixties, and was at first mainly related to social psychology, with the main emphasis on eating disorders. Most research at that time focused on how the disturbed body image or body ideal was perceived by the person herself: the fact that you did not see yourself as others saw you. This way of looking at body image-related concerns is for example reflected in the NANDA classifications (Ackly & Ladwig 2008). Here, disturbed body image is defined as "confusion in the mental picture of one's physical self". More recently, the concept of body image has received wider clinical application. Today, we know that bodily changes, and related body image concerns, occur independently of medical diagnosis. Most diseases cause bodily changes, whether they are temporary, recurrent or chronic. These changes may be visible or invisible, physical or psychological, and may interfere in various ways with our everyday lives. Such bodily changes are not merely objective visible changes, but are also subjective, and are linked to the ways in which we see our bodies, the world and our relationships with others. Health-related quality of life studies have explored this and have shown how changed appearance in relation to illness is an important issue, for example in cases of HIV and AIDS (Huang et al. 2006b; Huang et al. 2006a), as well as obstetrics (Hawighorst-Knapstein et al. 2004). It is also important irrespective of patients' age, gender, social situation or ethnicity (Cash T.F. & Pruzinsky T. 2002).

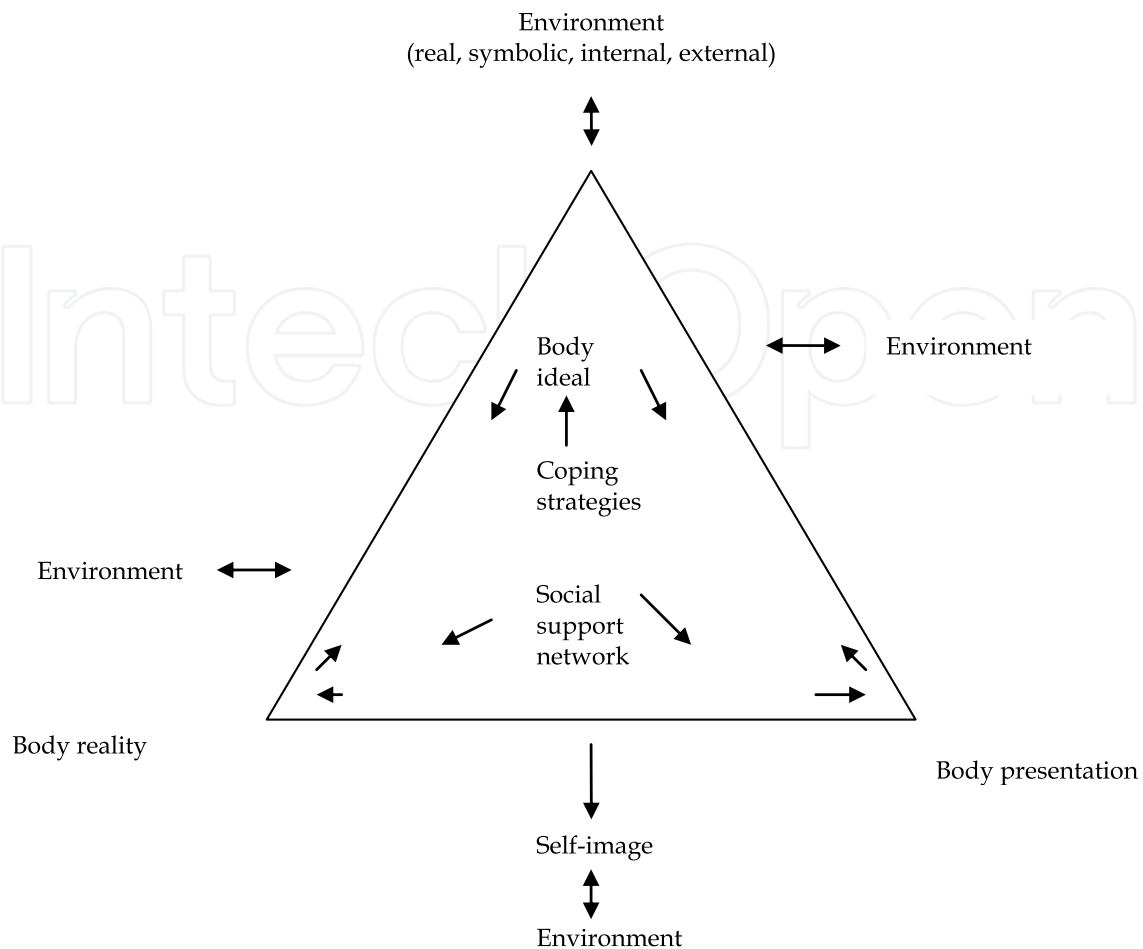


Fig. 1. The body-image care model. Arrows indicate direction, influence or interaction. (Price 1990)

