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Sexuality is not a priority when disease and treatment side effects are severe: conceptions of patients with malignant blood diseases.

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Aim. The aim of this study was to describe how patients with malignant blood diseases conceive the influence of chemo- or chemoimmunotherapy on sexuality, and their need of support related to this issue.

Background. Sexuality is often negatively affected in cancer patients with sex-specific diagnoses. For patients with malignant blood diseases the research is limited with regard to the effect on sexuality. Knowledge about their need for support related to sexuality is also needed as nurses are found to often avoid this area of their responsibility.

Design. Qualitative design.

Methods. Twelve patients treated for malignant blood diseases were interviewed twice. Phenomenography was used for the analysis.

Results. The analyses revealed an outcome space consisting of two main categories ‘Sexuality is overshadowed by the cancer experience’ and ‘No need of support but timely information might be helpful’, both comprehensively related to three interrelated description categories ‘Affected strength’, ‘Affected sexual desire’ and ‘Affected self-image’, which describe conceptions of how sexuality was affected.

Conclusion. Patients experienced negative effects on sexual function and sexual relationship during and after treatment period due to affected strength, sexual desire and negatively self-image. However, when disease and side-effects were experienced as severe, thoughts and interest of sexuality were overshadowed, and the need or wish for support related to this issue was very low. It is important to note that some patients expressed that pre- or post-treatment information might have been helpful.

Relevance to clinical practice. It is acknowledged in the cancer care of today that cancer follow-up should address psychosocial support in which sexuality is an important area. Therefore, it is imperative that cancer care is organized in a patient centered way, with adequate time for nurses to provide continuity in the nurse-patient relation and supportive care also during cancer rehabilitation.

Keywords: cancer patients, malignant blood diseases, nursing, phenomenography, sexuality, support

‘SI-SRH’

Sexuality is not a priority when disease and treatment side-effects are severe: conceptions of patients with malignant blood diseases

Introduction

The numbers of people who get diagnosed and treated for cancer are increasing, and more cancer patients achieve long-term survival (Hayat *et al.* 2007, Coleman *et al.* 2011, National Board of Health and Welfare 2011). As cancer diagnosis and associated treatments often imply complex and long-lasting physical and psychosocial problems for the individual, there is an increasing need for the health care to focus on cancer rehabilitation, which includes patients' sexuality. It is well known that sex specific cancer diagnosis and its associated treatment affect sexuality, and the research regarding fertility and sexual function for these patients is extensive. However, there are cancer diagnoses such as malignant blood diseases where the research is still limited with regard to the effect of treatment on sexuality. There is also a need for research on sexuality from a broader perspective than fertility and function.

Background

Sexuality is difficult to define since it is a multidimensional concept that includes physiological, psychological and social dimensions which often interact in a complex manner (Lavin & Hyde 2006, Wilmoth 2006). It has a broader meaning than activity and includes desire and identity (Lavin & Hyde 2006). Cancer patients receive a variety of treatments often in combination that can impact on sexuality (Ganz *et al.* 1996, Young-McCaughan 1996, Galbraith & Crighton 2008). Treatment in the pelvic area is found to interrupt nerve pathways or disturb vascular circulation that cause sexual dysfunction (Schover 2005, Wilmoth 2006, Galbraith & Crighton 2008, Hughes 2008), directly as a consequence of surgical treatment or after months or years due to late side-

1 effects of radiotherapy (Schover 2005, Galbraith & Crighton 2008). Chemotherapy has been
2 reported to negatively affected fertility and interest in sexuality. Patients' self-image may also be
3 affected for both women and men, due to such factors as hair loss, scars, weight gain and weight
4 loss. In addition patients who have been treated with radiotherapy and chemotherapy often
5 describe side effects such as fatigue (Hughes 2000), nausea, vomiting (Hughes 2000, Börjeson *et*
6 *al.* 2002, Barton-Burke & Gustason 2007), and nutritional problems that may also impact on
7 sexuality (Hughes 2000). Negative effects on the sexual relationship between the patients and
8 their partner are often described (Holmberg *et al.* 2001, Galbraith & Crighton 2008).