Facial disfigurement as a result of surgical treatment for head, neck or eye cancer, for example, poses a great challenge to the person experiencing it. The face is a major contributor to what is labelled “first impressions”, and it expresses a great deal of our personality (Bar M., Neta M., & Linz H. 2006; Hess U., Adams R.B., & Kleck R.E. 2009; Naumann L.P. et al. 2009). Changes in the face cannot be hidden, and are therefore often more difficult for patients to deal with than changes elsewhere in the body (Dropkin M.J. 1999). According to Callahan, facial disfigurement poses a challenge, in that the patient must deal with both a changed appearance and an altered sense of self (Callahan C. 2004). Facial disfigurement is associated with a high degree of psychosocial problems and a lower self-reported quality of life. The problems occur irrespective of the patient’s age or the extent of the disfigurement (Blood G.W. et al. 1995; Tebble N.J., Thomas D.W., & Price P. 2004), and include anxiety, depression and social isolation (D’Antonio L. et al. 1998; Rumsey N. 2003; Rumsey N. et al. 2004) Marks 2000, Tebble 2006). Close family members or partners may also be affected (Drabe N. et al. 2008; Krouse H.J. et al. 2004; Verdonck-de Leeuw I.M. et al. 2007; Vickery L.E. Latchford G. et al. 2003). In relation to quality of life, socio-cultural factors seem to matter more than physical dysfunction (Morton R.P. 2003). In 1983, Dropkin (Dropkin M.J. et al. 1983) found no differences in the evaluation of men’s and women’s degree of disfigurement after identical surgical treatment, whereas Lockhart found such

differences in 1999, and based the explanation of the results on a generally increased focus in society on “the perfect female body” (Lockhart J.S. 1999).