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10 Research in patients with malignant blood diseases showed changes regarding interest in
11 sexuality, desire and/or pleasure related to sexuality, sexual relationship, and ability for sexual
12 activity (Zittoun *et al.* 1997). In a study by Tierney *et al.* (2007) 73 % of women treated for
13 malignant blood diseases had decreased sexual desire and nearly half of them had side effects
14 related to treatment-induced menopause. Jonker-Pool *et al.* (2004) found that male patients
15 treated for malignant lymphoma estimated changes in sexuality as high as patients treated for
16 testicular cancer. However, research concerning how treatment impacts on sexuality in patients
17 with malignant blood diseases are mainly presented in studies where patients have undergone
18 bone marrow transplantation (Zittoun *et al.* 1997), or in studies about young adult patients in
19 relation to infertility (Zebrack *et al.* 2004).

20
21 Studies have indicated the importance of support to cancer patients related to their sexuality
22 during and after treatment (Nishimoto 1995, Schwartz & Plawecki 2002). It has been stressed
23 that the patients must be provided with the opportunity to express their thoughts about sexuality,
24 anticipated changes and associated consequences. However, studies have reported that patients
25 are lacking information and support concerning sexuality both during and after treatment
26 (Jonker-Pool *et al.* 2004, Hordern & Street 2007, Flynn *et al.* 2012). Olsson *et al.* (2012) found that

nurses who care for cancer patients considered sexuality as an area of their professional responsibility, but they seldom provided such support. The reasons for this were uncertainty in talking with patients about sexuality, lack of nursing experience, and knowledge about sexuality, which have also been described in other studies (Gamel *et al.* 1995, Stead *et al.* 2001, 2003, Katz 2002). Olsson *et al.* (2012) also found that the organization of the ward, the degree of continuity in nurse-patient relations, the working atmosphere and responsibility in the team could be both opportunities and obstacles for dialogues about sexuality.

Rationale for the study

This literature review showed that sexuality is often negatively affected in cancer patients with sex-specific diagnoses due to their treatment. For patients with malignant blood diseases knowledge in this area is limited. The studies found concerned rather young patients, and patients with malignant blood diseases are most often above their fifties. Therefore there may be areas that still need to be studied with in regard to the impact of treatment on sexuality in patients with cancer diagnoses such as diffuse large B-cell Lymphoma, Chronic Lymphocytic Leukemia or Acute Myeloid Leukemia. These patients are usually diagnosed around their sixties and are treated with chemo- or chemoimmunotherapy regimens associated with similar side-effect profile. Knowledge about their need for support related to sexuality during and after treatment is also of great importance as nurses are found to often avoid this area of their responsibility.

Aim

The aim of this study was to describe how patients with malignant blood diseases conceive the influence of chemo- or chemoimmunotherapy on sexuality, and their need for support related to this issue.

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3 1 **Methods**
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5 2 In the present study phenomenography was used. In phenomenography the reflected
6 3 conceptions are focused, which means that the underlying ways of experiencing the world, the
7 4 phenomenon or the situation is the subject of research (Marton & Booth 1997). Within
8 5 phenomenography it is assumed that a phenomenon can be conceived in a limited number of
9 6 qualitatively different ways. The conceptions vary from person to person as well as within the
10 7 same person, since different aspects of a phenomenon are conceived depending on the entirety in
11 8 relation to a given context (Marton & Booth 1997, Barnard *et al.* 1999). The analysis focuses on
12 9 similarities and differences in individual statements, and descriptive categories are defined from
13 10 clusters of common meanings (Marton & Booth 1997). The result of a phenomenographic study
14 11 is presented in the outcome space, which covers the categories and their logical relationships
15 12 (Uljens 1989, Barnard *et al.* 1999) and describes the conceptions on a collective level (Marton &
16 13 Booth 1997).
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39 17 **Informants**

40 18 Patients were selected purposefully from four hospitals in the middle of Sweden, between
41 19 January 2011 and July 2012. Inclusion criteria were that patient should have one of the diagnoses
42 20 diffuse large B cell lymphoma (DLBCL), acute myeloid leukemia (AML) or chronic lymphocytic
43 21 leukemia (CLL) and have been treated with chemotherapy or chemoimmunotherapy. They
44 22 should also understand and speak Swedish. In order to get a wide variety of conceptions, the
45 23 patients were chosen to represent different categories of sex, age, marital status and education
46 24 level. The patients should not have ongoing acute side effects of treatment. Specialist nurses in
47 25 oncology or hematology involved in patients' treatment or care identified and asked potential
48 26 informants verbally about participation in the study. Thereafter, the informants received written
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1 and oral information from the first author about the aim and design of the interview study,
2 voluntariness and confidentiality. Written informed consent was obtained. Twenty-two patients;
3 ten females and twelve males, were asked for participation and twelve agreed. Reasons for
4 declining participation were related to sexuality as an unimportant area, an area already affected
5 before treatment, or no sexual activity in the current relationship. The informants were females
6 (n=4) and males (n=8), age ranging from 50 to 82 years (median 60, mean 64) (Table 1). They
7 had completed treatment two to eight months before the interview took place. In the interviews,
8 two of the informants told that they also had received local radiotherapy to the cheek area. The
9 study was ethically approved by the Regional Ethical review Board in Uppsala (Dnr. 2010/065).

11 **Data collection**

12 Two thematic interviews with each informant were carried out with an open approach by the first
13 author in a private room based on the informant's choice. The first interview started with one
14 open-ended question 'What does sexuality mean to you?' in order to get a conceptual base for the
15 research questions how these patients conceive the impact of chemo- or chemoimmunotherapy
16 on their sexuality and their need for support related to this issue. Then followed the questions
17 'Can you tell me about your experiences of how treatment has affected your sexuality?' and 'How
18 are your experiences about information and support regarding sexuality? In order to facilitate
19 focus during the interview an illustration with time axis and themes was showed for the
20 informants during the interview (Larsson *et al.* 2007): 'changes of patient's sexuality during and
21 after chemotherapy' and 'wishes and needs for information and support regarding sexuality
22 issues'. The informants were encouraged to describe their experiences in focus as thoroughly as
23 possible and the interviewer asked for examples. Two to eight weeks after the first interview, a
24 second interview was carried out. By asking clarifying questions and extending unclear areas of
25 the first interview, the conceptions of the phenomena were validated and the variation of
26 conceptions could be further understood (Sandelowski 1999). The interviews were digitally

recorded and transcribed verbatim, and lasted between 30 min and 90 min. Both interviews were about 50 minutes long (mean 55 and 53 min).

Data analysis

In phenomenography, a series of analytic steps are followed. In this study, the analysis was inspired by Hyrkäs *et al.* (2003):

1. Reading and listening of the entire material in order to obtain an overall picture.
2. Selection of statements of interest for the research study, where each of the research questions are taken in to consideration.
3. Comparison of the statements with the content of the interviews.
4. Formation of pools of meanings by grouping the statements of the previous stage.
5. Comparison of the similarities and differences of the pool of meanings, naming the emerging categories and further testing them, by comparing them with the original text.
6. Generation of descriptions of categories and their interrelationships.
7. Finally, renaming of the categories by using concepts which describe the material as well as possible.

All researchers worked closely in the analysis, moving back and forth between the different steps, and between the entire interviews and their parts. The emerging categories were discussed until consensus was obtained.

Trustworthiness

Credibility was achieved in several ways. Through every step in the research process the researchers' took a step back from their own experience of the phenomenon and identified their preconception of the phenomena under study and set them aside as far as possible (Marton & Booth 1997, Barnard *et al.*1999). A pilot interview was carried out in order to make the

interviewer comfortable with the interview situation and to test the interview questions (Åkerlind 2005, Green 2005). Two interviews with each informant increased the opportunity to create a trustful relation between the interviewer and the informant and gave the opportunity to clarify unclear matters and validate preliminary findings (Sandelowski 1986). The research group compared and critically examined pools of meanings, categories and outcome space until consensus was obtained (Green 2005). In order to make the decision trail visible (Åkerlind *et al.* 2005) quotations were used, which also further contributed to *credibility*. In order to achieve *auditability* the researchers strived for clarity in the different steps of the research process (cf. Sandelowski 1986, Åkerlind *et al.* 2005). In order to obtain reflected data, which is essential in a phenomenographic study (Marton & Booth 1997), interview questions were open-ended and the informants were asked clarifying and exemplifying questions. The second interview improved the opportunity to get reflective data. *Fittingness* was ensured by the purposeful sampling, which resulted in a range of informants representative for the patient group focused on in this study. As the interviews were carried out in a relaxed atmosphere they provided rich variations in data.