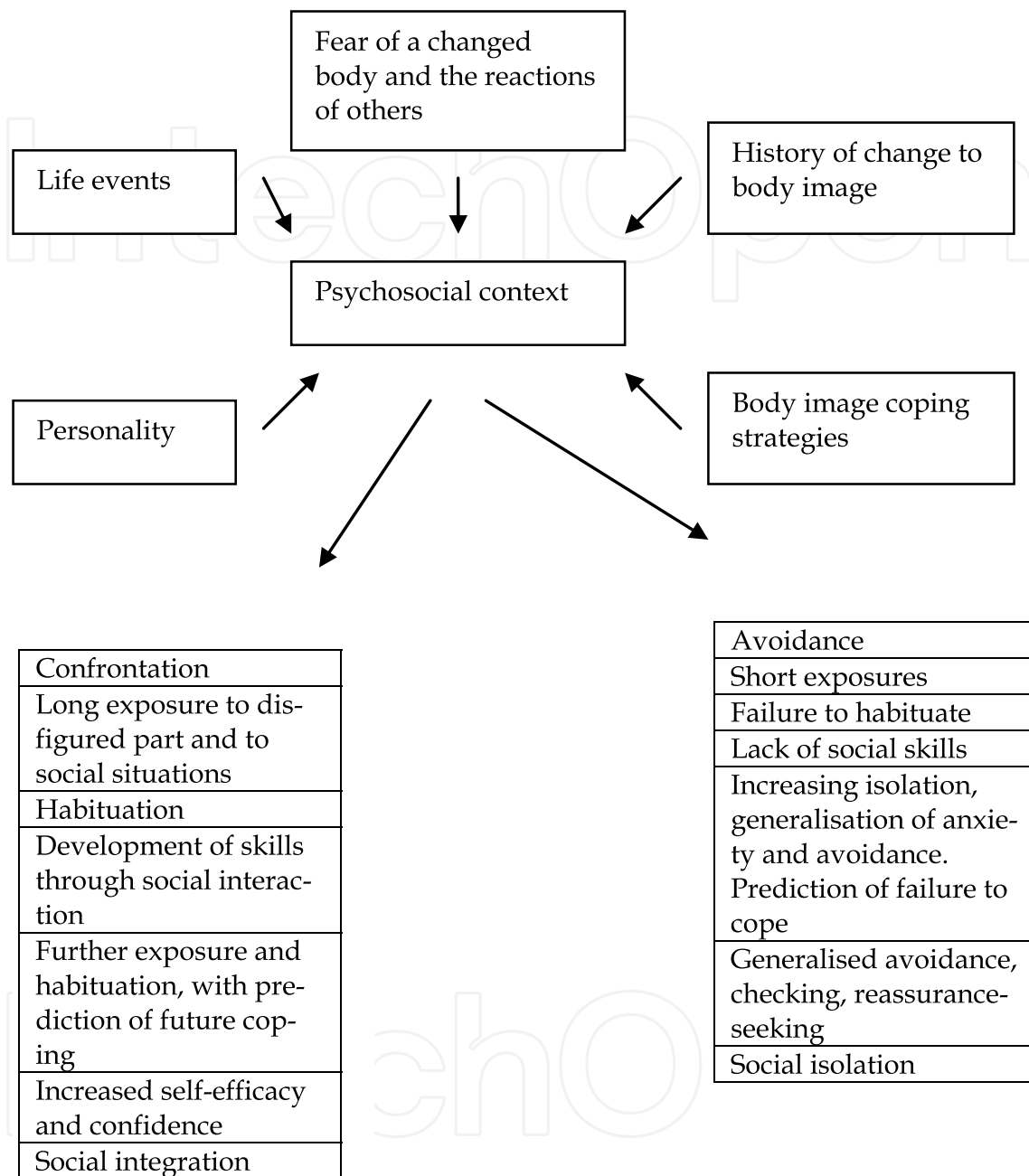


Fig. 2. A fear-avoidance model of psychosocial difficulties following disfigurement. (Newell 1999).

When we encounter illness our attention is directed towards the body, a mechanism Leder calls “the dysappearing body” (Leder D. 1990). When our body is changing, or not functioning as we expect, our attention is drawn towards it. Others have found that the experience of bodily change is influenced by various underlying self-schemas (Thompson A. & Kent G. 2001), the degree to which people have a negative view of themselves (Moss T. & Carr T. 2004), or social self-efficacy (Hagedoorn & Molleman 2006).

Cancer, i.e. the disease itself, its treatment and side effects, significantly interferes with the body. There are bodily changes associated with the specific cancer site, but in addition to this, many cancer patients also struggle with symptoms such as tiredness, pain, etc. Due to the seriousness of the disease, psychosocial concerns are also of great importance and influence the way in which the body is perceived.

In general, body image is a multidimensional concept which is used in many different ways. In 2002, White wrote that “much of the literature on body image and cancer is observational, atheoretical, and anecdotal. Though more empirical research has recently emerged, it is often of poor quality, resulting in inconsistent findings” (Cash T.F. & Pruzinsky T. 2002). This is still partly true, but body image as a research subject has been attracting increasing attention.

2. What we know

In the following, the literature relating to body image and cancer is briefly reviewed. What do we know about body image in relation to cancer patients? And what are the benefits and limitations of the research?

The research studies examined date from 1997 to 2010. As the aim is to understand how issues and concerns relating to bodily changes are experienced by adults, only studies which employed a qualitative approach have been examined. In order to obtain an overview, all of the studies were arranged according to the Matrix Method (Garrad J. 2011). The research includes studies of adult women, men, both men and women, and families. The medical diagnoses included breast cancer, gynaecological cancer, head and neck cancer, testicular cancer and colorectal cancer. A few also included persons with a mixture of different diagnoses. This indicates that the research has mainly concentrated on diagnoses for which treatment most often results in a visibly changed body.

2.1 Body image and gender

Overall, most of our knowledge about body image and cancer is related to the diagnosis of breast cancer, and thereby relates specifically to women. Breast cancer has been described as associated with the fear of losing one’s attractiveness and desirability (Elmir et al. 2010), and has been seen as a threat to intimate relationships (Ashing-Giwa et al. 2006) and as challenging a person’s female identity (Piot-Ziegler et al. 2010). Studies focusing on men are rare. A few studies have been undertaken of testicular cancer, e.g. (Chapple & McPherson 2004), and of male breast cancer (Pituskin et al. 2007). Even fewer studies have been undertaken of how the cancer experience relates to body image when gay or lesbian patients are involved; one example is a study by Katz (Katz 2009). In relation to body image concerns, it seems that the emphasis is on gender as a sexual component, and little is known about how women and men experience bodily changes in relation to cancer diseases that are not related to a person’s specific gender.

2.2 Body image as a static or changing problem

Problems relating to body image are often described as a static issue, clearly associated in time with the period after cancer treatment. A few studies have examined changes in body image pre- and post treatment, e.g. Adamsen’s study of how young athletes regain their bodily control and identity through exercise, and Bredin’s study of women with breast cancer, and how they experienced their body image in combination with therapeutic

massage (Adamsen et al. 2009; Bredin 1999). Body image problems are also often presented as being static post-treatment. In general, the findings give a picture of BI-related concerns at a specific point in time. We know that adjustment to other chronic diseases must be viewed over a substantial period of time if they are to be fully understood. Adjustment is the psychosocial adaptation to a life change, as expressed in the Nursing Outcome Classification (Johnson M., Maas M., & Moorhead S. 2000), so if body image is regarded as a chronic or stable situation, this approach could prove fruitful. In the case of multiple sclerosis, for example, patients diagnosed at least five years previously stated that it was a process that "one can learn to live with" in time (Irvine H. et al. 2009). For patients adjusting to lower-limb amputation, it has been found to be a question of developing an altered sense of self and identity over the months and years following the amputation (Horgan O. & MacLachlan M. 2004). In an article, Morse describes findings from a study of patients who survived traumatic injury, covering their experiences from the initial impact of the surgery until recovery (Morse J.M. & O'Brian B. 1995). She describes a four-stage process of vigilance, disruption, enduring the self, and striving to regain the self. In the final stage, the participants learned to redefine the self as a disabled person by accepting the consequences and reformulating their expectations. Learning to see oneself as a disabled person is also one of the end-points in a qualitative meta-analysis of the individual's responses to acute or chronic illness or injury (Morse J.M. 1997).

The elucidation and exploration of body image is also seen as a static problem, in that only a few studies describe the late effects of cancer and how these are experienced. Frid found that lower limb lymphedema exerts a considerable influence on the psychosocial situation of cancer patients in palliative care (Frid et al. 2006). There are very few studies that examine how a patient's body image concerns change over time. One example is the study by Roing on the experiences of patients with oral cancer of their illness and treatment (Roing, Hirsch, & Holmstrom 2007). The study found that the need of patients for support increased during treatment, and it was suggested that this need might be greatest at the conclusion of radiotherapy, when the patients returned home. This is an example of how the degree and extent of patient concerns can be greatest at the time of discharge, rather than, as is often thought, at the time of admission to hospital. Another way of elucidating change in body image over time is described by Frith in a study of chemotherapy-induced hair loss among patients treated for breast cancer (Frith, Harcourt, & Fussell 2007). Here it was shown that the women made use of the anticipation of altered appearance as a form of anticipatory coping.

A more detailed picture is required of interventions targeted at specific problems relating to body image; how do the problems change over time, and when is the most appropriate time for intervention?

2.3 Context-related or universal

In most of the studies, context is very sparsely elucidated. In some studies the cultural aspect is described, examining such issues as religious approaches in newly-diagnosed Iranian women coping with breast cancer (Taleghani, Yekta, & Nasrabadi 2006), how spiritual belief is part of the cancer belief among Asian American women with breast cancer (Tam et al. 2003), or how culture and the role of the woman in Lebanese families creates a foundation for various coping strategies among women with breast cancer (Doumit et al. 2010). Another study described women from a low-income socio-economic group with

early-stage breast cancer and their various styles of decision-making (McVea, Minier, & Johnson Palensky 2001). While it is plausible that body image-related concerns could have a universal inner structure, it is also plausible that body image-related concerns could be highly culturally dependent. The latter is suggested by a study of Jewish/Middle Eastern cancer patients from Israel, where religious belief systems, amongst other things, can influence how patients deal with existential concerns (including body image-related concerns) (Blinderman & Cherny 2005). It seems evident that body image-related concerns are not only dependent on how an individual experiences her own body. The surrounding society and the people with whom one interacts also have a substantial influence - an influence that is often overlooked in research.

2.4 Multiple effects

Body image is very often described as a concept that relates to the visible, objective signs of changed appearance: the absence of a breast or hair, deterioration in muscle function, or a change in bodily functions such as amenorrhoea or loss of control over bodily functions.