Findings

The analyses revealed an outcome space consisting of two main categories; 'Sexuality is overshadowed by the cancer experience' and 'No need of support but timely information might be helpful'. The first category describes the informants' conceptions about sexuality and the influence of treatment on sexuality during and after chemo-/chemoimmunotherapy. This category impacted on the second one which describes patients' conceptions about the wish for support related to sexuality in relation to cancer treatment. Both main categories were comprehensively related to three description categories 'Affected strength', 'Affected sexual desire' and 'Affected self-image' which describe conceptions of how sexuality was affected. The description categories were substantially different with regards to their content and meaning and were interrelated. Strength was found to be superior to the other two categories as it impacted on

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3 1 desire and self-image, and desire and self-image were mutually influencing. Throughout the
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5 2 interviews patients could express difficulties in distinguishing reasons for changes in sexuality i.e.
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7 3 if problems conceived were related to disease, the side-effects of treatment or both, which
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9 4 illustrated the complexity of the interrelation between the descriptive categories. (Figure 1).
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13 6 *[insert Figure 1 here]*
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18 8 **Sexuality is overshadowed by the cancer experience**

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20 9 The first main category describes that despite the view of sexuality and its importance, thoughts
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22 10 about sex and wishes for sexual activity were overshadowed by the experience of being diagnosed
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24 11 and treated for cancer.
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28 13 *“...If they had said that you lose all of that [sexual function], you don’t care, your main concern*
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30 14 *is to be cured, and it [sex] was of minor importance...”*
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35 16 Two ways of describing the concept “sexuality” were found – ‘sexual function’ and ‘sexual
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37 17 function together with sexual relationship’. Mostly sexuality was seen as both sexual function and
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39 18 relationship. Sexual function was described as sexual activity and the ability to manage intercourse
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41 19 for both sexes, and it included sexual desire and arousal. Sexual relationship was described as an
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43 20 interpersonal relationship sharing sexuality with another beloved person. This included intimacy
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45 21 and communication about sexuality. The importance the patients ascribed to sexuality, which
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47 22 varied from a very important part of life to not especially important, seemed to influence their
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49 23 conceptions about changes in sexuality during and after treatment.
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54 25 The patients who described sexuality as important described varying degrees of impact on
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56 26 sexuality from severe to almost nothing. When sexuality was expressed as less important few
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changes in sexuality was described. The analysis indicated several factors influencing the patients' view about importance such as age, closeness in the relationship and sexual activity prior to disease and treatment.

Severity of disease and side-effects, led to variations regarding patients' conceptions of influence of treatment on sexuality. When disease and treatment were perceived as severe, concerns for life were overshadowing, and most of the informants described that thoughts about sexuality and sexual activities were absent during treatment. Anxiety, fear of death and coping with side-effects of treatment decreased sexual interest. Side-effects could concern fatigue, nausea, nutritional problems and pain which affected both the physical and psychological dimension of strength, which decreased sexual desire and negatively influenced self-image.

No need of support but timely information might be helpful

The second main category describes patients' conceptions regarding needs and wishes for support related to the impact of treatment on sexuality. Variations were found from 'no need at all' to a few expressions of 'information might have been helpful'. The patients' needs and wishes seemed to vary depending on the importance sexuality was ascribed and how treatment was conceived to impact on sexuality. The more severe disease and treatment side-effects were experienced and the more this impacted on strength, sexual desire and self-image, the less were the wishes of support during treatment. The few expression about support concerned information before treatment in order to be better prepared about the expected impact of side-effects on sexuality. Information was also mentioned as eventually helpful after completion of treatment when strength was less affected and life had gradually started to return to the way it used to be. In case of information this should be given timely and individually adjusted. The findings clearly illuminated that sexuality was experienced as a sensitive topic to talk about.

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1 ‘...sexuality is sensitive but not taboo.’

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3 ‘...and this... I definitely believe sexuality is the most taboo issues.’