When body image is addressed in a study's results, the terms in which it is described are often powerful, such as identity-changing, hopelessness, fear, poor self-esteem, frustration and so on. The concept of body image itself is rarely defined, and is most often used without a theoretical basis. One of the few studies to actually define the term body image as it is used is Jenks et al (Jenks, Morin, & Tomaselli 1997), who state that the definition of body image they employ is based on the individual's own perception of the physical appearance and physical functions of the body.

However, as with any other concept in research, the use of the body image concept is strongly linked to how the concept is defined. This may be exemplified by examining three different studies.

In 1983, Dropkin developed a visual scale to measure the perception of the severity of visible disfigurement and dysfunction following head and neck cancer surgery (Dropkin et al. 1983). Evaluations were made by measuring how nurses assessed a certain disfiguring surgical procedure. The study argues that quantitative measurement of the grade of disfigurement could be used to foresee the course of a patient's rehabilitation. This thus implies that the way in which others perceive a person with a disfigurement is an important factor in the rehabilitation process.

Later, Newell developed his fear-avoidance model of psychosocial difficulties following disfigurement (Newell 1999). This model suggests that the problems experienced by patients with disfigurement could be compared to those experienced by patients with phobias. It therefore recommends cognitive behavioural therapy. The model thus implies that a person's own perception of himself or herself and their own way of behaving are important factors.

The third study is from 2006; here Furness argues that social support and a person's ability to cope with challenging situations are important (Furness P.J. et al. 2006). This study implies that social interaction and a person's own psychological resources are important factors.

These three studies present different theoretical perspectives on the psychosocial issues relating to disfigurement. These theoretical views contribute to determining how one might regard, elucidate and examine these problems, how data is collected and analysed, and where to look for data. Determining and describing the theoretical view of the concept of body image thus seems to be important in order to assess the results of the study. Doing so

could potentially strengthen the whole body of knowledge within this clinical area and improve the possibilities for developing adequate and effective interventions which will target the patients' problems.

2.5 Relationships

One major theme that emerges in connection with how patients with body image-related concerns relate to health care professionals is that of lack of support. In head, neck and eye cancer, for example, this is described by Konradsen (Konradsen, Kirkevold, & Zoffmann 2009) as an issue that is silenced in the communication between patient, relatives and professionals. In a study of patients surgically treated for laryngeal cancer, it was found that for a period of three years, the most difficult areas of psychosocial adaptation were work and family relationships (Ramirés M.J. et al. 2003), while in patients with orofacial injury, it was found that the perception of a diminished level of social support was associated with a higher risk of post-traumatic stress (Lui A., Glynn S., & Shetty V. 2009). Others have found that patients' family members also go through a process of adjustment, from being concerned about the survival of the patient to becoming concerned with how disfigurement might affect the patient socially (Bonanno A. et al. 2010).

It seems that for cancer patients, body image-associated issues relate to some of the basic and fundamental structures of a person's identity, and thereby also to social interaction in a broad sense. For patients with colorectal cancer, the experience of having to deal with a stoma is described as a loss of adulthood (Rozmovits & Ziebland 2004), which also influences their sense of dignity, independency and sexual confidence.

3. Future research

With the exception of one study's additional use of journal narrative, the research has exclusively employed individual interviews or focus group interviews for data collection. These are data collection methods which are well established in qualitative research, and are capable of collecting valuable data. However, a wider range of data collection methods might enrich the body of knowledge in the field of body image.

A closer look at changing body ideals in the surrounding society of patients might also be beneficial. How does the changing body ideal among both women and men influence the experience of bodily change? If more is learned about this, it might be possible to develop better patient trajectories.

All of the studies included an adult population, but few included old people. As an example, it has been shown that body image is important when older women are making treatment decisions about breast cancer, and that treatment outcomes influenced body image two years after treatment (Figueiredo et al. 2004). It might therefore be of great interest to examine the impact on body image of experiencing cancer either as an older person, or how this changes (or does not change) in the course of a lifetime. Collecting this knowledge and obtaining an overview might help the health care system to improve both the overall and the individual quality of treatment and care.

4. Interventions

Measuring body image implies a wide range of challenges. The definition of the term 'body image' reflects what is being measured. One proposal for a means of measuring body image,

specifically in relation to cancer patients, has been advanced by Hopwood (Hopwood et al. 2001). The scale focuses on how body image is experienced by the patients themselves. It is a valuable scale, but it may omit the contribution of relatives and society generally to the way in which patients experience their own body image. The scale can provide valuable knowledge about the extent of body image concerns among cancer patients. It has for example been used to describe how half of a multi-ethnic population of women in the USA diagnosed with breast cancer experienced two or more body image problems during the early months after diagnosis (Fobair et al. 2006). Another scale is Dropkin's disfigurement/dysfunction scale, which measures how others view the extent of a patient's disfigurement. This is also important, and has been used to show how body image reintegration is critical to subsequent quality of life after head and neck cancer surgery (Dropkin M.J. 1999).