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5 Most of the patients stated that they had not received any information at all from the health care
6 regarding how sexuality could be affected, and in the few cases when information had been given
7 this was related to sexual function. The health care personnel were conceived to be lacking time,
8 which hindered this topic from being discussed. Some patients referred to information in
9 brochures and the internet, available to use if needed. In addition, patients conceived that both
10 nurses and physicians mostly focused on physical problems and they doubted that they had
11 adequate knowledge and skills in order to grasp the whole complexity of sexuality. Expressions
12 also showed uncertainty as to whether sexuality was a part of health care personnel’s
13 responsibility due to the very private character of the topic.

14

15 **‘Affected strength’**

16 This descriptive category describes patients’ conceptions of how sexuality was affected by
17 decreased physical and psychological strength due to illness and treatment. Both dimensions of
18 strength were found to be affected in varying degrees ranging between ‘almost nothing’ to the
19 most common views ‘very much’. The most recurrent pattern was that the physical and
20 psychological energy the patients had retained during treatment was consumed by managing daily
21 life and thoughts about sexual activity were absent.

22

23 *"It's about getting through this period, then there is no place for... there is no place for it,*
24 *sexuality, the spice of life, all your energy and everything is concentrated in one direction [survival]."*

25

Decreased physical strength was described as difficulty in achieving and maintaining erection, lack of energy, tiredness and loss of shape.

"I do not think I would be able to get the physical capacity [erection], enough to perform sexual intercourse"

Decreased psychological strength was described as feeling down and negative stress related to uncertainty. This was conceived as impacting on patients' sexual relationship.

"You don't feel sexual when you are depressed."

Most patients described that sexual function and sexual relationships could return gradually after treatment, along with regained physical and psychological strength. Older patients could describe sexual function after treatment as still affected, but in most cases sexual function was perceived as coming back "good enough" in relation to the old age.

'Affected sexual desire'

This descriptive category describes patients' conceptions of how sexuality was affected by changes in sexual desire due to illness and treatment. Sexual desire was found to be affected in varying degrees ranging between total loss of desire to almost unaltered desire. Thoughts about sexuality were conceived as decreasing during treatment and the patients also described reduced or total loss of sexual arousal. This was related to troublesome tiredness and feelings of illness which were conceived as overriding sexual desire during treatment.

"...sexual desire was not there, there was a kind of tiredness instead, maybe a little bit of closeness but it never led to intercourse during these three months"

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5 2 Sexual desire could also be affected before treatment due to the cancer location. When for
6
7 3 example lymphoma was located in the uterus, patients described fear of pain, bleeding and
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9 4 discomfort during intercourse, which decreased sexual desire. After treatment, continuing
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11 5 physical problems and fear of pain could still impact on sexual desire.
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16 7 *“During the treatment I had no sexual desire at all, because I was sick, and I felt sick.”*
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20 9 Changes in sexual desire and their consequences for sexual activities also impacted on the sexual
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22 10 relationship. Patients who lived in relationships where problems related to sexuality could be
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24 11 talked about seemed to cope better with the problems than patients who lived in relationships
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26 12 where such discussions were avoided.
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31 14 ***‘Affected self-image’***
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33 15 This descriptive category describes patients’ conceptions of how sexuality was affected by
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35 16 changes in self-image due to illness and side-effects of treatment. Patients described that
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37 17 satisfaction with their own body and the appearance was important in order to function sexually.
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39 18 Both women and men told about changes in appearance that affected the self-image such as
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41 19 treatment-related hair loss, weight loss, and bad bodily shape, which led to feelings of being
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43 20 sexually unattractive. Feelings of not recognizing their own body, feeling disgusting, and being
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45 21 out of control could affect patient's self-image negatively. These changes in self-image led to
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47 22 decreased sexual desire and avoidance of intimacy.
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53 24 *“Because I felt so disgusting it was no fun to hug or be close, I felt “don’t touch me”, “you can*
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55 25 *become infected”, and you felt so disgusted with yourself”*
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1 In addition, some men described that self-image could be affected due to feelings of sexual
2 insufficiency and 'not being a whole man' when sexual dysfunction occurred.

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"It is important to know that you are a man and not a steer [castrated bull]"

6 Discussion

7 The aim of this study was to describe how patients with malignant blood diseases conceived the
8 influence of chemo- or chemoimmunotherapy on sexuality, and their need of support related to
9 this issue. The findings showed that these patients experienced negative effects on sexual
10 function and sexual relationship during and after the treatment period due to affected strength,
11 sexual desire and self-image. However, their experiences of being diagnosed and treated for
12 cancer overshadowed thoughts about sex and wishes for sexual activity. A need for support from
13 the health care personnel related to sexuality was expressed only by a few patients who thought
14 that pre- or post-treatment information might have been helpful.

15
16 The most outstanding finding of the present study, which is not found in previous studies on
17 patients with malignant blood diseases, is the emphasis on lack of physical and psychological
18 strength as the reason behind the negatively affected sexuality (Zittoun *et al.* 1997, McGrath
19 2012). The strength and power the patients had retained were described as being consumed by
20 managing daily life activities. Consequently, thoughts about sex simply were 'not on the agenda'.
21 The patients in our study described symptoms of affected strength such as lack of energy,
22 feelings of physical tiredness and mood disturbance, which are commonly included in the
23 description of cancer-related fatigue (Mock *et al.* 2000) in previous studies (Ahlberg *et al.* 2003
24 Luctkar-Flude *et al.* 2009). Fatigue is considered to be the most prevalent symptom in cancer
25 patients (Ahlberg *et al.* 2003, Barton-Burke & Gustason, 2007), a "multidimensional experience"
26 which is embracing the whole person (Mock *et al.* 2000).

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5 2 Although there is evidence regarding the impact of fatigue on physical, psychological and
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7 3 cognitive functioning (Glaus *et al.* 1996) and quality of life (Wettergren *et al.* 2003), its impact on
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9 4 sexuality in cancer patients has not to our knowledge been shown before. In our study lack of
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11 5 strength overrode sexual desire, which not is very surprising. However, lack of strength and
12
13 6 feelings of illness also affected the patients' self-image as it involved feelings of sexual
14
15 7 unattractiveness. These findings illuminate the complexity of the concept and the need of a
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17 8 holistic approach in cancer care regarding sexuality. The strength returned gradually after
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19 9 treatment and some patients described that information regarding sexuality might have been
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21 10 useful when life had returned to normal. This highlights the necessity to continuously assess
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23 11 cancer patients' symptoms in relation to the whole situation also after treatment. However, as
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25 12 follow-up care of cancer patients are mostly focused on the evaluation of treatment and detection
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27 13 of recurrence and fail to meet the needs of supportive care of cancer survivors (Swedish
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29 14 Government Official Reports 2009, Davies & Batehup 2011, National Cancer Institute 2010) this
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31 15 is an area for development.
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38 17 Nowadays sexuality is an issue that is illuminated in the mass media with great openness and
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40 18 permissiveness, which can give the impression that sexuality is no longer surrounded by taboos
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42 19 or is a private matter. Therefore the opposite view found in our study was interesting. The
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44 20 patients had difficulties in talking about sexuality, and saw it as sensitive and an area of utmost
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46 21 privacy. This may be the reason for why they did not express any need for support from the
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48 22 health care personnel in problems related to sexuality, which most of them had experienced
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50 23 during treatment and some of them still have. It is easy to understand that sexuality receded into
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52 24 the background when uncertainty regarding survival and the side-effects were as most intense.
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54 25 As previous studies (Wilmoth 2001, Larsson *et al.* 2007) have reported about the overshadowing
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56 26 effect that cancer and its treatment may have on other things in daily life, this part of our findings
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1 is not surprising. However, as the sexual changes also could be of a lasting character our study
2 highlights the need for improvement concerning support for this group of patients in the
3 rehabilitation phase with regard to sexual problems.