Qualitative studies are important when developing intervention studies targeted at the psychosocial problems experienced by cancer patients in relation to body image. In many areas there is a lack of effective intervention methods. In relation to head and neck cancer, for example, reviews have shown that no intervention method has so far been successful (Semple et al. 2004). Another example is in relation to gynaecological cancer patients; in this context there is only weak evidence to suggest an effect from cognitive behavioural interventions for body image-related concerns (Hersch et al. 2009). Overall, Bessell concluded in a review of the effectiveness of psychosocial interventions targeting individuals with visible disfigurement unrelated to diagnosis that none of the studies demonstrated adequate clinical effectiveness in the interventions (Bessell & Moss 2007).

Qualitative studies have the potential to direct the researcher's attention to possible elements of future interventions. Studies using grounded theory as a research method have for example demonstrated this in other contexts, such as diabetes care (Zoffmann & Lauritzen 2006). To demonstrate how this can be viewed, a case is presented elucidating how a longitudinal study of patients with facial disfigurement as a result of surgical treatment for head, neck or eye cancer could point to possible elements of future interventions (Konradsen H. 2010).

In the study, the researcher met and interviewed the participating patients several times during the first postoperative year. Grounded theory analysis of the early patient-nurse interaction during hospitalisation revealed that disfigurement in this context was silenced, and this situation continued. The researcher, on the other hand, brought up disfigurement as a central theme in every interview. The fact that the researcher became a familiar person who accompanied the patients throughout their trajectory also meant that the researcher knew the patient's history and was aware of his or her concerns. While hospitalised, the patients met various nurses, albeit a limited number, whereas during outpatient treatment they met a different nurse at almost every visit. In contrast to this, the researcher was the same person throughout the entire process.

Throughout the study, there were numerous signs of the patients' willingness to participate, e.g. repeatedly devoting their spare time to talking to the researcher, inviting the researcher to their homes and serving coffee and cake, wishing to continue talking after the interview was completed, and so on. Regardless of not being asked about the benefits of participation in the study, six of the twelve patients spontaneously stated that they had benefited from this. The positive effects were related to the patients' feeling that there was someone who

was willing to listen to their story, the feeling of being able to look to the future with some confidence, and a sense of being able to exert some kind of influence over how to tackle the possible obstacles the patient would meet in the future.

The positive effects of participation in the study indicate and help to point out various possible effective components of interventions, which future intervention studies may subsequently evaluate. Examples are shown in table 1.

- **Setting the issue on the agenda**
- **Regular meetings for patients and their significant others with a nurse at the hospital**
- **Emotional intimacy between nurse and patient**
- **Establish a relationship between nurse and patient**
- **Promote trust between the patient and the nurse to talk about any issue the patient wishes**
- **Encourage patients to tell their stories**
- **Give patients the time needed for reflection**
- **Explicitly ask the patients questions about disfigurement**
- **Ask open questions in order for the nurse to understand the patient's experiences and in order for the nurse to help the patient to understand own experiences**
- **Develop specific communication skills among nurses in order to redirect communication from the area of general practicalities and physical needs to patient-specific psychosocial needs**
- **Organise the entire patient trajectory towards higher nurse-patient continuity**

Table 1. Possible elements in interventions targeting psychosocial concerns related to body image

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Cancer is now the leading cause of death in the world. In the U.S., one in two men and one in three women will be diagnosed with a non-skin cancer in their lifetime. Cancer patients are living longer than ever before. For instance, when detected early, the five-year survival for breast cancer is 98%, and it is about 84% in patients with regional disease. However, the diagnosis and treatment of cancer is very distressing. Cancer patients frequently suffer from pain, disfigurement, depression, fatigue, physical dysfunctions, frequent visits to doctors and hospitals, multiple tests and procedures with the possibility of treatment complications, and the financial impact of the diagnosis on their life. This book presents a number of ways that can help cancer patients to look, feel and become healthier, take care of specific symptoms such as hair loss, arm swelling, and shortness of breath, and improve their intimacy, sexuality, and fertility.

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