4
5 The low interest in support and information found in our study is very interesting, as previous
6 studies have reported about cancer patients' unmet needs for information and support regarding
7 sexuality (Flynn *et al.* 2011, Wilmoth 2001, Hordern & Street 2007). According to our findings
8 only a few patients thought that information about sexual changes before and after treatment
9 could be valuable. They also expressed that if such information were to given this should be
10 done in a time and manner that was individually adjusted to each patient's needs and wishes.
11 These findings are well in congruence with the Hordern and Street's study (2007), where the
12 opinions about sexuality as a sensitive matter, and the request of individually adjusted
13 information provided in a sensitive way were reported. Hence, our findings illuminate several
14 challenges for professional nurses who are guided by the idea of holistic care (Benner & Wrubel
15 2009), implying that all the needs and problems of the individual patient must be taken into
16 consideration. Based on our findings the most demanding issue would be to discern the patients
17 with malignant blood diseases who experience problems related to sexuality, and really want
18 support.

19
20 Patients in our study also doubted whether sexuality is an issue of concern for health care
21 personnel, and whether nurses and doctors have adequate knowledge and skills in order to be
22 able to give support within this area. According to previous studies nurses in cancer care
23 consider sexuality to be an area of their professional responsibility (Olsson *et al.* 2012, Reynolds
24 & Mangan 2005). However, nurses seldom talk about sexual problems with their patients due to
25 lack of knowledge about sexuality and lack of skills in communicating sensitive topics. This is in
26 accordance with the present study since only a few patients received information, which was

related to sexual functioning. Furthermore, it is a common attitude among nurses in cancer care that patients put a low priority to sexuality irrespective of where in the trajectory of care they are. As a result of that, sexuality is seldom brought up (Wilmoth 2001, Katz 2002, 2005, Lavin & Hyde 2006, Olsson *et al.* 2012). Taking into account that questions about sexuality seems to be sensitive and that sexual interest and problems may vary among patients treated for cancer, it is important that nurses can address the issue in a professional manner. Therefore, improvement of nurses' knowledge and skills in the areas of sexuality, communication and counseling would be of utmost importance.

Methodological consideration

The use of two interviews enhanced the credibility of the findings especially when the phenomenon in focus was perceived as taboo, sensitive and complex. It presented the opportunity to make the informant more comfortable, which provided valid and reflected data required in a phenomenographic study (Baker 1997, Marton & Booth 1997). Perhaps some of the informants' would have responded more openly and truthfully if they had had the opportunity to describe their experiences by answering open-ended questions in a written form sent to them. On the other hand, this would have decreased the opportunity to pose probing questions which are needed in order to obtain reflected data.

Since sexuality is considered as sensitive and sometimes taboo, which was also prominent in this study, the question about choice of informants may be with regards to the transferability of the findings. It is often argued that in studies using interviews as method for data collection overrepresentation of social isolation may occur (Gledhill *et al.* 2008). However, in this study the majority of the informants lived in a relationship. Inclusion of informants in terms of gender was skewed, since more men than women chose to participate. One can argue that informants in this

study represent the population of patients with malignant blood disease in distribution to gender and age but additional women might have changed the findings.

Conclusion and relevance for practice

The patients in this study experienced sexual problems during and after treatment due to affected strength, sexual desire and self-image. However, when disease and side-effects were experienced as severe, thoughts and interest of sexuality were overshadowed and the need and wish for support related to this issue was very low. It is important to note that some patients expressed that pre- or post-treatment information might have been helpful. However, they doubted that the health care personnel had knowledge and skills enough to talk about such a sensitive topic as sexuality, and considered that lack of time also hindered them. It is acknowledged in cancer care of today that cancer follow-up should address psychosocial support in which sexuality is an important area. Therefore, it is imperative that cancer care is organized in a patient centered way, with adequate time for nurses to provide continuity in the nurse-patient relation and supportive care during cancer rehabilitation.

Contributions

Study design: CO, EA, AKSB, ML: data collection and analysis: CO, EA, AKSB, ML and manuscript preparation: CO, EA, AKSB, ML.

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Table 1. Demographic characteristics and medical data of the informants (*n* = 12)

Informants in the study	Number
Gender	
Female	4
Male	8
Age	
Median	60
Range	50-82
Marital Status	
Single	3
Living in a relation	9
Educational level	
Elementary school	2
Upper secondary school	3
University	5
Unknown	2
Diagnosis	
DLBCL	8
CLL	2
AML	2
Treatment	
Chemoimmunotherapy	10
Chemotherapy	2

Figure 1. The structure and relationship between the categories describing patients' conceptions of influence of treatment on sexuality, and need of support related to this issue.